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FACULTY OF HEALTH SCIENCES

A STUDY OF ENGAGEMENT IN CASUAL LEISURE OCCUPATIONS BY INDIVIDUALS WHO ARE LIVING WITH NEUROPALLIATIVE CONDITIONS

by

Anne Fenech

Thesis for the degree of

Doctor of Philosophy

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ABSTRACT

Faculty of Health Sciences

Doctor of Philosophy

A STUDY OF ENGAGEMENT IN CASUAL LEISURE OCCUPATIONS BY INDIVIDUALS WHO ARE LIVING WITH NEUROPALLIATIVE CONDITIONS

By Anne Fenech

Purpose. This study explored the following research questions:

1. What are the normal and sensory-overloaded behaviours exhibited by adults living with neuropalliative conditions?
2. How does engagement in casual leisure alter with different levels of sensory attributes?

It did this to determine whether there might be an approximate optimal level of sensory attributes that maximises occupational-engagement while minimising the potential for sensory-overload. The aim therefore was to create an occupational environment that participants could handle competently and enjoyably. This sensory threshold can only be approximate, since each individual has unique sensory preferences, interests and experience.

Method. The preliminary study involved a structured interview with a Residence Manager in order explore the normal and sensory-overloaded behaviours exhibited by nine adults living with neuropalliative conditions. The second study built upon this by conducting a multiple, case quasi experimental study involving marginal-participant time-sampled observations of engagement of individuals with neuropalliative conditions, with casual leisure occupations using the Individual Child Engagement Record. This study investigated whether engagement occupations alters with different levels of sensory attributes. Observations were made of 14 participants engaging in eight cases, who experienced profound levels of disability, each case differed (as part of the replication logic) by having different levels of sensory attributes.

Results. Analysis suggests that the symptoms of sensory-overload may be experienced by adults living with neuropalliative conditions. The effects of sensory-overload appears similar to definitions of a passive state (of engagement or non-engagement). The thesis therefore presents the linkage between passive engagement/ passive non-engagement and an individual's behaviour when experiencing sensory-overload, hopefully leading to increased vigilance and therefore avoidance. Furthermore, engagement was shown to alter with a combination of different levels of sensory and non sensory attributes, including supporter facilitation and with the potential for active participation. These contextual factors are proposed to pertain to the individual, the occupation itself, and to the physical and social environment; the role offered or level of support available. Therefore, enhancing active leisure engagement requires consideration of the occupation, the individual and their sensory preferences and the occupational environment.

Conclusions. Despite the reporting of sensory-overload symptoms by the participant of the preliminary study, the results showed that the anticipated reduction in engagement at the higher levels of sensory attributes (given the effects of sensory-overload) did not occur. In fact, engagement with leisure occupations appeared to increase as the sensory attributes levels increase, with larger differences in engagement level occurring where there are larger differences in the combined level of sensory attributes involved, a range of factors in the occupational context, are suggested to influence engagement, some of which pertain to the individual, the occupation and the environment.

Clinical Messages. The role of the leisure supporter was suggested to include adapting leisure to fit the person, including offering the choice of what, when, where, with whom and how to "do" their leisure occupations, including offering active participation and a sense of choice.

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Declaration of Authorship

I, Anne Fenech declare that the thesis entitled "Being fully human through engaging in leisure: a study of the factors which influence engagement in casual leisure occupations" and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

This work occurred wholly or mainly while in candidature for a research degree at this University;

Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly suggested;

Where I have consulted the published work of others, this is always clearly attributed;

Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

I have acknowledged all main sources of help;

Where the thesis is based on work done by myself jointly with others, I have made clear exactly what occurred by others and what I have contributed myself.

Parts of this work have been published as:

- Fenech A (2008) Why leisure occupations are a necessary, meaningful and therapeutic use of free time for individuals with neuropalliative conditions *Public Journal of Occupational Therapy*

- Fenech, A., & Sadlo, G. (2008) Being, belonging but not doing: a special case of occupational deprivation? *Public Journal of Occupational Therapy*

- Fenech, A., Baker, M (2008) Casual leisure and the sensory diet: a concept for improving quality of life in neuropalliative conditions *NeuroRehabilitatio*n 23 (3) 369 - 376

- Fenech, A. (2008) The benefits and barriers to leisure occupations *NeuroRehabilitation* 23 (3) 295 - 297

- Fenech, A (2008) It ain't what you do, it's the way that you do it!…….The meanings which can be attributed to leisure: a review of the literature *Maltese Journal Of Occupational Therapy* 16 (Jul) 4 – 21

- Fenech, A. (2009) Interactive Drama in Complex Disability Management *Disability & Rehabilitation* 31 (2) 118 — 130

- Fenech, A. (2010) Inspiring transformations through participation in drama for individuals with neuropalliative conditions Journal of Applied Arts and Health 1 (1) 63–80

- Fenech, A. (2011). Aquatic leisure satisfaction and engagement in neuropalliative disability management. Scandinavian Journal of Caring Sciences 26 (3) 519 - 527.

- Fenech, A., Shaw-Fisher, K. (2012) Lifelong and therapeutic recreation and leisure in Zasler, ND., Katz, DI., Zafonte, RD., Brain Injury Medicine: Principles and Practice (2nd Ed) New York: Demos Medical Publishing

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Introduction

0.1 Background

An individual's experience of sensory stimuli, the effects of occupational deprivation, and the opportunities to experience meaningful occupations, all have the potential to influence occupational-engagement. Throughout the history of occupational therapy, occupational-engagement has been valued as the primary goal of intervention (Fisher 2013). Inappropriate levels of sensory attributes may result in non-engagement, challenging behaviour, boredom, or the choice of a leisure role which is not satisfying. Consequently, individuals with neuropalliative conditions (NPC) could spend time differently than others. Given the importance of occupational-engagement on wellbeing and health (Wilcock, 2006), a study of casual leisure (Stebbins, 1997) amongst profoundly disabled individuals with NPC in residential care is essential. This thesis presents a study of casual leisure occupations, which include different levels of sensory attributes to consider how these occupations could become less repellent, and more appealing; thereby reducing the impact of occupational deprivation on individuals with NPC in residential care. It will therefore attempt to define the normal and sensory-overloaded behaviours exhibited by individuals with NPC to consider how engagement in casual leisure occupations alters with different levels of sensory attributes.

This thesis uses the term occupation throughout because human occupations include "any activity in which a person is engaged" (Merriam-Webster Inc. 2003), and this is a study of engagement in leisure occupations. Human occupations capture the participant's attention, and include everything that individuals do to occupy themselves, including self-care, having fun and contributing to their communities productively (CAOT 2008). Reed *et al.* (2010) suggest that humans engage in occupations all of the time. However, individuals with neuropalliative conditions (NPC), are at risk of not being able to do or to engage in occupations due to the limited opportunities to engage in occupations which suit their ability, motivation, or sense of well-being (Nilsson, 2006). Wilcock (2007) used the term 'occupationally deprived' to describe individuals who are deprived of the opportunity to engage in meaningful occupations by something which is outside their direct control. O'Sullivan and Chard (2010) demonstrated occupational deprivation and a loss of former leisure opportunities resulting from a neurological disability. Occupational science postulates that occupational deprivation and its costs on health are the opposite of (and therefore could be reversed by) occupational-engagement (Wilcock, 2006) such as leisure. It therefore seeks to suggest how these occupations could become less repellent, and more appealing to individuals with NPCs.

The terms 'resident' and 'participant' are used differently in this thesis. A resident is an individual who resides at the home studied. Whereas, a participant, is an individual who has consented to participate in the study, or an occupation. The residents and participants all have neuropalliative conditions (Turner-Stokes *et al.,* 2007) such as Huntington's Disease, Vegetative State, Locked-in Syndrome, end-stage Parkinson's Disease or Multiple Sclerosis. The severity and combination of

cognitive, physical, behavioural, communication issues (Turner stokes *et al.,* 2007), differentiate NPC from other neurological disabilities, influencing the individual's occupational-engagement. For example, the residents achieved Barthel scores (Kwon *et al.,* 2004) in the region of 0 to 30 out of 100, or Katz scores of 1 out of 6 (Katz *et al.,* 1970). The commonly used assessments, at the home, included the Barthel Index, Katz Scale, Modified Rankin Scale, Glasgow Outcome Scale and the Clinical Dementia Rating Scales. These assessments of functional performance (which are the core assessments used at the home and in its publications) indicate that the population studied experience profound neurological disabilities, which limit their leisure choices (according to Downs' qualitative research (2008)). All the home's staff were encouraged to use the term neuropalliative to emphasise the differentiation between complex neuro-disability and neuropalliative conditions following the publication of Turner-Stokes *et al.* (2007). Consequently, neuropalliative is the term used throughout this thesis (see section 1.1).

Occupational limitation occurs because the disabilities in question result in restrictions that are severe enough to prevent occupational performance. Individuals with such extreme levels of disability depend upon carers for their self-care. Furthermore, suitable employment is not readily available (Baker, 2012) so that leisure is the only opportunity for occupational-engagement that remains to them (Reed & Sanderson, 1999). Given this lack of ability and opportunity, occupational deprivation may result. Additionally, some formal and informal carers undervalue leisure (Bier *et al.* 2009) placing a higher priority on skin integrity and safety, rather than on the maintenance of self-identity. In other words, devaluing their only option for occupational-engagement, which could influence how they feel about themselves.

Leisure occupations should be self-determined (Dattilo & Rusch, 2012), transitory (Tinsley & Tinsley, 1986), being a subjective experience (Hultsman, 1995; Samdahl, 1991; Stokowski, 1994), which results in observable behaviour (Suto, 1998, 2004) and uses free time. Anderson and Brown Kress (2003) noted the stress-reducing effects of leisure-based friendships, freedom of choice and motivation, which could influence health and wellbeing. Primeau (1996) suggested that only the individual could define whether they consider an occupation a leisure occupation since what is leisure to one individual could be work to another (Taylor, 2008), and only the individual can determine the meaning "for them" (Yerxa, 1989). Therefore, the residents' rationale for joining in and their method of engagement is what determines whether an occupation is a leisure occupation.

Living in residential care could negatively influence emotional wellbeing, relationships and particularly the use of free time (Smith, 2004; Deshmukh, 2010; Winkler *et al.* 2011). Residents may face long periods of inactivity or 'reduced occupation' (Carey, 2011; Atwal *et al.,* 2003; O'Sullivan & Hocking, 2006), which is out of their control and so could be considered occupational deprivation (Whiteford, 2004, 2010). Hearle *et al.* (2005) suggested that 70% of residents' time involves sleeping or inaction, whereas the residents would prefer to spend more than half their time involved with social occupations. Furthermore, individuals with neurological disabilities may withdraw from all but the most passive and solitary occupations due to the environmental and care restrictions imposed (Farrow & Reid, 2004). If residents do not participate consistently in meaningful and engaging occupations (see Appendix i), the potential effect of such occupational deprivation requires consideration (see 2.3.5 and Appendix ii).

Whiteford (2010) suggested that family and community attitudes, and the political and economic climate, could all influence occupational-engagement. Wicks (2005) further suggested that occupational deprivation could influence an individual's self-image, even dehumanising them to a degree (Whiteford, 2000). Whiteford (2009) suggested that occupational deprivation occurs in groups, such as displaced refugees, prisoners, the geographically isolated, unemployed individuals, or those experiencing gender role stereotyping. Other researcher's have suggested that poor health, disability, lack of transportation, isolation, poverty and homelessness (Scaffa & Brownson, 2005), or sudden cessation of a caring role (Keesing *et al.,* 2011), could lead to occupational deprivation. Occupational deprivation resulting from profound disability, according to Whiteford (2004, 2010) is the result of potentially overcome-able circumstances that are not external to the individual, thus implying that profound disability is not a true cause of occupational deprivation. Thankfully, Scaffa & Brownson (2005) argued against this point of view. While others, such as Downs (2008), suggested that individuals with severe cognitive or physical limitations might be unable to participate in leisure. The researcher believes that some of the effects of occupational deprivation (see 2.3.5 and Appendix ii) may result from limitations to, or the absence of, opportunities for occupational-engagement caused by their disabilities, which are out of the individual's control (Townsend & Wilcock, 2004).

0.2 Sequence of research

In 2005, the researcher took up a post as International Fellow (with a special emphasis on recreation and leisure) at a home for individuals with profoundly disabling NPC. Throughout her career, the researcher had observed the effects of the sensory world on individuals such as her husband (who has several Autism Spectrum Disorders (ASDs)), herself (who is sensory hypersensitive), and individuals with NPC. Marriage to an appreciably disabled individual, alongside her caseloads have given her insights into assistive and virtual technologies. Her occupational therapy (OT) practice has included experience of sensory approaches to therapeutic interventions, especially around and in preparation for normalising movement to enhance independence and autonomy. The researcher was interested in occupational deprivation and its effects, and the opposite of occupational deprivation, i.e. occupational justice. Several issues influenced the domain of interest of the Fellowship including virtual reality and sensory leisure.

1 Virtual reality

At the time of the Fellowship's inception, other centres were researching virtual reality and computer games as a therapeutic tool, or for simulating experiences to train staff (e.g. air traffic control, lifeboat service, firearms training, wheelchair driving) or for pleasure (e.g. flight or driving simulators). Virtual reality leisure was an intriguing topic, but had significant resource implications and warranted a research fellowship in its own right. Additionally, business cases to gain funding for virtual reality projects soon highlighted that this area of study was out of the price range of the Fellowship.

2 Sensory leisure

The sensory processing of leisure occupations and occupational environments reminded the researcher of individuals at the home. These individuals appeared overwhelmed; shutting down when too much was going on. A limitation of Multi

Sensory Environment (MSE) use at the home included a lack of sensory profiling to determine sensory preferences, prior to use. The researcher considered the potential to do harm to the residents by exposing them to levels of stimulation that were overwhelming. However, reading at the start of the Fellowship had brought the work of Robert Stebbins (about serious and casual leisure) to the researcher's attention. With this came the realisation that casual leisure includes a high sensory attribute, and that there had been little research into casual or sensory leisure involving individuals with disabilities, other than research using MSEs. Therefore, the researcher's focus switched to casual sensory leisure (Stebbins, 2008). The researcher's concerns about occupational justice and the potential for sensory-overload led her to consider the literature on developmental disabilities, which has a long history of interest in the effects of sensory attributes. This raised questions about whether sensory-overload was the phenomenon that the researcher was observing when residents' shutdown if more was going on than they could cope with. Other staff had classed this as fatigue (see text box 1). Additionally, it seemed likely that other factors were circumventing sensory over or under-stimulation in situations where engagement in an occupation was meaningful to the individual, enabling them to work through their sensory-overload. Furthermore, from the researcher's observations in the home, there appeared little opportunity for self-determination and thus for occupational justice on the part of residents. This view led to a period of reflection about occupational deprivation and disability, and in the light of her interest in sensory processing and the use of assistive technology, on occupational-engagement and especially leisure. Consequently, the researcher felt that the Fellowship should follow a pathway of studying leisure from the point of view of engagement in casual sensory leisure (but excluding MSEs).

The first studies of the Fellowship commenced in 2006 with the production of a Mapping Discussion Document (2006), which led almost immediately to a study of the Interactive Drama Project. A Leisure Satisfaction Audit followed in 2007. Data collection for this thesis began in 2008 with an exploration of the resting and sensory-overloaded behaviour of individuals with NPC. This investigation produced preliminary data, which informed the design for a study involving observations of sensory leisure engagement (2008). The Fellowship concluded with an Aquability Leisure Satisfaction Evaluation (2008). Data collection for the thesis concluded in 2008, and the research for the Fellowship culminated in a secondary thematic analysis to highlight the meanings of occupations experienced by individuals with NPC.

0.3 Overview of the thesis

The thesis contains a number of chapters to define the normal and sensory-overloaded behaviours exhibited by individuals with NPC, and to consider how engagement in casual leisure occupations alters with different levels of sensory attributes:

Chapter One describes NPC and the leisure opportunities available at the home. It then moves on to leisure and how people participate in leisure (differentiating between therapeutic, recreational and leisure occupations) to justify why the focus of the thesis is on leisure. Additionally it introduces the relationship between sensory-overload and occupational deprivation and thus how leisure can avert occupational deprivation for individuals with NPC.

Chapter Two covers two distinct domains. Firstly, it reviews of literature concerning the sensory concepts around occupations, such as neurotypical and impaired sensory gating and sensory processing, sensory-deprivation, sensory-

overload, sensory-based theory, occupational therapy involving sensory modalities, including Sensory Integration (SI) and the model of sensory processing (MoSP). The second part of the chapter introduces occupational science, occupational-engagement and leisure, and occupational deprivation and its relevance to NPC; and finally the human costs of occupational deprivation.

Chapter three explores research design considerations such as the methodologies used by others, the researcher's epistemological stance and the practical and ethical principles involved in studying leisure with individuals with NPC. These included gaining consent from individuals with reduced mental capacity, privacy and confidentiality, risk in relation to the benefits of research, the length of the study, the efficacy of physiological tests in this clinical group, measuring engagement and the confounding factors encountered.

Chapter Four presents a preliminary study of resting and sensory-overloaded behaviour, describing the methodology, and the data collection tool. The chapter describes the procedure, piloting the questionnaire and the data collection and analysis before presenting a reflective review of the methodology used. The results in relation to the research question: what are the normal and sensory-overloaded behaviours exhibited by individuals who are living with NPC? Are then presented, which includes an overview of the residents' non-engaged behaviour as a group and of the residents' observed and attributed behaviour when experiencing sensory-overload. These are discussed along with how the findings of the Residence Manager interview influenced the observations of engagement study. The influence of sensory-overload on engagement is hypothesised, and the validity, credibility, reliability and transparency of the data for use in the following study of engagement is proposed.

Chapter Five presents a description of the methodology, the participants, their Recruitment and how consent to participate was gained for a study about how engagement alters with different levels of sensory attributes. Furthermore, the data collection tool: The Individual Child Engagement Record (ICER) is discussed including its use with adult neuropalliative participants. Next, the procedure of data collection, the cases (and their sensory attributes) and the analysis of the observations findings are described. This chapter provides an analysis of the residents as a group, as well as an occupational analysis of each case. The rationale for studying these cases is that they are instances of fairly representative of the leisure occupations offered on a menu at the home, however the participants are a rare group of profoundly neurologically disabled individuals (Fishman, 1999). As a result the cases offer a combination of both distinctiveness but also relevance to the real world (Fishman, 1999). It then presents a comparison of engagement between the passive and the potentially physically active occupations, a comparison of supporter-to-participant ratios with engagement, the reliability of the time-sampled observation data and the validity, credibility, reliability and transparency of the results.

Chapter Six reviews the researcher's publications and indicates the influence of this work on individuals with NPC, and their carers.

Chapter Seven discusses the limitations of the study, including those associated with the characteristics of the sample, the study design, data collection, data analysis, and therefore, the reliability of the findings. It then discusses the results of the interview with the Residence Manager (described in Chapter Four), and of the observations of engagement study (Chapter Five) and the researcher's publications (Chapter Six). It also reviews the implications of sensory-overload on

the behaviour observed, and discusses factors that could be overruling the individual's sensory threshold, thereby enabling the participants to continue to engage at the higher levels of sensory attributes. The chapter concludes with clinical implications and proposes directions for future research.

Chapter ONE

Neuropalliative conditions and the leisure opportunities available at the home

Chapter One describes NPC and the demographics of these conditions in the United Kingdom. It then moves on to leisure and how people participate in leisure to justify why the focus of the thesis is on leisure. It describes the resident population, and considers the leisure occupations available to them. Additionally it introduces the relationship between sensory-overload and occupational deprivation. It then discusses the value and importance of leisure in averting occupational deprivation.

The literature reviewed describes NPC, and leisure, which in combination does not yield many publications. For example, a search of Google Scholar using the word neuropalliative produced only sixty-nine publications since 2000. Google Scholar is an appropriate search engine to use, because it offers literature across many disciplines including leisure science, which is absent from other databases familiar to the faculty of Health Sciences. For example, a search of TDNet, produced no articles, and a search of PubMed produced two results, both of which were about the home studied in this thesis. The literature comprised primarily of articles in peer-reviewed journals, but there were also books, and university websites. The literature reviewed included mainly human research. Consequently, some of the literature is about conditions which become neuropalliative, but which do not explicitly use the term.

1.0 Neuropalliative Conditions

Neuropalliative conditions (NPC) (Turner-Stokes *et al.,* 2007) include rare conditions such as Locked-In Syndrome (Krasnianski *et al.,* 2003) or Huntington's Disease (Huntington, 1872). They also include common conditions in their advanced stages, such as Parkinson's Disease (Hudson *et al.,* 2006) or Multiple Sclerosis (Multiple Sclerosis Society, 2007). The main diagnostic categories producing NPC include:

Acute onset disorders producing generalised damage to the brain, such as Anoxic Brain Damage

Acute onset producing local damage to the brain, such as Locked-In Syndrome

Congenital disorders, such as Spina Bifida

Progressive degenerative disorders, such as Huntington's Disease

Taken individually, the physical, cognitive, perceptual, communication and awareness difficulties experienced could all influence an individual's ability to participate, and to understand or offer communication (Leng *et al.,* 2003). In combination, however, these limitations become so complex that the individual becomes profoundly disabled and is

dependent on others for the majority of their care as Baker (2012) described. This is relevant because, Downs (2008) suggested that individuals with severe limitations in cognitive or physical ability could be unable to participate directly in leisure occupations that others enjoy.

The National Service Framework for Long-term (Neurological) Conditions (DoH, 2005) highlighted the requirement for service provision including specialist neurology, rehabilitation and expert neurological palliative care (neuropalliative) services. Specialist neurology services provide investigation and diagnosis, interventions to modify the process of disease and for its neurological consequences. Neurological rehabilitation involves holistic support and disability management to maximise autonomy and independence. While the management of NPC, their distressing symptoms, limited life (or quality of life) expectancy, and progressive conditions; requires symptomatic management.

A condition becomes neuropalliative at the point where improvement in terms of health, autonomy or independence is no longer probable. At this point rehabilitation usually ceases and the individual's care changes emphasis to enhancing quality of life. The role of non-cancer palliative care relevant in degenerative or fatal neurological conditions, (Addington-Hall *et al.,* 1998; O'Brien *et al.,* 1992; Abrahams *et al.,* 2003; O'Brien, 2001; and Murtagh *et al.,* 2004) and several guidelines recommend early referral to palliative care services (Royal College of Physicians, 2003; National Institute for Clinical Excellence, 2004). However, there are some significant differences in the palliative care needs of individuals with NPC, compared with cancer (O'Brien, 2001; Voltz & Borasio 1997; Miller *et al.*, 1999). Having ceased rehabilitation, the expectation becomes one of compensation for limitations through modification of the built, social, physical and occupational environment, to empower the individual as much as possible.

Specialised rehabilitation services are high-cost, low-volume services for individuals with complex patterns of disability. Complex disability includes within it a small subgroup of people with 'profound disability'. These are more severely disabled individuals who need assistance with all their self-care, requiring additional interventions such as spasticity management, postural support, and/or assistive technology (e.g. individuals in vegetative or low awareness states). NHS Specialised services (2010) subdivides specialised rehabilitation services into three sub groups:

- **restoration of function** (e.g. after a 'sudden onset' or 'intermittent' condition) focussing on improving independence and roles participation
- **disability management** (e.g. for those with stable or progressive conditions) focussing on maintaining existing levels of functioning; compensating for lost function, and supporting adjustment to deteriorating function
- **neuropalliative rehabilitation** focussing on symptom management, improving quality of life during the later stages of a progressive condition or very severe disability, at the interface between rehabilitation and palliative care

The World Health Organisation (2012) defines palliative care as involving the prevention and reduction of suffering by means of pre-emptive assessment and treatment, without curing. Palliative care is a team approach to:

- relief from, better understanding of and management of distressing symptoms;

- affirming life;
- neither to hastening or postponing death;
- integrating physical, psychological and spiritual aspects of care;
- offering support for as active a life as possible until death;
- offering support for family and carers during the illness and in their own bereavement;
- enhancing quality of life (World Health Organisation, 2012)

1.0.1 Demographics of Neuropalliative Conditions

Neurological disabilities affect individuals of all ages. Their incidence is increasing due to improved survival rates, healthcare, and infection control, increased longevity and improved diagnostic techniques (Neurological Alliance, 2003). Monti *et al.* (2010) however, have suggested that greater numbers of individuals with disabilities are surviving, and are living longer, but with greater impairments and fewer occupational choices.

In the most recent Neuronumbers report, 10,000,000 individuals in the UK had significant neurological disabilities (Neurological Alliance, 2003). This included 135,000 with a brain injury, 85,000 with Multiple Sclerosis, 120,000 with Parkinson's Disease, and 300,000 with stroke (Neurological Alliance, 2003). In the UK, approximately ¼ of individuals with a disability aged between 16 and 64, had a neurological disability (Neurological Alliance, 2003). Approximately 350,000 individuals required assistance with their necessary occupations, and approximately ⅓ of individuals in residential care had neurological disabilities (Neurological Alliance, 2003).

Overall, neurological disability is one of the greatest global threats to public health, which could become an unmanageable problem (World Health Organisation, 2007). Consequently, satisfying leisure is the goal of many individuals who cannot return to their past life roles (Cicerone & Azulay, 2007). However, individuals with neurological disabilities appear to face many barriers to engagement in free time occupations (Baker, 2012).

1.0.2 The Neuropalliative Population at the Home

The facility studied is home to 158 Individuals with a wide range of NPC (see Table 1). The residents live in residences of approximately 20 residents each, each of which has an Residence Manager. The 2007 annual audit reported that 83 (52.5%) of the residents were female and 75 (47.5%) were male, with an average age of 52.5 years. Their ages ranged from 20 to 88 years.

Table 1 The diagnoses of the resident group during the home's audit of satisfaction conducted in 2007

Diagnosis	Number of Residents (n=158)
Brain Injury/Damage	46
Huntington's Disease	39
Multiple Sclerosis	19
Brainstem CVA/ Pontine Infarct	10
Vegetative State	7
Extra/Subdural Haematoma	7
Intracerebral Haemorrhage	6
Subarachnoid Haemorrhage	6
Ventilator-Dependent Tetraplegia	5
Cerebral Palsy	2
Parkinson's (Post Encephalitic)	2
Friedreich's Ataxia	2
Meningoencephalitis	3
Athetoid Cerebral Palsy	1
Autosomal Dominant Cerebellar Degeneration	1
Status Epilepticus	1
TB/Meningitis	1

Five percent of the residents were in a vegetative state and so were not able to demonstrate any awareness of the world around them, based on the SMART test (Gill-Thwaites & Munday, 1999). A further 4% were in low awareness states. (For an exploration of some of the issues that this level of disability leads to in relation to leisure engagement see Appendix iii)

The measurement of disability falls into four subtypes such as activities of daily living assessments, instrumental activities of daily living assessments, short outcome trials, and global health and life status measures (Collin 1997). This thesis uses assessments from two of these categories to describe the resident group (to contextualise their engagement and the study as a whole). The use of standardised neurorehabilitation measurement scales such as the ones used means that results can be compared at a service audit level or in research, especially when data records pre and post intervention scores. Standardised measures included Barthel Index, Katz Scale, Modified Rankin Scale, Glasgow Outcome Scale and the Clinical Dementia Rating Scales. Assessment scores are recorded in each residents care record.

Wade and Collin (1988) suggested that the Barthel Index (BI) was the gold standard for comparison between services. Collin (1997) describes it as particularly relevant to neurorehabilitation because it does not consider communication, cognition, mood or motivation, but gives a sense of overall functional ability. Gresham et al (1980) rated the Barthel as more useful than the Katz Activities of Daily Living (ADL) Index (1987) when comparing them for completeness, sensitivity to change, amenability to statistical analysis and familiarity on the part of professionals.

The two most well known short outcome scales which include management of acute neurological illness or injury include the Rankin Scale (developed in 1957, but modified in 1988) and the modified Glasgow Outcome Scale (Jennett *et al.,* 1981). Unlike the ADL measures already described they do not highlight week by week change but emphasize longer term outcomes reliably. These two scales, demonstrate predictable patterns of recovery if used for 3-monthly repeated assessments, and for multi centre trials (Collin, 1997).

The home also used the Clinical Dementia Rating Scale (Hughes *et al.,* 1982) to assess cognition and functional performance of its residents, because it is a sensitive (if subjective) assessment. Lim *et al.* (2007) suggested that it was better as a snapshot rather than offering a reliable picture of changes over time if used as a repeated measure. The Clinical Dementia Rating Scale was used because of the global nature of the cognitive impairments experienced by residents. It assesses not only executive functioning but also the impact on occupational performance.

The results of the Clinical Dementia Rating Scale (Hughes *et al.,* 1982) showed that 65% had severe cognitive impairments (see Table 2) and were significantly or completely dependent on others when participating in ADL. A further 16% had moderate cognitive impairments, while 6% had mild cognitive impairments and so were largely independent in carrying out personal ADL within the limits of their physical ability. Lastly, 4% had no cognitive impairments and so had no cognitive dysfunction to influence their functional ability.

Table 2 Cognitive status of the resident group during the 2007 audit of satisfaction

Clinical Dementia Rating Scale category	Clinical Dementia Rating Scale Score (Hughes *et al.,* 1982)	Percentage of resident population
Not or minimally aware		9%
Severe impairment	CDR 3	65.3%
Moderate impairment	CDR 2	16.3%
Mild impairment	CDR 1	6.4%
Healthy	CDR 0	4%
Total		100%

The average length of stay within the residence was 8.8 years,(range 5months – 57 years). Only 33.5% of the 158 residents were able to control a switch to use a computer, wheelchair or communication aid. Nearly all of the residents (95.5%) required a hoist to transfer between furniture, and 96.2% were continuing wheelchair/bed users.

The terms mild, moderate, severe, and profound describe levels of disability (Gupta *et al.,* 2004). According to Gupter et al. the categories of ability with respect to ADL include:

Independent (modified Rankin Scale [mRS] 0–1; Glasgow Outcome Scale [GOS] 5; Barthel Index [BI] 90/100);

Mild disability (mRS 2; GOS 4; BI 85/100);

Moderate disability (mRS 3; GOS 4; BI 60/100);

Severe disability (mRS 4–5; GOS 2–3; BI < 60/100);

The average BI score of the residents, was 7/100, whilst the average Katz score was 1/6, which was lower than Gupta *et al's.,* (2004) description of severe disability. Therefore, throughout this thesis the term used is profound levels of disability.

1.1 Leisure

Leisure involves freedom from commitments and responsibilities, when one can rest, relax and enjoy occupations chosen for fun (Dictionary.com, 2007). For individuals with disabilities, leisure interventions are a significant part of occupational therapy practice (Cunningham *et al.,* 2012; Pereira & Stagnitti, 2008). These interventions can include adapting leisure occupations or the occupational environment, assisting an individual to develop new leisure interests (Jongbloed & Morgan 1991), and using leisure occupations as a beneficial media (Drummond & Walker, 1996).

The disparity between the leisure wished for and experience increases because of NPC (Wise *et al.,* 2010), due to constraints such as loss of interest and enthusiasm, lack of facilities, reduced ability, lack of time (Backman, 1991) and environmental obstacles (Bier *et al.,* 2009), as well as reduced concentration, memory, initiative, practical transport or compensatory strategies (Peterson & Stumbo, 2000; Wise *et al.,* 2010; Douglas *et al.,* 2006). These restrictions, being outside the control of the individual, could lead to occupational deprivation. Occupational deprivation can result in longer periods asleep, altered quality of life, lack of social acceptance, diminished sense of self-efficacy, deteriorated occupational capacities, loss of self-identity, social exclusion, altered occupational patterns and time use, enforced dependence, and limitations to hand or tool use (Whiteford, 2004, 2010). These effects perpetuate occupational deprivation and further limit the individual's opportunities to engage.

The American Occupational Therapy Association (AOTA) (2008) classifies leisure as an optional activity engaged in during discretionary time, and which therefore could be intrinsically motivating. Individuals with NPC experience limitations in self-care, productivity or leisure occupations (Colantonio *et al.,* 2004; Gordon *et al.,* 2006; Kozlowski *et al.,* 2002; Whiteneck *et al.,* 2004). Profound disability could result in a "catastrophic reaction" (Martelli *et al.,* 2008), which exacerbated the disability experienced, leading to a steep decline in the individual's overall health, wellbeing, self-esteem, valued roles, and self-identity and quality of life (Martelli *et al.,* 2008; Reynolds, 1997). Apart from time away from commitments, Whiteford and Wright-St Clair (2004) describe leisure occupations as freely chosen, meaningful and done for their own sake. Besides the reduced ability to participate, leisure opportunities may be limited because supporters view them as unearned (Scanlan *et al.,* 2010; Lobo 1999), or unsuitable (Suto 1998). However, leisure is of particular importance to individuals whose lifestyle is altered by unemployment (Hoofien *et al.,* 2001; Eriksson *et al.,* 2009; Steadman-Pare *et al.,* 2001; Teasdale & Engberg, 2005; Wilson, 2008).

Swanson and Chenitz (1993) and Kleiber *et al.* (2002) suggested that individuals with long-term conditions may need to redefine their sense of self, their roles and their goals; re-frame their place in the world whilst learning to accept a new self-image (Jensen & Allen, 1994). Jensen and Allen (1994) also developed a theory of wellness and illness, suggesting that adjustment to disability, involves understanding it, managing it, and feeling part of a community. Therefore, facilitating

engagement in leisure occupations should begin as soon as the individual is medically stable, in order that they can begin to redefine their sense of self, their roles and goals (Jensen & Allen, 1994), avoid occupational imbalance, and stave off the negative impacts of acquiring an NPC.

1.1.1 The difference between therapeutic, recreational and leisure occupations

Leisure Occupations involve choice and freedom from demands (Dattilo & Rusch, 2012). Recreation is the rejuvenation gained through the amusement, stimulation, relaxation and enjoyment of leisure occupations. Therapy is the process whereby a planned intervention facilitates recovery or cure.

Leisure involves freedom from responsibilities, whilst relaxing & enjoying activities chosen for fun (Dictionary.com 2007). Leisure interventions should be central to therapeutic practice with individuals with disabilities (Reynolds 1997). These interventions can include adapting leisure occupations, or the occupational environment; assisting an individual to learn new leisure occupations (Jongbloed & Morgan 1991); and using leisure occupations as therapeutic media (Drummond & Walker, 1996). Leisure is one of the ‘‘life situations’’ included in the International Classification of Functioning, Disability and Health (World Health Organisation, 2001). As such, leisure may include active or passive occupations (Dahan-Oliel et al., 2012), which may be may be formal, i.e. have rules and a leader; or are informal and more spontaneous (Law et al., 2006). Klaas *et al.* (2010) suggested that participation in informal activities could equate to passive, sedentary activities, as opposed to formal activities that may require a group of people and a specific location.

Suto (1998, 2004) suggested that leisure is an observable phenomenon, using quantifiable time, and is a subjective experience (Hultsman, 1995; Samdahl, 1991; Stokowski, 1994). Tinsley & Tinsley (1986) suggest that the leisure experience is transitory, rather than sustained for a long duration. Samdahl (1991) further described how individuals experience degrees of leisure satisfaction rather than absolute dis/satisfaction. Similarly, Primeau (1996) and Taylor (2008) implied that only the participant can determine whether they deem an occupation as leisure.

Recreation involves refreshment resulting from an agreeable amusing, stimulating, and enjoyable pastime (Dictionary.com 2007a). The British Columbia Ministry of Forests and Range (2007) defines recreation as the “physical or psychological revitalisation” resulting from the voluntary pursuit of leisure time.

Therapy is the term applied to any form of treatment for any condition. Therapy means “the treatment of illness or disability through rehabilitation” (Roberts & Boothroyd, 1984; Signet Mosby Medical Encyclopedia, 2007), or possessing a healing quality (Houghton Mifflin Company, 2003). Definitions of therapy include the planned use of helping techniques (Etheridge Chiropractice, 2007), a planned activity aimed at increasing or achieving wellness (The American Massage Therapy Association, 2007), or the “dynamics in support of growth and purposive change” (Gestalt Global Therapy Construct Library, 2007).

Drummond & Walker (1996) are among many writers who discuss the use of leisure by Occupational Therapists (UK), or Recreational Therapists (USA) or Diversional Therapists (Australasia) as a therapeutic media. These therapeutic interventions involve planned therapeutic intervention using recreational activities as the medium and to improve functional abilities (NCRTA, 1992). A major difference between therapy and leisure is the quality of recommendation vs. self-determination respectively. Equally the purpose for which the action is undertaken is another differentiating factor. Taylor (2008) pointed out that what is leisure to one individual could be work to another and so it is the reasons why, and the

participation method which determines whether it is a leisure occupation. Furthermore, Leng et al (2003) differentiated between short term leisure effects i.e. those which did not carry over between sessions or locations, and longer term therapeutic effects i.e. those which carry over into other contexts, detectable up to 4 weeks later. This is consistent with Tinsley & Tinsley's (1986) findings. This thesis will focus on leisure (as opposed to recreation or therapy) because the residents involved are not being rehabilitated and so face a stable or declining pattern of ability.

1.1.2 The relationship between sensory-overload and occupational deprivation

Section 2.1.1 discusses neurotypical sensory gating and sensory processing in greater depth, while 2.1.2 explores impaired sensory gating or sensory processing. Furthermore, section 4.5 will describe the clinical reasoning which enabled linkage between sensory-overload and passive engagement or non engagement; and between sensory-overload and occupational deprivation. However, at this point, the researcher proposes that sensory-overload links to occupational deprivation because of persistent reduced engagement through the reduction of occupational capacity resulting from an inundation of sensory stimulation. This could result from a change in the sensory attributes level which could temporarily reduce an individual's ability to cope with an occupation or the circumstances around it, by under or over stimulating them. Equally, the sensory gating/ processing problems caused by the NPC could cause a more pervasive, longer-term reduction in occupational performance. This may underpin Burllau (2007), Whiteford (2000) and Townsend and Wilcock's (2004) suggestion that becoming physically disabled involves a transition from being able, to occupational disruption, on to occupational dysfunction (with potential for reduced engagement) which could evolve into occupational deprivation. Additionally, an individual who is at risk of sensory inundation following basal ganglia damage, may only experience casual leisure occupations (with all the sensory attributes involved) because they are less able to engage in serious leisure (Stebbins, 2008). Likewise, O'Sullivan and Chard (2010) and MS Society (2009) suggested such occupational deprivation in relation to leisure, could be due to a loss of or avoidance of former opportunities, or reduced occupational capacity following a neurological disability.

1.1.3 leisure to avert occupational deprivation

This section will consider leisure engagement against a backdrop of current knowledge about leisure, disability, occupations and residential care.

From a leisure science point of view, this thesis presents insights into disability and leisure in combination. It therefore challenges Aitcheson's (2009) assertion that the engagement of leisure studies' with disability has ceased, by presenting a study of leisure in relation to a group of profoundly disabled individuals. Although leisure studies as a discipline has developed a close association with social policy (Kay, 2000), conventional definitions of leisure have marginalised disability related leisure studies research (Aitcheson, 2009). Instead research has focused on <u>where</u> leisure takes place, <u>what</u> leisure individuals participate in and <u>when</u>, or <u>why</u> they engage in it, and the degree of self-determination involved.

Equally, the researcher suggests that leisure is the poor relation of health care, where greater emphasis may be on returning to work, self-care and tissue viability. In fact, some writers suggest that the majority of time-use in residential care involves personal care (Stewart & Craik, 2007; Farnworth, 2004; Farnworth *et al.,* 2004). In some instances residents may require permission to engage in leisure occupations, because others do not consider them appropriate (Suto, 1998, 2004),

earned (Scanlan *et al.,* 2010), or available (Suto, 1998, 2004). This influences the meaningfulness of time use – i.e. the use of leisure to kill or fill free time (Lobo, 1999; Stebbins, 2009), with what was once a leisure occupation changing into an imposed occupation. This thesis does not take a biomedical model approach to recreation (as a medium for rehabilitation), but has chosen instead to focus on enabling lifelong leisure after rehabilitation. Indeed Colaianni (2011) suggested that the founding philosophies of occupational therapy and the biomedical model have been in conflict within the practice of occupational therapy for more than 60 years.

Unlike Aitcheson (2009), this thesis has not used the word activity, but rather it has taken an occupational science standpoint. Defining leisure as an activity has been central to discussions of physical education and human movement. However, the Department of Health has been promoting physical activity as something with a much wider relevance than the where, when, why, and what of sport and physical education per se. Therefore, through the publications to emanate from this thesis, neuropalliative rehabilitation could inform leisure science about the social and psychological benefits of leisure. Defining leisure as freely chosen may be problematic as Aitcheson (2009) suggested, for example when prescribing leisure occupations as part of a rehabilitation or recreation regime, or it requires facilitation by others.

Wise *et al.* (2010) reinforced the idea that disability could reduce the number, frequency and duration of leisure opportunities, and increase the amount of support required due to demands such as balance, coordination, vision, and decision-making. Because of this, individuals with disabilities may withdraw from all but predominantly passive, solitary, home-based, casual leisure occupations (Pollock & Stewart, 1990; Wise *et al.,* 2010). These occupations allow them to be independent, rather than engaging in active leisure occupations with assistance from others. Physical difficulties may have less influence on the quality of life of an individual than the cognitive, perceptual, communication, sensory and awareness sequelae of an NPC (Bateman *et al.,* 2005). However, Engberg and Teasdale (2004) found that maintenance of free time interests and general life satisfaction after becoming disabled fell markedly, therefore leisure goals are among the most common goals set during neurorehabilitation (Bateman *et al.,* 2005).

While the distinction between structured and unstructured leisure activity predominates in time use literature, another means of classification defines active or passive leisure (Desha & Ziviani, 2007). Weeder (1986) defined active leisure as recreation, sports, hobbies, card playing, rambling, dancing, reading, etc; and passive leisure as watching television, listening to the radio or music, or just relaxing. The distinction between active and passive leisure time is of relevance to depression (Desha & Ziviani, 2007), also Weeder (1986) and Minato & Zemke (2006) suggested a link between schizophrenia, passive occupations and inactivity. Passmore and French (2000) highlighted the passive, often solitary nature of 'time-out' leisure and its costs on mental health. Equally, Trail et al (2003) reported a link between amyotrophic lateral sclerosis and passive leisure, changed leisure patterns and leisure lack. Whilst home's could provide residents more free time than self-care or productivity opportunities (Pentland *et al.,* 1998; Pentland & McColl, 1999), it is noteworthy that a number of studies have suggested an association between a balance of occupations and wellbeing for non-working individuals. Law *et al's.* (1998) review of 22 studies suggested a relationship between occupation and health and well-being. As did, Marino-Schorn (1986) whose participants spent most of their time in rest and leisure occupations and had reduced morale. Similarly, Bird and Fremont (1991) and Passmore (1998) found that passive leisure improved health up to a point, after which it could negatively influence health and self-esteem in the absence of occupational balance. This is relevant because the researcher perceived

half of the occupations observed as physically inactive (see Chapter Five). Such potentially non-engaging leisure may be detrimental to wellbeing and health.

An increasing number of individuals could be at risk of occupational deprivation because of the increasing numbers of and levels of neurological disability globally (World Health Organisation, 2007). This is important, given that individuals are at their most human when occupationally engaged (Yerxa *et al.,* 1989). Furthermore, leisure may provide freedom, competence, self-determination (Peterson & Stumbo, 2000), thereby promoting self-efficacy, quality of life, and combating the negative impact of a "catastrophic reaction" (Martelli *et al.,* 2008) and of occupational deprivation. The non-medical character of leisure could enhance wellbeing. For example, leisure and its resultant relationships could reduce stress (Sellar & Stanley, 2010), offering self-protection and adjustment to life role changes (Kleiber *et al.,* 2002), as well as more normal blood pressure, body weight, bone density and joint mobility (Godbey, 2003). Furthermore, leisure engagement has social benefits such as social support networks (Broach *et al.,* 2000), social identity, social interaction skills, friendship and the expression of creativity (Kinney & Coyle, 1992; Iwasaki, 2007; Wendelborg & Kvello, 2010; Kvello, 2006 Asbjørnslett *et al.,* 2011).

Leisure choices could reflect ability and the cultural value judgments of the participant and those about them (Larsson *et al.,* 1995). An inability to maintain previous leisure occupations could reinforce uncertainty about the future (Kleiber *et al.,* 1995), redefining the individual's sense of self, roles and goals, and therefore requiring a new self-image (Jensen & Allen, 1994; Swanson & Chenitz, 1993; Kleiber *et al.,* 2002). Consequently, leisure satisfaction may be a predictor of quality of life (Iwasaki, 2007; Kinney & Coyle, 1992), and associated with wellbeing and adjustment to disability (Kleiber *et al.,* 2008). Additionally, leisure engagement may enhance physical fitness, coping with stress, self-esteem, self-identity, and occupational balance, influencing hope and optimism (Hutchinson *et al.,* 2003; Wise *et al,.* 2010; Sellar & Stanley, 2010).

Knowing that individuals with NPC have more 'free' time at their disposal (Pentland *et al.,* 1998, Pentland & McColl, 1999), means it is important to consider not only the occupations engaged in, but why (Chan et al, 2012; Pereira & Stagnitti 2008), in the context of an individual's personal, cultural and historical background (Stebbins, 2009). Free time and leisure are different. Imposed free time (Suto, 1998, 2004), without the means to fill it (Lobo, 1999); may seem oppressive and unsatisfying (Parry & Shinew, 2004; Russell & Stage, 1996). Therefore, free time boredom, or occupations imposed to fill free time, do not equate to leisure (Lobo, 1999; Stebbins, 2009).

Wilcock (1993) suggested that humans have an innate need to spend time in a purposeful way, a factor that influences their health, survival and individual development. Furthermore, Yerxa *et al.* (1989) suggested that individuals were at their most human when occupationally engaged. Therefore, leisure engagement could encourage the establishment of friendships, the expression of creativity, and the development of skills and a social identity (Iwasaki, 2007; Kinney & Coyle, 1992; Wendelborg & Kvello**,** 2010; Kvello**,** 2006; Asbjørnslett *et al.,* 2011). Iwasaki (2007) and Kinney and Coyle (1992) further suggested, that leisure satisfaction may facilitate rehabilitation, life satisfaction, and value restructuring.

Enabling engagement for individuals with NPC is challenging. Therefore, Turner; Dixon and Hamill; and Reed all proposed in 1994, that the organisation of leisure and interaction opportunities was a core skill for staff working in homes. However, Nolan *et al.* (1995) and Waters (1994) suggested that instead there was a task-orientated approach to care which

limited opportunities for leisure engagement, which Evers (1981) suggested could lead to depression, embarrassment and boredom contrary to the ideal of personalised care. Whereas, a “just right” social environment around leisure engagement, could encourage self-actualisation, through the provision of opportunities, which provide choice, rather than prescriptions, influencing subjective wellbeing (Rebeiro & Cook, 1999; Strong & Rebeiro, 2003).

1.1.4 Leisure Participation

Leisure participation research has focussed on different aspects, for example what, how and why leisure occurs:

- What – sports, arts, crafts and hobbies (Bishop & Hoggett, 1986)
- How – the approach to engagement, and thus focusing attention away from the occupation and onto the meaning of engagement in the occupation, as well as the implications of this on the individual's role and identity (Stebbins, 1997).
- Why – achievement, social and time-out leisure (Passmore & French, 2003)

This study uses the how and why approaches, and considers the number of sensory attributes of the occupation.

The home studied has a philosophy of inclusivity and increasing life satisfaction through leisure engagement. Casual leisure occupations require little physical ability to enjoy, being instantly and intrinsically rewarding (Stebbins, 1997). Table 3 therefore shows some of the casual leisure occupations carried out by residents prior to this study. These tend to have a high sensory content and were defined as casual leisure occupations by the researcher:

Table 3 Casual leisure occupations carried out

Leisure occupation	**Percentage of total resident population who engaged**
Current Affairs/Media Group	24.70%
Dance (Watching)	3.20%
Drinks/Pub Lunch/Eating Out	11.30%
Films/Movies	17%
Massage	4.40%
Music (all types) – Individual and Group	63.30%
Outings	27.20%
Pets	10.10%
Radio	7.60%
Books, Magazines and Newspapers (including being read to)	27.8%
Shopping/Sales Of Beauty Products, Clothes And Plants	5.10%
Singing/Karaoke	32.90%
Socialising	27.20%
Aquability	9.50%
Table Games/Bingo/Quizzes	31.60%
Theatre/Shows	8.90%

In comparison, serious leisure, such as the methodical pursuit of an amateur or hobby occupation, requires determination, valuing the process rather than the product, leading to a sense of accomplishment. This kind of occupation could involve collecting, making, competing, or being an enthusiast (Stebbins, 1998). Table 4 shows the serious leisure occupations carried out by residents at the home:

Table 4 Serious leisure occupations carried out

Leisure occupation	Percentage of total resident population who engaged
Art/Pottery/Knitting	19%
Gardening	14%
Family History	4.40%
Fundraising	3.20%
Poetry Group	2.50%
Language classes	0.6%

It is noteworthy that far fewer residents engage in serious leisure occupations. Lockwood and Lockwood (2007) suggested that highly dependent individuals tend to prefer a spectator role. The residents, tended to engage in leisure that was inactive or solitary (according to Pollock & Stewart's, (1990) survey data). In a spectator role, they could possibly feel independent rather than requiring help to engage in active leisure occupations. Their profound level of disability limits their opportunities to experience physically active leisure (Goodman, 1996), given their need for support, the absence of enabling adaptation and their desire to remain independent (Liverton, 1994). This is unfortunate because Liverton (1994) suggested that physical leisure occupations (when experienced) led to high satisfaction rates. The home's audit of leisure satisfaction, (carried out in 2007,) also suggested a desire for more challenging occupations. However, spectator leisure occupations appeared to dominate the experiences of residents of home's (e.g. Royal Hospital for Neuro-Disability (RHN) 2007), as illustrated by many of the occupations identified in Tables 3 and 4.

1.2 Summary

This chapter has described NPC, the demographics of the resident group, and casual leisure, to put the study participants into context and to demonstrate that the number of individuals with these conditions is rising, illustrating the importance of this topic to explore. It has also demonstrated that the residents who took part in the study had many opportunities for leisure. However, their profound disability created barriers to their participation, which could have led to a state of occupational deprivation. This discussion described the residents as a group, analysing their leisure opportunities.

Given what we know about the individuals with NPC, consideration of the literature around occupational deprivation and how its costs influence these individuals is required. The researcher believes that individuals with NPC could be at risk of occupational deprivation; unlike definitions in the literature, which seem to describe their position merely as occupational disruption, imbalance or alienation (Whiteford, 2004, 2010; Cronin-Davis *et al.,* 2004). This occupational deprivation could be aggravated due to the sensory gating deficits (Arciniegas *et al.,* 1999) experienced by individuals with NPC, over which they have no control.

The next chapter will therefore provide an overview of the sensory concepts around leisure and occupations, and will then review the issues surrounding occupational deprivation.

Chapter TWO

Literature Review

Chapter Two reviews literature concerning the sensory concepts around occupations and occupational science, especially engagement and occupational deprivation, and their effects and relevance for NPC. It describes the search strategy to identify the literature about neurotypical and impaired sensory gating and sensory processing, sensory-deprivation, sensory-overload, and occupational therapy involving sensory modalities. The second part of the chapter gives an overview of occupational science and a discussion of the meaning and types of occupation, occupational balance, occupational deprivation and its relevance to NPC. It describes the effects of occupational-engagement and leisure and the influences on occupational-engagement other than the sensory influences which made up the earlier part of the chapter and finally the human costs of occupational deprivation.

2.0 Search Strategy

The literature used includes psychology, neuroscience, occupational science, therapeutic recreation, neurological rehabilitation, and occupational therapy. The search included peer reviewed documents published in English from 01/01/1990-28/03/2012, which were mainly about human subjects. The search used the Boolean/Phrase Search terms presented in appendix iv. The literature search used EBSCOhost, to interrogate several literature databases at once. The E-Journals database includes electronic journals, MEDLINE includes medical articles, and PsycARTICLES® and PsycINFO®, include articles about psychology, behavioural science and mental health. The Teacher Reference Centre includes education journals, while the eBook Collection includes eBooks. The SPORTDiscus database includes sport and fitness related journals, while CINAHL Plus® includes nursing & allied health journals. The literature reviewed highlighted the different effects between how individuals with different disorders coped with sensory stimulation.

There are several different types of literature reviews, with varying degrees of rigour (Roundtree *et al.,* 2008). Narrative reviews such as this one include an overview of a papers findings and discussion, which could reflect the reviewer's bias in both the summarising and the selection of the literature to give a summary of a broad topic (Cook *et al.,* 1997).

In contrast, a systematic approach to reviewing the literature uses an explicit search strategy (Sauerland & Seiler (2005), Mullen & Ramirez (2006), Petitti (1999) which includes the search terms (and implicitly the inclusion/exclusion criteria) to limit bias in identifying the studies to review (Cook *et al.,* 1995). A systematic literature review includes a critical appraisal of each paper located to give a summary of the literature on a specific topic. However, it could not link the evidence into a whole narrative underpinning a body of evidence (Cook *et al.,* 1997) and so would not "tell the story"; which is why the researcher offered a narrative review. At their best, systematic literature searches and reviews enforce higher standards, thereby drawing more conclusions, making them more appropriate to incorporate into research. To demonstrate the quality

of the literature, it is necessary to review the methodology selected, and the conclusions drawn (Moher *et al.,* 1998, Huwiler-Muntener, 2002), particularly when they report new or competing intervention recommendations (Shea *et al.,* 2001).

Greenhalgh *et al.* (2004) proposed meta-narrative literature reviewing, which presents the storyline of research into a body of knowledge, commenting on the methodology and rigour of what they called "an associated set of primary studies". This thesis uses just such a mixed approach i.e. a systematic search strategy to identify the literature. The research questions result from the narrative format and argument proposed, i.e. it attempts to "tell the story" behind the research topic prior to designing the study. Furthermore, after data collection, the literature was re-reviewed (using this meta-narrative approach) to inform and update the discussion of the results.

2.1 Sensory Concepts

This section reviews of literature concerning the sensory concepts around occupations, especially engagement and occupational deprivation, and their effects and relevance for NPC. It describes the literature about neurotypical and impaired sensory gating and sensory processing, sensory-deprivation, sensory-overload, sensory-based theory, occupational therapy involving sensory modalities, including SI and the MoSP. These concepts will be linked with those of occupational science in the chapter summary.

2.1.1 Neurotypical sensory processing

Neural processing of sensory information in typically developing (neurotypical) individuals is continuous (Cisek & Kalaska, 2010) and occurs throughout the brain (Nolte, 2007). As an example, the ventral stream (which recognises shapes and objects over a long-term period) supplies information for the selection of behaviour based on information from the basal ganglia and from the regions of the prefrontal cortex that foretell the rewards of any planned behaviour (Sheth *et al.,* 2011). This makes sensory processing sound like part of a perception–cognition–behavioural process, since Cisek & Kalaska (2005) suggested that cognition and sensorimotor control were linked. However, behavioural responses result from cortical–basal ganglia interactions (Nolte, 2007), which includes predictions (about the rewards for the behaviour) generated within the cerebellum (Koziol *et al.,* 2011). Nolte (2007) therefore describes sensorimotor interaction, or behaviour as reflexive, rather than a perception–cognition–behavioural process (Cisek & Kalaska, 2005).

The first part of the sensory process occurs within the sensory receptors, which include the epithelial cells that line the cavities and cover the surfaces of structures and connective tissue throughout the body. The epithelium converts chemical, mechanical and sensory stimulation detected by the body, from the environment into an electrical signal (Vanzetta & Grinvald, 2008), which travels via the central nervous system to the brain for processing (Nolte, 2007). These cells occur in and around the ear, tongue, skin, nose, eye, muscles, joints and viscera (Nolte, 2007). The screening and processing of information occurs within the Reticular Activating System (RAS) in the brainstem, which regulates alertness, consciousness and circadian rhythms (Sherwood, 2010). This processing of information, influences occupational-performance by maintaining muscle tone, controlling reflexes, movement and visceral functions, assisting in the regulation of breathing, heartbeat, wakefulness and attention, and processing sensory information (Edmans, 2010; Nolte, 2007).

Processing sensory information enables the individual to understand their internal and external environment and the relationship between the two, thereby supporting occupational-performance (Dunn, 2009). Sensors map the internal environment, which informs the brain about body position, what is happening to the skin, where the body is within the occupational context, movement, and what is in the mouth, light and colour, sounds, and smells (Dunn, 2009). This makes the occupational context a key variable in the Occupational Therapists domain of concern (AOTA, 1994).

Sensory information leaving the RAS goes in two directions. While sensory-specific cortices respond to uni-sensory stimulation, multiple sensory stimulations combine to produce multi-sensory integration (Macaluso, 2005; Todman, 2008; Harrison *et al.,* 2008). Therefore, occupational-performance requires both uni-sensory and multi-sensory processing.

- The brain divides both anatomically and functionally – e.g. the frontal lobe deals with thinking, the parietal lobe with visuo-spatial processing, the occipital lobe with sight, and the temporal lobe with smell and sound (Hagmann *et al.,* 2008). The coordination of uni-sensory inputs occurs within uni-sensory lobes of the brain (Pirotte *et al.,* 2008; Marrelec *et al.,* 2008).
- However, multi-sensory information processing also occurs to enable occupational-performance (Spence *et al.,* 2009).
- Sensory integration is the result of processing the uni- and multi-sensory inputs in the RAS and interpreting them in different areas in the brain. Through SI, the brain relates many sensory attributes to understand the internal and external environment.

2.1.2 Impaired sensory gating or sensory processing

Occupational Therapists acknowledge the presence of sensory integration, sensory processing, and sensory modulation disorders (SMD). For example, Bar-Shalita *et al.'s* (2009) experimental study suggested that sensory modulation disorders include hypo and/ or hyper-responsiveness to sensory stimuli when writing up their pilot study of the Participation in Childhood Occupations Questionnaire. Miller *et al's.* (2007) collation of evidence from literature reviews, focus groups, case studies, and pilot studies, categorised SMD into three subtypes. These included sensory over-responsivity, sensory under-responsivity, and sensory seeking/ craving, which James *et al's.,*(*2011)* exploration of SMD involving 98 participants later disputed, while Koziol *et al.* (2011) suggested that they did not help the observer to understand the behaviours observed.

In fact, the existence of sensory integration, sensory processing, and SMD is controversial. While the Diagnostic Classification of Mental Health and Developmental Disorders in Infancy and Early Childhood (National Centre for Clinical Infant Programs 2005) includes Regulation Disorders of Sensory Processing, neither sensory integration, sensory processing, nor SMD are present in the DSM-IV or ICD-9. However, Owen et al (2013) highlighted a decrease in white matter structural integrity in individuals with sensory processing disorder. Koziol *et al.* (2011) suggest that problems of sensory processing have not been relevant to the fields of psychiatry, neuropsychiatry, or neurology, and only appear in the language of the Allied Health Professions. However, despite the lack of supporting evidence, Occupational Therapists continue to use sensory-based therapies with individuals with behavioural disorders and developmental disabilities (Rosen *et al.,* 2012).

The meaning of the term “sensory” lacks clarity in the eyes of Koziol *et al's.,* (2011) rather ill informed and biased literature review. Therefore, this section will attempt to define sensory processing. Dunn's (1997) Model of Sensory Processing (MoSP) (Figure 2) describes categories of behavioural strategies which rely not only on sensory stimulation, but on personality traits such as being passive or active in their response to stimuli and so appear multifactorial to non AHP's such as Koziol *et al.* (2011). Furthermore, Koziol *et al.,* criticised the Sensory Profile assessment (Brown *et al.* (2001) because it mixes unisensory (auditory, visual, tactile, oral) factors and multisensory processing within each category and it mixes observed and attributable emotions and behaviours (Myles *et al.* 2004). Bagatell (2012) also collected data about the behavioural and attributable aspects of engagement. Some of these categories are criticised by Koziol *et al.* (2011) because they include endurance and tone, affect, emotional and social responsiveness. Arguably, these could have no link to sensory processing, overlapping with behaviours listed in the biomedical model diagnostic categories of the DSM.

To make things even less clear, proprioception and vestibular stimulation are part of the sensory experience of sensory processing, which must be surprising from a medical model standpoint. This could have influenced James *et al.* (2011) whose experimental study identified two subtypes of sensory processing problems. One was externalised and the other internal to the individual, both however, could lead to behavioural presentations. According to Godot (2006) and Maddux *et al.* (2004) the biomedical model has a deeply entrenched influence on psychological research, assessment, and treatment which Wampold (2001) suggests is a position based more on custom and practice than empirical evidence. This led the researcher to challenge the validity and appropriateness of Koziol *et al's.* (2011) standpoint.

Damage to the RAS could reduce an individual’s ability to analyse and respond to undifferentiated and rapidly presented stimuli such as those experienced during casual leisure occupations, e.g. watching a musical firework display (Stonier, 2008; Wood, 1991). This damage could therefore influence cognition and sensory motor functioning, reducing processing capacity leading to attention deficits, and its resulting memory problems (Kumar *et al.,* 2005). Wood (1991) also suggested that sensory regulation for individuals in Vegetative States prevents sensory-overload whilst unconscious, which could slow recovery by focussing energy on processing unnecessary information. He suggested that the unconscious individual experiences constant sensory noise or overload, which could potentially deepen their Vegetative State. Wood therefore suggested a modified sensory environment, which neither over-aroused nor habituated the individual was used, introducing limited stimulation interspersed with rest. This is a similar conclusion to Kovach’s model of imbalance in sensoristasis (2000). Sensory gating was not an acknowledged phenomenon at the time of Wood’s (1991) proposals. However, he described a similar phenomenon in brain-injured individuals, advocating the use of an individualised sensory programme. Unfortunately, the use of a sensory profile prior to offering sensory stimulation to determine sensory preferences and sensitivities is not yet standard practice at the home, leading to conclusions, based upon third party perceptions.

Howell's (1999) literature review linking the RAS to occupational performance, suggested that Intensive Care Units provide individuals with an environment that, in combination with their condition, could overload them or deprive them of sensory stimulation, and could lead to hallucinations, reduced concentration, anxiety and confusion. The similarities between Howell’s participants and individuals with NPC included restricted movement, reduced cognitive functioning, lack of stimulation while unattended, and occupational deprivation. Similarly, individuals with NPC could experience simultaneous

sensory-deprivation and overload, or sensory-deprivation could switch to sensory-overload after receiving unexpected stimulation following a period of deprivation.

Other studies in low-stimulus and meaningless environments suggested that awareness depends on the interaction between the RAS and the cerebrum, and that a range of stimuli are necessary to support adaptive behaviour, according to Meyer *et al's.* (2010) and Parent's (1978) experiments. A sensory imbalance may leave the RAS unable to prioritise, organise, or interpret information (Howell, 1999; Meyer *et al.,* 2010). The resultant disorientation, hallucinations, confusion, reduced concentration and agitation are non-observable, they are attributable as causes of behaviour, such as those internal states described by James *et al.* (2011) and Bagatell (2012) which has informed table 7. By observing behaviours such as those reported by Howell (1999), sensory processing can be measured, "using measures of behavioural response to sensation" (Brown *et al.* (2001, pp. 75). This is possible because (as suggested in Granberg et al's. (1996) qualitative study) an observable change in behaviour may result from a combination of sensory-overload and deprivation. However, Wood (1991) suggested that sensory-overload or deprivation was due to changes in awareness, rather than changes in arousal (which is more dependent on vigilance than awareness, according to Parasuraman's (1983) book chapter. Consequently, in spite of all these studies, publications such as Wortzel & Arcinegas' (2011) experimental study continue to suggest that there is limited evidence to support the use of coma stimulation.

Alteration and interruption to sensory processing could result in disinhibition and excitation of body processes such as levels of arousal, cardiovascular function, and respiration (Zec *et al.,* 1996). Arciniegas *et al.* (1999), Nagamoto *et al.* (1989), Adler *et al.* (1993) and Freedman *et al's.* (1994) experimental studies all suggested that distractibility, inattention, and perceptual and memory problems resulted from this disruption, particularly following damage to the RAS, giving sensory processing another name: sensory gating. Sensory gating could therefore influence an individual's ability to process sensory information and participate in occupations. This process has a similar function to the sensory processing described by Dunn (1997).

Research conducted into the effects of sensory gating deficits has included a range of clinical conditions. For example, Arciniegas *et al.* (1999) demonstrated disturbances in sensory gating in individuals with traumatic brain injuries using physiological tests. The researcher's suggested that the sensory gating deficits found were similar to those of individuals with Alzheimer's disease and Schizophrenia. Arciniegas *et al.* (1999) was the first article linking NPC with sensory gating deficits, and thus that, on the one hand, sensory stimulation enables normal functioning, but on the other hand, impaired processing of sensory stimulation leads to impaired functional ability, which is crucial to the theory of SI (Ayres, 1979).

Other experimental research into the effects of sensory gating deficits has included conditions such as Alzheimer's disease (Cancelli *et al.,* 2006; Jessen 2001), Schizophrenia (Ringle *et al.,* 2004; Nagamoto *et al.,* 1989; Thoma *et al.,* 2003; Wan *et al.,* 2006), post-traumatic stress disorder (Ghisolfi *et al.,* 2004), Huntington's Disease (UC *et al.,* 2003), Multiple Sclerosis, Parkinson's Disease (McCarley *et al.,* 1997; Morton *et al.,* 1995), Autism Spectrum Disorder's, and head injury (Kumar *et al.,* 2005). All these conditions have in common the impairments reported by Arciniegas *et al.* (1999).

Freedman *et al's.* (2002) experimental medication trial suggested that schizophrenia-related deficits in sensory gating could correlate with behavioural reports of difficulties in filtering stimuli, coupled with sensory inundation. However, the only empirical exploration of sensory inundation among schizophrenic participants, refuted the concept having examined 32 participants with and without schizophrenia (Jin *et al.,* 1998). Experimental studies by Kisley *et al.* (2004) (on healthy adults) and Freedman *et al.* (2002), confirmed that electrophysiological parameters of sensory gating and behavioural factors may be associated with perceptual modulation, but unrelated to over-inclusion or distractibility. McGhie, et al (1961) described sensory inundation and inappropriate orientation to irrelevant stimuli, as either an attentional or a perceptual disorder.

Kumar *et al's.* (2005) experimental study explored the impacts of sensory gating on concussion following brain injury, using Bunney *et al*'s*.,* (1999) Structured Interview for Assessing Perceptual Anomalies and the Neurobehavioural Rating Scale. Kumar *et al.* concluded that post-concussive symptoms such as reduced processing capacity, attention and memory, as well as behavioural changes caused by anxiety following head injury, were likely to result from sensory gating deficits. This further evidence of the impact of sensory gating, contributes to the justification for studying the effects of sensory stimuli on the engagement of individuals with NPC, especially given the anticipated impact of these symptoms on occupational performance.

Pfeiffer & Kinnealey (2003), Kinnealey *et al.* (1995) and Pfeiffer's (2002) experimental studies all suggested that sensory processing could have a social–emotional impact. They suggested that sensory defensive individuals could feel anxious and uncomfortable in social situations and having to adapt or eliminate activities because of their responses to sensory stimuli in those contexts. Kinnealey and Fuiek (1999) and Pfeiffer & Kinnealey (2003) suggested a significant relationship (following experimental studies) between the level of anxiety and sensory defensiveness in adults to the point of interfering with occupational-performance (Pfeiffer & Kinnealey, 2003).

Pfeiffer & Kinnealey's (2003) experimental study explored the relationship between sensory defensiveness and anxiety, and suggested that the effects of sensory defensiveness extend beyond observable social–emotional behaviours. Sallee and March (2001) supported the RAS's involvement in controlling arousal and attention levels and linked this to the emotional distress associated with anxiety disorders. They further reported that the limbic system, amygdala and hippocampus affect the emotional-processing circuits, linking sensory defensiveness and RAS dysfunction (Lane, 2002). Pfeiffer & Kinnealey (2003) provided additional support for the relationship between emotion and sensory processing/ gating dysfunction.

Myles *et al's.* (2004) multivariate analysis of assessment results, suggested that SI dysfunction manifests itself in terms of (a) low endurance and tone, (b) poor registration of stimulation, (c) tactile challenges, (d) fine motor/ perceptual problems, (e) self-regulation, and (f) oral sensitivity. This view coincides with other studies such as Ayres & Tickle (1980), Bagnato & Neisworth (1999), Ermer & Dunn (1998), and Kientz & Dunn (1997). Furthermore, Ayres (1964) initially suggested that sensory defensiveness could lead to fearfulness, cautiousness, or avoidance. Sensory defensiveness is the behavioural manifestation of a dysfunction in sensory processing/ gating altering the individual's capacity to regulate and organise the quantity, quality, and type of response to sensory stimulation (Lane *et al.,* 2000). The literature around sensory processing emphasises its possible impacts on functional abilities, behaviour, emotional aspects and mental health (Engel-Yeger & Dunn,

2011). To come to this conclusion Engel-Yeger & Dunn (2011) studied 135 healthy individuals' sensory profile and Spielberger's State-Trait Anxiety Inventory results. The impacts on functional abilities, behaviour, emotional aspects and mental health should be evident, because the Sensory Profile measures problems with sensory processing and concomitant behavioural and emotional/reactivity responses to sensory stimulation (Myers *et al.*, 2004). Therefore (like James *et al.,* 2011 and Bagatell, 2012) an interview with the Residence Manager (chapter four) will consider both attributable and direct behavioural responses to sensory-overload, which will include behavioural manifestations of emotions such as anxiety.

2.1.3 Combined sensory thresholds

Many investigators have tried to determine whether there is a point at which a stimulus becomes noticeable, what factors influence the threshold of stimulus detection, the difference necessary between two stimuli (e.g. the number of sensory attributes offered) in order for them to become distinguishable, and even whether combined sensory thresholds exist (Swets, 1961). Some have suggested that these thresholds are unstable, while others hold that they follow a normal distribution of combined sensory levels (Swets, 1961). Moreover, Swets (1961) also suggested that overly positive observers could attribute sensory excitation to increased sensory stimulation when it should be attributed to a lack of sensory gating. This was potentially a threat to this thesis, avoided by using the preliminary study to define the signs of overloaded non-engagement in this population.

Additionally, Luce and Edwards (1958) suggested that low-level stimulation could be difficult to detect if the combined sensory threshold was lower than the level of environmental interference or noise. Above the combined sensory threshold, Swets *et al's.* (1955) low threshold theory suggested that sensory excitation would be perceived within the distribution range of general environmental interference. These two studies appear to imply that at the extremes of sensory stimulation intensity, environmental interference could influence the detectability of sensory stimulation (masking it or exaggerating it).

Swets (1961) assumed that the observer's attitude could affect the threshold. This supported the DCS' stipulation that observations were made only by experienced observers, who (she perceived) would gather informed and consistent data. However, this informed stance could equally have led to bias. Swets (1961) acknowledged that experimental study designs cannot adapt the observer to detect combined sensory thresholds (which vary continuously) on the one hand, whilst limiting them to collecting data against pre-determined categories of response on the other. The ideal observer theory (Geisler, 2011) suggests that observations depend on the concrete measurability of the factors observed, which would appear non-applicable to an occupational context, due to the lack of neuropalliative specific measures of engagement.

Swets (1961) further suggested that all data contained some unintended environmental interference or sensory processing, both of which could vary continually. For that reason, Swets *et al.* (1955) concluded that there could be a combined lower sensory threshold near to the mean level of environmental interference (Swets, 1961), making it difficult to gather reliable data below it. Guest & Spence (2003) conducted a series of randomised studies of attention which suggested that sensory discrimination is most effective when stimulation to multiple senses occurs in combinations of two senses. Additionally, Swets (1961) suggested training the observers to avoid false positives by gaining experience of what they are observing (signs of engagement) and the measures used (in this case, piloting the ICER). Training them to criterion to avoid false positive responses was also suggested to be useful, which informed this study. Swets (1961) also suggested that

overloading the observers with the signs of engaged and non-engaged behaviour, as well as the definitions of each engagement category, was unhelpful. To overcome this problem the measure used in this thesis was reframed in such a way that the observer was looking for negative responses, and so had to opt out of the pre-populated positive response, which influenced the ICER format used in this thesis (Appendix v). Additionally, it appears that other researcher's have also considered the factors that contribute to the occupational context and could influence whether a sensory stimulus is perceived. They highlighted that the threshold at a low level could vary in detectability, casting doubt on the potential non-engagingness of the lower level casual sensory leisure occupations.

2.1.4 Sensory-deprivation

Sensory-deprivation results from a reduction in variety, meaning, or intensity of stimulation (MacKinnon-Kesler, 1983), causing a reduction in attention (Parent, 1978). Sensory-deprivation results from long term stimulation according to Zuckerman's (1964) review of experimental articles (some of which would now be regarded as unethical). In his book about floatation tanks, Hutchison (2003) gives examples of how unvarying stimulation include the effects of the touch of clothing, gravity, temperature, sounds and light on the nervous system, muscles, and sensory receptor organs; so that unless a change in stimulation occurs, habituation results. Experimental studies have suggested that sensory-deprivation causes negative outcomes such as the weakening or removal of synaptic connections within the brain (Finnerty *et al.,* 1999; Allen *et al.,* 2003; Shepherd *et al.,* 2003; Schierloh, 2003; Bender *et al.,* 2006), and could lead to altered consciousness (Tart, 1990). While Wallace & Fisher's (1991) textbook suggested that a reduction of stimulation following a period of over-stimulation could be relaxing; a total removal of sensory stimulation could result in hallucinations while the brain tries to fill the gaps in information.

Stagnant stimulation, exacerbated by physical, sensory and cognitive impairments, may compound the problems which result from group rather than individualised leisure, such as specific sensory needs being missed (Baillon *et al.,* 2002). The resultant lack of appropriate stimulation could lead to stress, withdrawal, depression, reduced motivation, anxiety, agitation or disturbed behaviour (Baillon *et al.,* 2002) as well as diminished abstract thinking, according to Harrison & Newirth's (1990) controlled trial. Furthermore, Zubek's (1964) experiments, and Parent's (1978) article both suggested that deficits in motor coordination, cognitive abilities and perception could result from a sensory-deprived environment. Sensory-deprivation and subsequent behavioural changes such as hallucinations, confusion and decreased concentration could occur very rapidly (Heron, 1961; Menon *et al.,* 2003), the findings of these two experimental studies therefore reinforced the requirement for sensory balance, between what could be over- or under-stimulating for each individual (Brown & Dunn, 2002). Therefore, stimulation should be available to residents in adjustable amounts to avoid sensory-deprivation or overload.

Perhaps the most widely explored forms of sensory-deprivation are among those with visual and auditory impairments, and these studies have highlighted the conflicting outcomes of sensory-deprivation. Sensory-deprivation is suggested to be largely detrimental, other studies suggest that deprivation in one sensory organ leads to the enhancement of the remaining, functioning sensory systems. For example, Chan et *al's.* (2011) experimental study suggested that many of the studies on cross-modal plasticity have involved participants with a visual impairment. Cross-modal plasticity allows information from different senses to be amalgamated to inform behaviour. Among visually impaired participants, there was a

heightened activation of the occipital cortex as a response to auditory or tactile stimuli (Lewis *et al.,* 2010). Furthermore, Collignon *et al's.* (2011) book chapter suggests that a visually-deprived occipital cortex may have higher degrees of organisation and specificity as compared to non-visually impaired subjects. Moreover, several studies revealed that deprivation of auditory senses could lead to the recruitment of the brain's auditory areas for visual or somatosensory functions instead (Finney *et al.,* 2001 (brain imaging experiment); Sharma, 2007 (editorial)). Similarly, experimental evidence suggested that stimulation of the auditory system in long-term visually deprived subjects could lead to the activation of the visual cortex (Piché *et al.,* 2004).

2.1.5 Sensory-overload

Harvey's (2010) book chapter, suggested that sensory-overload resulted from increased quantity or quality of internal stimuli, such as pain or anxiety, or external stimuli, such as intrusive diagnostic tests, contact with strangers, or an inability to disregard stimuli selectively. Studies of complete or partial sensory-overload have included individuals with developmental or psychiatric conditions who could have neurological elements to their symptomatology, but few have involved individuals with exclusively neurological disabilities.

Sensory-overload can lead to partial or total shutting down, either temporarily or long-term, in response to either momentary intense or prolonged low-grade over-stimulation. Bunney *et al's.* (1999) qualitative study suggested that an inundation may cause inability to understand or react appropriately, a phenomenon also known as dissociation. In particular, visual and auditory sensory-overload occurs when unexpected (high quantity or intensity) stimulation occurs, e.g. a phone ringing after a period of silence (MacKinnon-Kesler, 1983). This inundation overloads the brain, which compensates by diverting attention away from lower status or intensity stimuli. Granberg *et al's.* (1996) literature review suggested that this reduces attention, differentiation and responses to additional (often-ignored) stimuli.

Behrendt's (2006) literature review suggested that passivity and hallucinations could follow a period of over-stimulation. Wood's (1991) analysis of sensory stimulation for vegetative individuals suggested that low awareness could reduce selectivity, allowing irrelevant stimuli to be processed, thus adding to the sensory-overload. Additionally, Martin *et al.* (2012) and Edmund and Morris (2000) suggested that people become bored by the increasing amount of irrelevant or interfering information processed each day, which may become background 'noise'. This noise could leave the individual feeling overloaded and unable to process fast enough, which Parasuraman and Purohit's (2000) survey data described as distressing, frustrating and leading to disconnectedness, boredom and anxiety. Total sensory-overload could leave an individual unresponsive, with altered muscle tone, and losing all ability to function, having shut down, eventually sleeping, and on waking, needing time to recover, whilst being more susceptible to repeated overload (Miller & Loos, 2005). Simultaneous sensory-deprivation and sensory-overload (Howell, 1999; Easton & MacKenzie, 1988; Geary, 1994; Glide, 1994; Sosnowski & Ustik, 1994) may decrease cognitive functioning, causing visual, auditory, or perceptual hallucinations (Howell, 1999), agitation, restlessness, confusion, and anxiety (Easton & MacKenzie, 1988; Geary, 1994).

Environments that result in an inappropriate level of stimulation are common in daily life – e.g. when leaving a crowded concert. The throng of individuals, the bright lights, loud noises, sights and smells all at once could be overloading. In

contrast, an under-stimulating environment could be a library or an examination hall, where silence reigns for long periods. After time in such an environment, an individual could seek additional sensory stimulation by shouting as they leave. Like occupational deprivation, these examples include limitations to control and choice for individuals with NPC, who cannot escape or verbalise their distress easily, (according to Glide's,(1994). Therefore, they could experience sensory-deprivation or sensory-overload, with the RAS being unable to organise the confused, jumbled, and inaccurate information, received from ineffective sensory gating, poor sensory adaptation, and impaired perception. All of which could influence the individual's occupational capacity.

Howell's (1999) literature review hypothesised that to address sensory problems; interventions should remediate sensory impairment rather than addressing the behavioural outcomes attributed to the individual. This could involve altering the amount and type of sensory stimulation received (Parent, 1978), to improve the function of the RAS and reduce the behavioural alterations, and occupational performance. Wilbarger and Wilbarger's (2002) book chapter refers to this approach as the sensory diet (a selection of individualised sensory stimuli offered across the entire range of sensory receptor organs), while Wood (1991) refers to this as sensory regulation.

The link between sensory processing and occupational-engagement will be further explored. The context influences behaviour, which should be considered when assessing the individual's potential for occupational-engagement (Dunn *et al.,* 1994). Likewise, Majic *et al's.* (2011) experimental study suggested that sensory gating and sensory processing protect the individual from sensory inundation and overload. The signs of sensory-overload may include hypersensitivity to touch and sound, distractibility, emotionality, social withdrawal, hyperactivity, difficulties with self-regulation such as anger management (wizzkids, 2011). Furthermore, overloaded individuals could experience impulsiveness, incoordination, and altered speech skills. Other examples suggested by Hahn's (2012) literature review include visual, auditory, touch, taste, smell, proprioceptive and vestibular sensitivity. Notbohm *et al's.* (2010) book described signs of sensory-overload such as a loss of balance and body orientation, flushed or pale skin, refusal to participate, altered pulse, crying, sweating, agitation or anger, echolalia, repetitive calming behaviours, or physical aggression. Delaney's (2008) book also mentions oral defensiveness, and altered muscle tone. Monologueing and perseveration could also worsen in overloading environments, according to (Turner, 1997) book chapter. Sensitivity to sensory attributes, a defensive protective reflex and an exaggerated startle reflex could be active longer after stimulation than usual. Furthermore, they discuss distractibility or hyperactivity vs. passivity and withdrawal. Furthermore, Wilmshurst's (2010) casebook described a loss of balance, and poor coordination. Individuals experiencing significant sensory-overload may experience pain in response to visual and auditory sensory stimulation (Sainsbury, 2000; Murray, 2006). Hahn (2012) and Cascio *et al.* (2008) suggested that when overloaded sensory stimulation appeared magnified, taking over all thought processes. This could encourage the individual to over focus on minutiae (Hahn, 2012), experiencing reduced orientation to time place and person, and slower information processing poorer thinking, learning and memory (Shearer *et al.,* 2006; Williams, 2006; Majic *et al.*, 2011).

Pillay & Suniti Bhat's (2012) literature review, added reduced ability to vocalise, and resorting to humming and grunting, which could interfere with communication with supporters, according to Clare *et al's.* (2012) validation article. Furthermore, Falk-Ross *et al's.* (2004) strategies for teaching highlighted increased word finding difficulties. Bellando & Pulliam's (2009) clinical guidance article suggested a reduced ability to maintain eye contact as a way to stave off a negative physiological response to the over-stimulation. Tortora's (2011) book added being less able to direct their eye gaze. While,

Language and communication, social skills, peer relationships, self-regulation, and adaptive behaviour may be at risk according to Pfeiffer *et al's.* (2011) pilot RCT study and Koenig *et al's.,* (2009) model. Additionally, Williams (2006) book about the insider's experience reported a reduced understanding of speech or sounds, influencing social interactions (Clare *et al.,* 2012). Similarly, having a monotone tone of voice (AllPsychologyCareers, 2010), could suggest that the individual was bored or disinterested, rather than being overloaded. Furthermore, Melnyczuk's (2010) book suggested that lower mood results. Cascio *et al's.* (2008) experimental study described heightened auditory acuity, while, Grandin (2000) described moving in a stereotypical manner to shut out painful sounds, as well as difficulty with distinguishing the specific stimulant from the background. Furthermore, Hahn (2012) reported problems with dressing, moving around in a space or general clumsiness, reduced balance and posture, or the ability to maintain previous speed and direction of movement. In 1972, Ludwig described the "psychedelic effects," of sensory-overload experienced by individuals experiencing a stimulation inundation, which could result in disturbances in the individuals' sense of time, feelings of a loss of control, somatic effects, reduced reality testing, and "otherworldly" emotions could result from sensory-overload.

Williams (1995) suggests the potential to overwhelm susceptible individuals with very small alterations in sensory stimulation. Additionally, Attwood (2007) described the distress caused by stimulation which is sudden and unexpected, or which is confusing and complex. Furthermore, avoidance behaviour could increase as individuals become more overwhelmed (for example Angeli & Whitehorn's (2004) book; and Dunn *et al's.* (2002) preliminary investigation). Cascio *et al.* (2008) described how an individual experiencing sensory-overload could be hyposensitive to one stimulus and yet hypersensitive to another in the same moment.

2.2 Sensory-based theory and Occupational Therapy Practice

In her national conference keynote presentation, Dunn (2001) suggested that human experience reflects the sensory events of everyday life to such an extent that personal sensory processing and preferences could define our individuality. Therefore, sensory processing is a domain of concern for Occupational Therapists because it influences occupational-engagement (according to Brown *et al.* (2001)). Sensory processing is described as a performance attribute by AOTA (1994), which Occupational Therapists usually assess in terms of behavioural responses (Brown *et al.*, 2001). Furthermore, sensory stimulation influences occupational-performance (Dunn, 2001; Ayres, 1979), and links to cognitive level according to Allen's (1985) and Pool's (2007) resource books. Additionally, Kovach's (2000) literature review described the need for a balance between sensory-stimulating and sensory-calming activity, and proposed that sensory imbalance caused agitated behaviour and a decline in occupational-performance and social skills. Kovach's (2000) model of sensoristasis explained the challenging behaviour of individuals with NPC who experience under-stimulating environments, or who cannot explore their environment due to their limitations (according to Lewis's (2006) PhD thesis). Therefore, leisure could offer opportunities for individuals with NPC to experience sensoristasis and optimal arousal (according to books such as Ellis (1973) and articles such as Jennett (1992, 1993).

Hollingsworth's (2007) literature review and Dunn's (2009) book suggest that "not only are people sensory beings, but the world is a sensory place" leading to constant sensory stimulation which must be processed to function effectively. This

philosophical stance stems from the occupational therapy profession's belief that occupational-performance is contextual. The CMOP-E (see glossary) as presented in Polatajko *et al's.* (2007) book, and describes occupational-performance in terms of the person doing it, the occupation and the environment surrounding it. Therefore, the holistic vision of occupational therapy goes beyond the biopsychosocial elements, according to (Trentham & Cockburn's, (2011) book chapter. As such Occupational Therapists take a holistic occupation-focussed view of engagement, considering the what, why and how of doing. The sensory attribute of the CMOP-E includes the person's sensory preferences, the occupation itself and the occupational environment (Polatajko *et al.,* 2007). Therefore, Occupational Therapists in particular, have studied sensory processing and its affect on individuals' everyday life (Dunn 2001).

It may be difficult for a person with a sensory processing dysfunction, to interpret sensory information properly and then act on the information received. This assumption builds on the belief that impairments can occur in some or all sensory systems including tactile, auditory, visual, gustatory, olfactory, proprioceptive, and vestibular systems, according to Bundy & Murray's (2002) book chapter. Occupational-performance and engagement could therefore be challenging for individuals with sensory processing problems. A significant number of individuals experience difficulty processing and integrating sensory information (e.g. Lane and Schaaf (2010) literature review), and this includes at least 15% of neurotypical and healthy adults who do not regard themselves as disabled (Engel-Yeger & Dunn, 2011). In fact, Ahn *et al's.* (2004) survey data, suggested that one in twenty individuals suffers from sensory processing disorder, while Ben-sasson *et al's.* (2009) experimental data, approximated that one in six individuals has a sensory processing pattern that influenced their occupational performance. However, a study by Miller *et al.* (2007) suggested that this was changeable, having conducted a pilot randomised-controlled trial on the effectiveness of combining SI with occupational therapy. SI interventions could therefore ameliorate the difficulties experienced by children with sensory modulation disorders.

Consequently, Occupational Therapists approach the sensory preferences of their clients from several stances. Firstly, some conditions have distinct patterns of sensory processing, which can influence the occupational therapy interventions (according to Dunn & Westman's (1997) experimental study). Beyond that, every human being's unique sensory profile could reflect genetic and socialised preferences (Dunn 2009), which link to an individual's temperament (according to Dairmant's PhD thesis (2011)), contributing to their uniqueness. The domains of neurological, developmental and mental health conditions particularly, reflect this in their research profile. For example focussing on the neurological domain, there were many Neurodevelopmental Theorists to influence practice during the 20th century (Cole, 2008) such as Margaret Rood, Berta & Karel Bobath, Signe Brunnstrom, Herman Kabat and more recently Janet Carr & Roberta Shepherd, which include a sensory component to intervention.

Occupational Therapists enable their clients to relearn occupational-performance skills (a rehabilitative approach) through therapeutic interventions, adapting the environment (a compensatory approach) to enable the person, the occupation and the environment to converge at a point where their occupational-engagement satisfies them. These neurodevelopmental theories espoused a behavioural learning approach to motor control based on the sequence of normal development, harnessing the effects of sensory stimulation to relearn normal movement after neurological damage. For example:

Rood, the earliest theorist, stressed the importance of reflexes (in response to sensory stimulation) and positioning in the relearning of sensorimotor control, aiming to normalise muscle tone and evoke voluntary movement (Cole 2008).

The Bobath's approach, focused on the sensation of movement; because it is this (not movement itself) that is learned and remembered. Their theory used Reflex Inhibiting Positions to inhibit primitive reflexes and discouraged the use of unilateral compensatory techniques (Cole 2008).

Brunnstrom's approach focused on reflexes that provide the attributes of normal movement and elicited these using proprioceptive (resistive) & exteroceptive (tactile) stimulation. Patients think about the movement whilst it was occurring to gain control over them (Cole 2008).

Kabat's proprioceptive neuromuscular facilitation approach used diagonal & spiralling patterns of movement to reproduce the sequence of normal development (Cole 2008).

Carr & Shepherd's motor relearning programme again emphasised the interaction between individual and environment, discouraged the use of compensatory strategies but did not accept the hierarchical sequence of motor relearning proposed by other theorists (Cole 2008).

Trombly's occupational functioning model combined reflexive and voluntary motor control and proposed experimentation with different strategies & contexts to learn motor skills (Cole 2008).

Moreover, Kamiloff-Smith (1998) argued that a developing brain is considerably more plastic than previous studies conducted on adult acquired neurological disorders suggested. Therefore a theory used by Occupational Therapists in helping residents recover following brain injury involves the principle of "use it or lose it." Neuroplasticity was suggested by Barbay *et al's.* (2005) and Nudo and Milliken's (1996) experimental studies, to protect neuronal networks that could be damaged following brain injury. In animal models, focal ischaemic lesions in the motor cortex led to the loss of ability to mobilise adjacent regions of the cortex. On the other hand, rehabilitative training of a reaching task was suggested to prevent neuronal loss and promote functional reorganisation (Kleim *et al.,* 2003; Nudo *et al.,* 1996).

Evidently, occupational therapy has a history of focussing on the sensory aspects of occupational-performance as demonstrated by the CMOP-E (Polatajko *et al.,* 2007) and other models which have included the occupational environment, not just the person and occupation. Unfortunately, the history of the profession and the evidence base behind OT mean that there are several examples (including Sensory Integration, Bobath) which have pervaded practice, but were not supported by research until later. In relation to NPC, sensory gating (Arciniegas et al, 1999) or sensorimotor gating (Kumari et al, 2012) and sensory processing deficits could further reduce the occupational capacities of individuals. This is significant, since the residents experience of leisure appears more likely to include casual than serious leisure (see tables 3 & 4). Casual leisure occupations are short-term in duration and effect, and tend to have a high sensory level (according to Stebbins (1997) conceptual statement). On the other hand, regulation of the combined number of sensory attributes offered could increase an individual's ability to process information and participate (Wood, 1991). Therefore, an understanding of sensory

processing could explain some of the difficulties that individuals with NPC have when they are engaging in occupations and especially leisure.

Nudo and Dancause's (2012) book chapter, suggested that neuro-rehabilitation was based until recently on empirical data, but without fully understanding the neural processes of recovery. Since the 1980's experimental evidence about neuroplasticity has been emerging which has suggested that behavioural approaches, robotics and nano-electronics and neural prosthetics will be the main approaches to therapy. Focussing on behavioural approaches results, demonstrating modulation of the auditory, visual and motor cortices' have reinforced the belief that neuroplasticity has a generalised effect across the entire brain, and that behaviour changes as a response to sensori-motor stimulation. Furthermore, Nudo and Dancause suggest that sensory stimulation may influence motor based behaviour, and that sensori-motor influenced behaviour may effect sensory processing and sensory gating in return.

2.2.1. Occupational Therapy involving sensory modalities

Green *et al.* (2006), Harrington *et al.* (2006), and Mandell *et al's.* (2005) survey data, suggested that sensory modalities are used during occupational therapy based on the belief that they enhanced sensory processing, SI and organisation, therefore influencing occupational-performance (according to Ayres (1972, 1979) books). Yet in 2010, Lane & Schaaf's literature review still suggested that there was little direct evidence that improved processing and improved SI influenced occupational performance.

To understand why Occupational Therapists focus on the sensory aspects of occupational performance, it is important to differentiate between sensory gating (the way in which the brain filters out unnecessary stimuli) and SI (the way in which the brain organises sensory information). In combination, they enable selective attention and association, attach meaning through comparing sensations with experience, enable motor coordination and thus are the basis of perception (according to Ayres (2005) book). Individuals experience degrees of sensory organisation and integration on a continuum which links skill level with SI effectiveness (Dunn 1999). Therefore, a high level of SI could enable expert occupational performance, whereas an individual with low SI could be clumsy or dislike the occupational environment (Ayres 2005).

Sensory processing limitations result from unsuccessful gating of sensory information. This could influence learning, self-image and coping with demands, resulting in emotional or behavioural difficulties (according to Bundy, Lane & Murray's (2002) book). Examples include hyperactive or inattentive individual's who are pulled from one stimulus to the next, unable to maintain the attention necessary for successful performance, and experiencing the world as confusing and threatening. To survive the sensory chaos, specific functions of the brain shut down making the individual appear to have a visual or auditory impairment or be 'slow' to function and react. To counter this, vestibular information acting on the reticular formation may result in a calm alert state. Experimental research by Cermak & Daunhauer (1997) and Lin *et al.* (2005), has shown that slow movement such as using a rocking chair may calm and organise an individual and could be substituted unconsciously by the individual e.g. pictures shown on TV of institutions full of silent children rocking back and forth (Cermak & Mitchell, 2006).

According to Dunn's (2001) review of the empirical, theoretical and pragmatic considerations around the sensations of everyday life, "the experience of being human is embedded in the sensory events of everyday life". Sensory preferences influence their responses to environments, individuals, situations, and occupations (Champagne, 2003b), while sensory preferences enable individuals to make sense of their environment (Bronson & Bundy's and Brown's research (both 2001)), developing strategies necessary to respond to their preferences, and adapt to the environment (Brown, 2001; Champagne, 2003b).

Examples of occupations using the seven sensory systems include:

- Eating, salty, sour, or sweet foods (taste).
- Listening to music or conversation (sound).
- Playing with a tangle ball, textured items or worry beads (touch).
- Reaching, joint compression/ weight bearing during any occupation, weighted blankets or using a bat (proprioception).
- Rocking, being joggled across uneven ground in a car or wheelchair, swinging or swimming (vestibular).
- Smelling lavender, coffee, or citrus (smell).
- Watching indoor birds or fish, looking out of a window, or at an artificial window projection (sight).

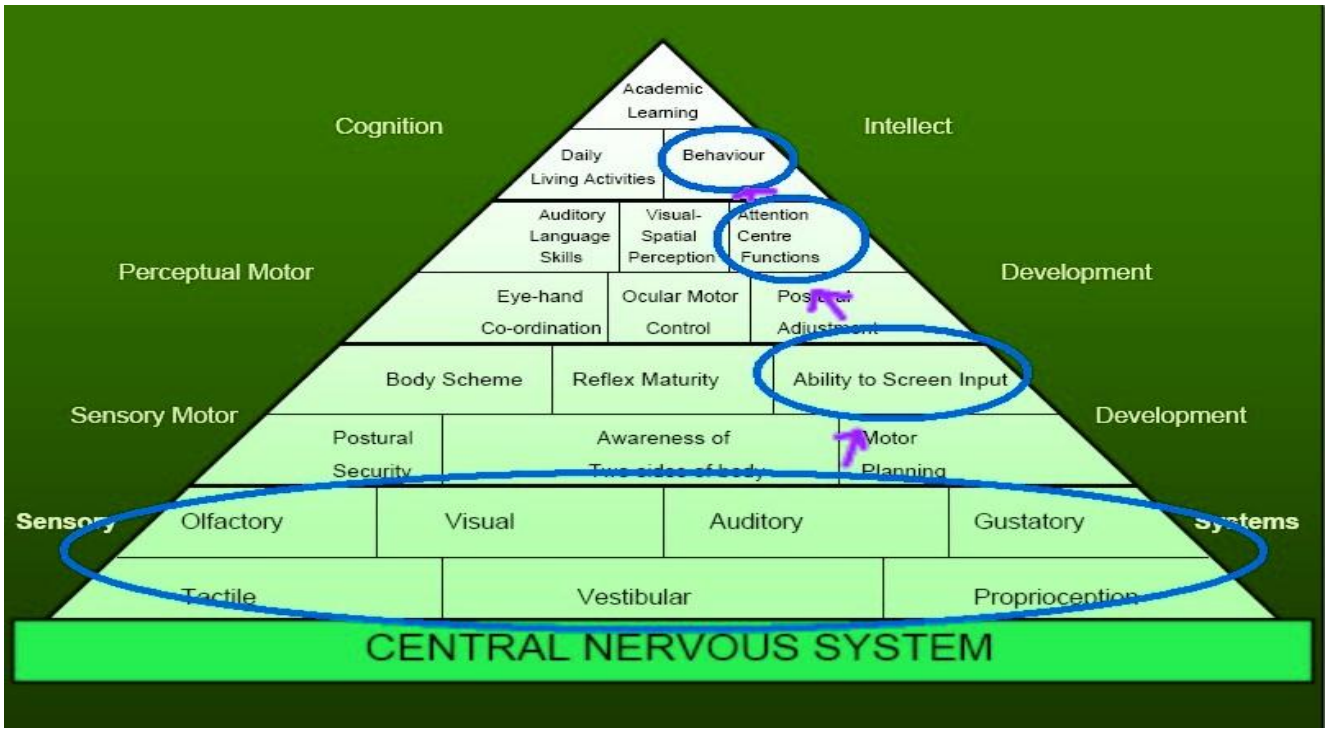
Thelen & Smith's (2000) book suggested that experience of the environment is informed by all of the senses. Williams & Shellenberger's (1994) training presentation demonstrated this using a pyramidal diagram (figure 1) adapted from Trott et al's (1993) training package about SI theory. A similar adaptation, in Mccarthy's (2004) conference presentation, portrays the hierarchy of sensory activity as a tree. All three perceive an integration between sensory stimuli and derive from the developmental progression of Jean Ayres (1969) who in turn enhanced the work of Gesell (1940). Therefore, the idea of a sensory hierarchy has been through many incarnations.

These diagram's all describe the interrelationship of different levels of a hierarchy of sensory stimulation processing and integration. No sense works in isolation and so sensory stimuli used in isolation could appear out of context; or in context with the environment (involving many senses, with some being predominant). For example, watching a scene through a window involves eye movements and their perceptual consequences, creating a spatial map in the brain (Thelen & Smith, 2000). Although the individual could focus on a primary source of sensation as coming from one, or many sensory systems; the sense making process involves integrating information and experience from both the sensory and motor systems, according to both Thelen (2003) and Thelen & Smith's (2000) books. Recent research on brain mechanisms of multisensory integration is challenging the view that sensory systems dealt with information from a single sense at a time. Ghazanfar & Schroeder's (2006) research proposes that integration between the senses occurs right from the very beginning stages of

sensory processing. Hence, most of the forms of stimulation and sensory- based occupations described in Borg & Bruce (2002) and Bundy, Lane & Murray (2002) and Champagne (2003b) textbooks have sensori-motor outcomes.

Williams & Shellenberger's (1994) (figure 1) hierarchy of sensory stimulatory activity, requires lower level occupations available for "success" at a higher level. This became part of a bigger picture of sensory motor evidence, when Feinberg's (2012) literature review suggested that the central nervous system included receptors and pathways that encode exteroceptive or interoceptive stimuli in order for the brain to organise sensory stimuli into patterns of behaviour. In 2012, medical research caught up with and reinforced occupational therapy beliefs about sensory integration, when Feinberg suggested that sensory stimulation slotted into and became part of a neural hierarchy. Feinberg (2012) and Williams and Shellenberger (1994) and many other writers in between portrayed sensory systems as contributing information to sensori-motor occupations such as motor planning, body scheme, postural security etc. These sensori-motor occupations contribute to higher-level occupations such as perceptuo-motor skills e.g. postural adjustment, which in turn contribute to cognitive processes such as behaviour, learning etc (see Figure 1). Thus, an occupation may require postural adjustment, based on postural security and awareness of the two sides of the body, and body scheme, all of which come about because of sensory attributes such as visual, tactile, proprioceptive and vestibular information. According to this model, the shutting down behaviour noted by therapists (see Text box 2) whereby some individuals could not tolerate occupational-engagement for long due to "fatigue" could be partly due to sensory-overload as demonstrated below:

Figure 1 Sensory Integration Pyramid adapted from Williams and Shellenberger (1994)



A sensory stimulating activity without first assessing the individuals sensory profile (Dunn 1999a, 1999b) could involve more stimulation than the individual can handle at that point in time. For example, carrying out a therapeutic intervention such as joint compression whilst reaching to move an object across the midline in a brightly lit and noisy room, if carried out before lunch with the all-pervading smell of lunch wafting into the room would involve tactile, visual, olfactory, auditory, vestibular and proprioceptive stimulation.

To add some semblance of order to the integrated sensory system, Spence's (2002) petroleum industry report proposes that the body works within a hierarchy of senses. According to Mugge *et al's.* (2009) experimental study, when the senses send messages to the brain which conflict with each other, different senses take priority i.e. giving visual information more weight than information presented to the other senses. Although vision has been thought the most important sense throughout history, (according to Synnott's (1991) literature review), recent evidence has demonstrated that hearing has greater weight. For example, Welch et al's research (1986) suggested that the rate of perception of a flashing light depends on the rate of the shutter sound than the flash. This weighting of the senses agrees with Welch and Warren (1980) and Freides (1974) experimental research. Their studies proposed that the sense that provides the most accurate sensory information dominates our perceptual judgments. According to their 'modality-appropriateness' hypothesis, vision dominates the other senses whenever the individual makes spatial judgments. Hearing was suggested to dominate chronological judgements, by Guest & Spence (2003) and Shimojo & Sham's (2001) research. Smell and touch were later suggested to dominate emotional reactions by Spence's (2002) industry funded research. Tseng & Ho's (2011) conference paper also suggested that vision, hearing, smell, touch and taste dominate emotional reactions to objects. This is relevant to this thesis because humans could be moving from rational consumption into emotional consumption and therefore, from rational engagement to emotional engagement influenced by the sensory attributes of an occupation (Tseng & Ho, 2011). This explains why table 7 includes both observable behaviours and emotions attributed to causing behaviours, demonstrated as a response to sensory-overload.

2.2.2. Sensory Integration (SI)

Olson's (2011) PhD thesis suggested that our current understanding of sensory processing arose from SI theory. Ayres (1972) having studied children with developmental disabilities, suggested that problematic sensory processing could influence occupational-performance resulting in withdrawal from engagement (Bundy & Murray, 2002; Olson 2011). Recently adult research has shown that humans may experience dysfunction across the lifespan (Pfeiffer, 2002; Watling *et al.,* 2006; Olson 2011). Over the years, others have built on the concept of sensory modulation and conducted studies to understand its nature and any dysfunction resulting from its lack (Olson 2011).

Participation in occupations in part depends on the ability to process and integrate sensory information within the body and from outside it (e.g. Gal, Cermak, & Ben-Sasson's (2007) book chapter or Bar-Shalita *et al.,* 2008; Bundy & Murray, 2002). Contrastingly, Bundy and Murray (2002) suggested that modulation disorders may present as: aversion to movement, gravitational insecurity, sensory defensiveness, and under-responsiveness (Bundy & Murray, 2002; Olson 2011). Although behaviours related to under-responsivity are dependent on the sensory system affected, some individuals may appear unengaged or uninterested in their environment, while others engage in sensory seeking behaviours. Because individuals may

vary between over- and under-responsivity, Royeen and Lane (1991) proposed a cyclical model (Olson 2011). So that individuals may over- or under-respond to individual sensory stimulation, until they reach sensory-overload, at which point, they may flip into demonstrating behaviours related to sensory under-responsivity (Olson 2011).

Engel-Yeger & Dunn's (2011) experimental study suggested that individuals experience life through their senses. Sensory processing refers to the ability to register and modulate sensory information and to organise these sensory attributes in response to situational demands (according to Humphry's (2002) experimental study). A significant number of individuals experience difficulty processing and integrating sensory information (e.g. Lane and Schaaf (2010) literature review), resulting from either sensory hyper or hypo-sensitivity, which can influence behaviour, emotional reactivity and quality of life (according to Parham and Mailloux's (2001) book chapter) as well as anxiety and coping with overloading and stressful situations (Engel-Yeger & Dunn, 2011).

SI (as well as being a theory) is a therapeutic approach used by practitioners to enhance occupational-performance (according to Davies & Gavin's (2007) validation study). Both the theory of SI and the sensory processing model build on the literature of neuroscience and especially the concept of sensorimotor-based neuroplasticity. Sensory processing is central to Ayres theory of sensory integration. Although validated with children with developmental disabilities, Ayres theory explained the relationship between the neurological processing of sensory information and behaviours such as engagement. SI theory also links to casual leisure since as Schaaf & Miller's (2005) literature review suggested opportunities for occupational-engagement that involve tactile, vestibular, proprioceptive stimulation for example could facilitate sensory integration. SI theory highlights the importance of matching the individual (and their sensory preferences and occupational capacity) to the occupation (however novel, challenging, meaningful) and the occupational context (Dunn 2001). Dunn (2001) and Ayres (1979) both stress the relationship between an individual's sensory processing ability and the occupational context, which is why this thesis focuses on the third influence; that of the number of sensory attributes offered by the occupation itself.

However, evidence based SI interventions are problematic, according to Lane & Schaaf's (2010) examination of the neuroscience evidence for sensory driven neuroplasticity. Much of the research in this field is unreliable as the approach lacks fidelity. May-Benson & Koomar's (2010) systematic review of the effectiveness of SI interventions on occupational-engagement, suggested that the SI approach may have positive outcomes in many areas. The findings of research into SI is limited by small sample sizes, lack of comparability between sample populations, variable intervention intensity, and a lack of meaningful goals; therefore, there is lack of conformity to intervention protocols, when it is used in practice. So it is not surprising that Miller's (2003) review of the empirical evidence around SI suggested that it is unproven and ineffectual. Furthermore, Shaw's (2002) literature review, suggested that SI simply does not work. Separately these authors had all reinforced the difficulties with the generalisability of the results of SI research into occupational therapy interventions because of the sample sizes, circumstances and the lack of controls. Lane & Schaaf (2010) examined many previous studies to establish the effectiveness of sensory-based interventions. Consequently, they have commented on how much of the research has cited "classic" studies, suggesting that the age of the texts cited is problematic. Despite this, they suggested that the foundations for SI theory are still secure (Lane & Schaaf 2010). They reached this conclusion because they found many studies suggesting the contribution of sensory stimulation to neuroplasticity, particularly when used in combination with motor activity. Additionally two RCTs which studied the effectiveness of SI (Miller *et al.,* 2007; Pfeiffer *et al.,* 2011) and which

included the use of specific SI outcome measures, showed positive outcomes of sensory integrative intervention. Furthermore, Lane & Schaaf's (2010) review of previous studies reported that the sensory environment could influence brain functioning, in turn influencing behaviour. Moreover, they suggest that sensory stimulation that is part of a meaningful occupation could facilitate neuroplasticity, long lasting development, and more immediate behaviour. This reinforces Ayres (1972) message that active engagement in meaningful, sensorimotor occupations that involve an achievable challenge could have a positive impact on neuroplasticity and information processing (Lane & Schaaf 2010).

Ayres (1972) theory of sensory integration therefore explained the link between behaviour and faulty selection, gating, understanding and interpreting at the sensory processing stage. In 1979, Ayres suggested that an individual's ability to behave appropriately alters as a response to the sensory environment, with a sensory imbalance resulting in maladaptive behaviour. Like others Arendt *et al's.* (1988) and Polatajko *et al's.* (1992) literature reviews, questioned the methodology, replicability and recommendations of Ayres' research. While Hoehn and Baumeister (1994) raised serious doubts about the effectiveness of SI, and about the validity and reliability of SI research. Similarly, Treweek's (2011) critical appraisal of best evidence, reported that there is very little literature about the effectiveness of SI for individuals with sensory processing disorders. However, Spitzer *et al.* (1996), whilst acknowledging that researcher's challenged the validity of research into sensory integration, suggested that there was still a place for sensory integrative intervention in the Occupational Therapist's toolkit.

A range of individuals experience sensory processing limitations including those with neurological or developmental disabilities, or who have been sensory-deprived. They could show signs of neurological dysfunction such as dys/ataxia, dys/ apraxia, choreiform movement, abnormalities of stance or gait and anxiety amongst others. These symptoms could resemble developmental delay, fatigue, attention deficits, clumsiness and the like. However, May-Benson & Koomar's, (2010) and Roberts *et al's.* (2007) literature reviews, alongside Pfeiffer *et al's.* (2011) pilot study suggested that SI was no more effective than other interventions. Pfeiffer *et al.* (2011) called for a large Randomised Controlled Trial using standardised outcome measures to collect data, while May-Benson and Koomar (2010) recommended a meta-analysis of currently existing smaller studies. May-Benson and Koomar (2010) also drew attention to the need for qualitative research to gain a clients view of SI interventions. Having said this SI theory stresses the need to match the individual's abilities to the environment, and occupation (Ayres 1979, Dunn 2001) which all depend on the individual's ability to process sensory information. Whilst it is difficult to define SI (due to inconsistencies across the literature), a common approach used by Occupational Therapists includes a sensory diet (Wilbarger 2002). Nackley's (2001) literature review defined a sensory diet as a planned activity programme designed to accommodate an individual's sensory preferences and facilitate attention and engagement.

Perhaps because it has been so criticised, SI is an evolving theory, according to Schaaf & Davies' (2010) article charting the evolution of sensory integration. Ayres (1989) test manual proposed a typology of sensory processing limitations, which became apparent through using the Sensory Integration and Praxis Tests (SIPT). Later Fisher *et al's.* (1991) and Bundy *et al's.* (2002) book chapters both proposed models that delineated between dyspraxia and poor modulation. Data collected using the Sensory Profile (Dunn, 1999), and the Sensory Processing Measure (Miller-Kuhanek *et al.,* 2008), led to the development of models to describe the continuum from over to under responsiveness to sensation (e.g., Fisher *et al.'s* (1991) book and Royeen & Lane's (1991) book chapter). This data also led to more complex models that describe behavioural

responses to sensation on the basis of proposed underlying sensitivity e.g. Dunn's (1997) MoSP. Smith *et al's.* (2007) literature review suggested that it was necessary to distinguish intervention based on the principles developed by Ayres from other interventions that use sensory stimulation, because many of the publications that deviate from the original principles of Ayres' work, but which have been mistakenly associated with sensory integration. Research is therefore continuing to examine the effectiveness of occupational therapy using a sensory integrative approach with specific clinical groups (for example Baranek *et al's.* (2009) experiments with behaviour changes following sensory stimulation; and Miller *et al's.* (2007) RCT).

Smith *et al.* (2007) also noted that part of the controversy about the effectiveness of the sensory integrative approach could be that its effectiveness in practice is compromised, by its lack of faithfulness to its original principles. Therefore Parham *et al.,* (2007) evaluated inferences made in research, and whether some method of standardised application to practice was required, to make research findings in the future more reliable. One important part of enhancing fidelity is that research describes its intervention methodology thoroughly, to standardise techniques and to differentiate it from alternative interventions. Both May Benson & Koomar (2010) and Parham et al., (2007) commented on rarity of description of therapeutic interventions to enable their replication. For instance, Parham et al., (2007) recommended systematic documentation of the observable elements of the intervention and its environment, such as number of staff, session length and content and the presence of specific environmental characteristics. Furthermore, description of the nature and quality of the therapeutic alliance between client and therapist, to ensure that the intervention reflects its underlying principles. This is a problem so widespread that Miller's (2003) literature review argued that the lack of attention to the fidelity issues in SI research compromises the extent to which any conclusions can be drawn about its effectiveness.

However, the controversy surrounding SI theory remains. Reflecting, that until recently there has been little evidence to test its biomedical model assumptions using brain imaging techniques or physiological tests and to determine whether behaviours resulting from SI dysfunction influence malfunction in brain processing as Ayres (1972) suggested. The brain activity demonstrated should differ from neurotypical brain activity when presented with discrete sensory stimulation. This is why Davies & Gavin (2007) studied 53 individuals with sensory modulation (regulate behaviour in response to sensory stimulation (Mulligan, 2002)) dysfunction (28 with Sensory Processing Disorder and 25 without) using electroencephalography. Davies & Gavin's results supported the assumption of SI theory that behaviour could alter because of impaired sensory processing. Furthermore, they suggested that studies (albeit in laboratory conditions) have now demonstrated that sensory stimulation can lead to alterations to motor abilities (and so demonstrate neuroplasticity because of sensory stimulation), and may be detected using physiological tests such as brain scans. These included Bach-y-Rita's (2004) experiments into sensory substitution of vibrotactile substitution for participants with visual impairments as a tool for postural control. Additionally, Bavelier *et al.* (2001) fMRI experiments to suggest that deaf signers were better able to detect peripheral movement and heightened selective attention than other participants. Furthermore, Braun *et al.* (2001) demonstrated that electromyographic activity was greater during a writing task than when at rest and that greater co-ordination, motor activity and control were localised to the stimulated hand. Doucet *et al.* (2005) experiments into sound localisation suggested that plasticity underlies the enhanced performance of participants with visual impairment, thus assuming a link rather than demonstrating it. Guest & Spence's (2003) RCT study of attention suggested that sensory

stimulation individually contributes to discrimination process, but is most effective when stimulation to multiple senses occurs in combinations of two senses, but that multiple stimulation beyond two senses may be superfluous.

As Ayres's theory proposes, appropriate sensory stimulation could change neural mechanisms, so that brain activity could change in individuals with sensory processing limitation after therapeutic intervention, as evidenced during a brain scan or electroencephalography. To explore this from an OT standpoint, Lane & Schaaf (2010) reviewed 37 studies spanning 40 years, all of which used physiological tests to measure the effects on neuroplasticity of sensory stimulation. They concluded that there was evidence to suggest that neuroplasticity results from direct sensory input, and during motor activity. Their findings indicated that changes in neuronal function and structure, and in some studies changes in behaviour, could link to neuroplasticity. Some of the studies appear insufficiently generalisable outside of a laboratory or clinical situation, but do not detract from the weight of evidence because early stage neurological occupational therapy tends to occur in a clinical setting. This reinforced the view that sensory stimulation influences behaviour, which could include engagement.

Lane & Schaaf (2010) reviewed studies of environmental enrichment, and concluded that many studies suggested the contribution of sensory stimulation to neuroplasticity, especially once used in combination with motor activity. Furthermore, they reported that the sensory environment influenced the structure and function of the brain, influencing behaviour. Consequently, they suggest that sensory stimulation that is part of a meaningful occupation could facilitate neuroplasticity and thus long-lasting development, and behaviour that occurs shortly after stimulation is experienced. This again reinforced Ayres (1972) message that active engagement in meaningful, sensorimotor occupations that involve an achievable challenge context has a positive impact on neuroplasticity and information processing (Lane & Schaaf 2010). It is also of interest to note that Lane & Schaaf (2010) suggest that passive stimulation appeared to have less of a therapeutic effect than intervention that involves movement and sensory stimulation. Again, this links to Ayres (1972) belief that enriched sensorimotor experience enhances the brain's processing of information and opportunities for development.

In summary Engel-Yeger & Dunn (2011) reinforced that life is experienced through the senses with an ability to organise, process and integrate sensory information being central to responding to situational demands (Gal, Cermak, & Ben-Sasson (2007); Bar-Shalita *et al.,* 2008; Humphry, 2002; Bundy & Murray, 2002). Furthermore, sensory preferences, may affect behaviour and emotional reactivity (Parham and Mailloux, 2001) and ability to cope with the environment (Engel-Yeger & Dunn, 2011). SI theory also links to casual leisure since as Schaaf & Miller's (2005) literature review suggested opportunities for occupational-engagement with a high level of sensory attributes may facilitate sensory integration. SI theory also stresses the importance of matching the individual (and their sensory processing ability) to the occupation (and its context) (Dunn 2001). This fundamental belief is why this thesis focuses on the number of sensory attributes offered by the occupation itself. Additionally and because of the concerns about fidelity, chapter five describes (using an occupational analysis) the occupations and the occupational environment observed.

2.2.3. Model of Sensory Processing

In 1997, Dunn proposed a model of sensory processing, based upon thresholds of responsiveness to sensory stimulation or sensory thresholds, self-regulation strategies, and the interaction between them resulting in a behavioural

response (Dunn, 2001). The categories of behavioural response proposed, were sensation seeking, low registration, sensation avoiding and sensory hypersensitivity, as shown in Figure 2.

Figure 2 Dunn's Model of Sensory Processing

	Passive strategy	**Active strategy**
High sensory threshold	Low registration	Sensation seeking
Low sensory threshold	Sensory hypersensitivity	Sensation avoiding

As shown in Figure 2, Dunn described sensation-seeking individuals as having high sensory thresholds and an active self-regulation strategy. Individuals with this pattern of sensory processing crave sensory stimulation (Dunn, 2009).

Low registration results from high sensory thresholds and a passive self-regulation strategy. Such individuals may not notice sensory stimulation and can appear disinterested, self-absorbed, or unemotional (Dunn, 2009) in an environment that does not contain a sufficient amount or intensity of stimulation. Their passive strategies mean that they do not seek out stimulation, and hence they could appear oblivious to things that are going on around them (Dunn, 2009).

Those with sensation avoiding behaviour have low sensory thresholds and an active self-regulation strategy. They appear ritualistic and determined to limit overwhelming sensory stimulation (Dunn, 2009). This could result in active disengagement from participation in everyday life.

Those with sensory hypersensitivity have low sensory thresholds and a passive self-regulation strategy. They noticing everything, appearing distractible and anxious. They use a passive behaviour strategy, such as remaining in an overly stimulating environment despite being uncomfortable (Evans *et al.,* 2012) or commenting on them rather than modifying the situation to make themselves comfortable (Dunn 2007, 2009).

However, Bar-Shalita *et al's.* (2009) study (which collected data using questionnaires and experimental testing) took a contrary stance to the belief that low sensory thresholds contribute to sensory over-responsiveness. They suggested that individuals with sensory modulation disorders seemed to perceive more pain at longer durations, further demonstrating that sensory over-responsiveness does not imply the presence of low sensory threshold, rather rests on the presence of abnormal processing suprathreshold.

The demands of an occupation, the characteristics of the sensory environment and the individual's self-regulation strategies all influence the individual's occupational capacity (Dunn, 2009). Therefore, to maximise opportunities for engagement, the intensity, amount, predictability, repetitiveness, familiarity, speed and competition of sensory stimuli within an occupation and its environment require consideration. One of the drawbacks of Dunn's model is that it did not suggest any interventions to enhance engagement for individuals in each of the four categories until "Living Sensationally" was published in 2009. This book suggested management of sensory preferences ideas in relation to clothing, work, and home and co-existing with others with similar or different sensory preferences. Furthermore, the model does not appear to take account of the cognitive state of the individual, which arguably could alter the sensory threshold by altering how much attention the

individual pays to the environment. Instead an individual's sensory profile is a stable trait (Brown *et al.,* 2001), and an enduring state (Brown & Dunn, 2002). However, Pohl et al. (2003) suggested that there were age related differences in the way that individuals notice sensory stimuli, which challenged this concept of stability.

The validation study for Dunn's MoSP (1997) involved children. It later expanded to include adults (Brown & Dunn 2002). However, the majority of sensory processing literature focuses on the autism spectrum (Adamson, O'Hare, & Graham, 2006), healthy adults (Engel-Yeger & Dunn, 2011) and individuals with mental health conditions (Brown *et al.,* 2002, Rieke & Anderson, 2009). Furthermore, much of the research involves small convenience samples, rather than being representative of an entire population. While, neurological thresholds, which appear so crucial to the MoSP, appear uncertain, since they fluctuate between contexts and individuals (Pohl *et al.,* 2003).

Another issue is that the model assumes normally functioning sensory receptor organs, which might not always be the case. Furthermore, the model depends on effective sensory gating, since an inundation of sensory stimulation following faulty screening in the RAS leaves the individual with too much information to assimilate. This sensory gating may not be reliable for individuals with NPC. Many NPC include elements of alterations to attention, arousal, activity levels, coordination, muscle tone, mood, levels of anxiety etc. These, could be the result of damage to the RAS, or the number of sensory attributes experienced.

Sensory processing refers to the ability to register and modulate sensory information and process and understand it to execute adaptive responses to bodily and environmental demands and thus engage in occupations (Humphry, 2002). Evidence is growing that individual's process sensory information in idiosyncratic ways. Specifically, some individuals are more sensitive than others are to sensory information (Aron & Aron, 1997; Dunn, 2001). They could perceive sensory events as noxious (Bundy, Lane, & Murray, 2002) and exhibit behaviours with catastrophising traits. This section will demonstrate the evolution of Dunn's research into sensory processing between 1994 and 2011 by focussing on 15 of the many articles contributed to or written by Winnie Dunn.

In 1994 Dunn, explored the performance of neurotypical children using her sensory profile assessment. The sensory profile is based on the sensory history items reported in the literature, to evaluate children's responses to sensory events. It consisted of 99 items divided into six sensory categories (auditory, visual, taste/smell, movement, body position, and touch) and two behavioural categories (emotional/social and activity level). This study captured which items on the sensory profile were uncommon behaviours in neurotypical children, to rule out sensory processing dysfunction as their cause. It involved a convenience sample of parents (of 64 neurotypical children), who completed a Sensory Profile and reported the percentage of time that their children engaged in each behaviour. Her sample was part of a larger study of the sensory integration of children with and without disabilities. The parents completed the sensory profile, and the researcher took completion of the sensory profile to indicate consent to participate in the study, rather than gaining formal written consent. Dunn (1994) highlighted that 2/3 of the items on the sensory profile could rule out sensory processing dysfunction which were unfamiliar to neurotypical subjects, because they were uncommon experiences for children without sensory processing difficulties. This could have resulted from the unsuitability of the tests to measure that item, or incomprehensibility of the test to the participants.

Additionally, in three categories (activity level, taste/ smell, and visual) fewer than half of the items were uncommon, perhaps being poorly described, unfamiliar or not significant. Equally, these behaviours could be prevalent in the typical population (thus ruling out sensory processing dysfunction as being their cause). Three other categories (movement, body position, and touch) included a high number of items that were uncommon behaviours. These became the most commonly examined sensory systems in the literature on SI (Fisher *et al.,* 1991). A convenience sample may not be representative of the entire population especially when it is such a small sample. No demographic data or data about cultural background were included in the article therefore again this sample may not represent the entire population; therefore the results should be treated with caution.

One of the recommendations from this study was a series of comparison studies between individuals with sensory processing dysfunction and neurotypical children. These occurred later, conducted by Dunn & Westman (1997), Kientz & Dunn (1997), Dunn & Brown (1997) and Ermer & Dunn (1998). However, even if the items discriminated between typical children and children with sensory processing difficulties, this does not explore the sensory systems themselves, only the behaviours produced. In contrast, a validity study that tested children on the sensory portions of the Sensory Integration and Praxis Tests (Ayres, 1989) and the Sensory Profile, or on the Touch Inventory for Elementary-School-Aged Children (e.g. Royeen & Fortune's (1990) experimental study) and the Sensory Profile, could have confirmed the relationship between validated tests and the Sensory Profile.

Another issue is that Dunn (1994) analysed only the item data and not the categories of items, which would have validated which items were in each category. For example, behaviour such as "becomes anxious or distressed when feet leave the ground" was uncommon for neurotypical children. Assessment for this occurred in isolation from the other items in the movement category, but could also be associated with the emotional/social category in a factor analysis, because of the use of the word anxious. Therefore, Dunn recommended further study of each of the categories of items on the Sensory Profile. Furthermore, anxiety is an emotion attributed to causing behaviour, and not directly observable. Despite these problems, this early study demonstrated in a perverse way that the Sensory Profile had the potential to contribute to the assessment of and understanding of sensory processing difficulties. It took a different stance from other assessments because it gathered information about behaviours and occupational performance.

In 1996, Dunn & Westman published their article about the performance of a nationwide sample of 115 neurotypical children, using a 125-item revision of the Sensory Profile (Dunn 1999). Parents' completed the Sensory Profile and reported the percentage of time spent on behaviours and to identify trends in performance. Data analysis highlighted no gender differentiation, and only 2 aged differentiating items on the revised Sensory Profile. Since approaching ¾ of the items on the profile were uncommon for neurotypical children, it could facilitate intervention planning for children with disabilities. This built on existing knowledge about comparisons between children with and without disabilities.

In combination with her other studies (e.g. Kientz and Dunn (1997)), Dunn highlighted unique patterns of performance between clinical groups. However, an additional strand of research comparing the sensory profile and other tests such as the Touch Inventory for Elementary-School-Aged Children (Royeen & Fortune, 1990) or the Sensory Integration

and Praxis Tests (Ayres, 1989) was required to determine whether the Sensory Profile highlighted similar or unique factors in occupational performance.

Similar to the clinical reasoning presented in Table 7, the eight categories represented on the Sensory Profile typify the sensory and behavioural systems that influence occupational performance, however, information about the categorisation of these constructs have been helpful (Dunn & Westman, 1996). Despite this, Dunn & Westman (1996) suggested that the Sensory Profile contained many behavioural items that are uncommon in neurotypical children. Later Kientz & Dunn (1997) demonstrated that some of these items are significantly more common for one clinical group than another. This differentiation between conditions led Dunn & Westman (1996) to suggest that the Sensory Profile could be a useful assessment where formal and standardised testing is problematic.

In 1997, Dunn described the sensory processing model, as an important factor in social, cognitive, and sensorimotor development and ultimately in occupational performance. The article suggested that neuroscience and behavioural science could interact to offer information that is relevant to supporting individuals with sensory processing difficulties. To do this it analysed a series of studies using the Sensory Profile with samples of individuals with and without disabilities.

Dunn acknowledged that by 1997, there were several standardised assessments that documented sensory processing abilities, but none captured their influence on occupational performance. To counteract this, Dunn and her colleagues began collecting data about occupational-performance using the sensory profile. Similar to the preliminary study presented in chapter four, the items on the sensory profile resulted from an interview with a carer of individuals with NPC. Consequently, Occupational Therapists hold the belief that the items represented an untested sensory processing difficulty. To address this issue, Dunn led a series of studies to identify the nature of the items on the Sensory Profile, including which items were uncommon for neurotypical children, which items were characteristic of specific disabilities. This series of studies comprised a study pilot (n =64) and a national study (n =1,115) using a sample which mirrored the 1990 USA census.

Dunn (1997) also conducted a factor analysis on the neurotypical children's data, to examine patterns of performance. The result highlighted factor groupings in children with disabilities, as suggested in the other studies about the behavioural patterns seen in neurotypical children. The nine factors were:

1. Sensory seeking (n =17 items)

2. Emotionally reactive (n =16)

3. Low endurance/tone (n =9)

4. Oral sensitivity (n =9)

5. inattention/distractibility (w =7)

6. Poor registration (n =8)

7. Sensory sensitivity (w =4)

8. Sedentary (w =4)

9. Fine motor/perceptual (n =4)

When compared to neurotypical children, each clinical group of children with disabilities exhibited unique patterns of responses to the items on the sensory profile. Dunn therefore suggested that the behaviours in the sensory profile could be useful in differentiating diagnoses, since using the nine factors, the children studied were diagnosed correctly 89% of the time. In hindsight, it appears inequitable that each of the factors included different numbers of items, ranging from n=17 to n=4. However, Dunn suggested that this analysis provided preliminary evidence about the nature of sensory processing; and suggested that the patterns of behaviour might differ in rate, intensity, or influence on occupational performance.

Dunn & Brown (1997) conducted a factor analysis on the sensory profile from a national sample of neurotypical children. They did this to identify the relationships in the 125 items of the revised Sensory Profile. Data was collected from the parents of 115 children ages 3 to 10 years and without disabilities who completed the revised Sensory Profile and who also reported the percentage of time that their children engaged in each of the behaviours assessed. During the data analysis, factor analysis revealed nine factors that could indicate sensory modulation and responsiveness: sensory seeking, emotional reactivity, low endurance/tone, oral sensory sensitivity, inattention/distractibility, poor registration, sensory sensitivity, inactivity, and fine motor/perceptual skill. Consequently, consideration of the individual's sensory profile was recommended, since sensory processing problems could be related to the intensity or duration of behaviours, which influenced occupational performance.

Dunn & Brown's (1997) study changed occupational therapy practice away from sensory history taking based around the effect of the sensory system involved (Larson, 1982; Royeen & Fortune, 1990). Instead it advocated identifying the impact of the individual's responsiveness to sensory experiences on occupational-performance (Dunn & Brown, 1997). The Sensory Profile can therefore demonstrate over or under reactivity to daily life i.e. the sounds, lights, touch, pain, odours, temperatures, and the movement involved in occupational performance. This was consistent with proposals to make sensory modulation a key factor in sensory processing evaluation and intervention (Dunn, 1994; National Centre for Clinical Infant Programs, 1994; Wilbarger, 1995).

Kientz & Dunn (1997) explored whether the Sensory Profile distinguished children with autism from neurotypicals, and which items on the profile discriminated between these groups best. The parents of children with autism aged 3 to 13 years (n=32) and without autism aged 3 to 10 years (n=64) completed the Sensory Profile. However, this small convenience sample could not have represented the entire population studied. This study occurred because research had reported that the stereotyped and repetitive body movements exhibited were due to poor sensory modulating skills, which included a lack of responsiveness or an exaggerated reaction to sensory input (Ayres, 1979; Ornitz, 1974, 1989). Kientz & Dunn (1997) conducted a descriptive analysis, which identified the distribution of responses on each item. A multivariate analysis of covariance of the results differentiated between the sensory processing ability of 85% of the subjects with autism and those of subjects without. Accordingly, Keintz & Dunn suggested that a behaviour listed on the Sensory Profile could

occur frequently in one individual, and infrequently in another, resulting in a different distribution of responses across items. They also suggested mapping all the behaviours exhibited was just as important as quantifying their occurrence. This philosophy informed the design of the study reported in chapter Four. Again, this study recommended a range of matching studies to differentiate the sensory processing patterns of other conditions and to validate the Sensory Profile further.

In 1998, Ermer & Dunn studied which factors on the Sensory Profile best discriminate among children with pervasive developmental disorder (PDD), attention deficit hyperactivity disorder (ADHD), and neurotypical children. They used an unrepresentative but convenient sample of 38 children with PDD, 61 with ADHD, and 1,075 without disabilities. Unlike Dunn (1994), Ermer and Dunn (1998) ensured that parents provided informed consent before filling out the Sensory Profile during clinic visits or when received through the post. The researcher was available by phone to answer the respondents' questions, and, in some instances was present while the forms were being completed, which opened the authors to accusations of having tutored their responses. The researcher's conducted a discriminant analysis on the three groups, using group membership as the dependent variable and the nine factors of the Sensory Profile as independent variables. This was a large study but the groups with each disability were not of equal size, rather, each group approximated a normal distribution. Discriminant analysis suggested which characteristics discriminated between groups and analysed the precision of these characteristics for group classification (Pormey &Watkins, 1993; Stevens, 1992). Discriminant analysis differentiated children with disabilities from neurotypical children, and the two groups of children with disabilities from each other, since many of the behaviours either generated or avoided sensory stimulation. Therefore, determining an individual's threshold for tolerating sensory stimuli could help them and others to understand their reaction to experiences tolerated by others. Ermer & Dunn (1998) therefore suggested that the Sensory Profile could classify 90% of participants into disability categories based on the frequency or intensity of certain behaviours.

Dunn and Brown's (1997) study of 432 (8.3%) group item means included 123 (1.6%) items for the children with ADHD and 319 (6.7%) items for the children with autism. Unfortunately, missing data was present throughout the samples, rather than removing the child's data. Group means were missing from the data about neurotypical children, resulting in the analysis of 671 children from this group. The authors suggested that the Sensory Profile factors found in neurotypical children would discriminate between children with and without disabilities. This resulted in the correct classification of 90% of the 769 cases (using the nine Sensory Profile factors as discriminators). Of these nine factors, Sensory Seeking, Oral Sensory Sensitivity, Inattention/Distractibility, and Fine Motor/Perceptual appeared the most reliable discriminators. The limitations of this study included the use of convenience samples for the two groups of children with disabilities, which reduced its generalisability. Larger and more equal groups would have enhanced the validity of the findings. Because the study included only two types of disability, no predictions were possible about how other clinical groups could be discriminated and classified. The results of this study indicate that the Sensory Profile contained items and factors that not only had the ability to discriminate children with disabilities from neurotypical children, but also to discriminate groups of children with disabilities from each other, however the results should be considered cautiously.

In 2001, Dunn presented at the AOTA's national conference. This lecture reviewed the literature around sensory processing, neuroscience and behavioural science. Additionally, it summarised the MoSP discussing how human beings demonstrate four sensory processing patterns, with one or some taking precedence, in response to unique patterns of

habituation and responsivity in skin conductance, reflecting the needs of the individual's nervous system, and contributing to temperament and personality. She proposed that different disabilities exhibit group sensory profiles, responding differently than non-disabled groups or to groups with different diagnoses.

Later in 2001, Brown *et al.* argued that because sensory processing preferences are stable traits, revalidating the sensory profile across age cohorts was appropriate. This article therefore reported the results of a series of studies designed to evaluate the reliability and validity of the Adult Sensory Profile as a measure of the four patterns of sensory processing described in Dunn's (1997) MoSP.

Brown et al's. (2001) article suggested that one way to capture an individual's sensory profile was to obtain a sensory history. These would be relatively easy to obtain from the individual or those who know them well (Dunn, 1994). Sensory histories make the individual the focus of the evaluation. However many of the studies about sensory processing in young children necessarily rely on third party data, and so may not truly reflect the individuals sensory profile. Furthermore, observing an individual's response to sensory stimuli to complete the sensory profile is a judgement-based process, which could therefore be open to bias such as lack of insight, scepticism, or overly positive reporting. An alternative methodology would be to observe behaviour in response to sensory stimulation either in context or in a clinical setting. Furthermore, as Brown *et al.,* have shown it would be possible and appropriate to use galvanic skin responses to highlight physiological or psychological alterations in response to sensory stimulation. However, this would be inconsistent with the freely chosen nature of leisure.

A pragmatic study acknowledges expertise that can be brought to the research, which is not negotiable (Fishman, 1999). Using a similar process to that used to produce table 7, Brown *et al.* (2001) used expert clinical reasoning to match the factors highlighted in the sensory profile to the quadrants described in Dunn's (1997) MoSP. They then explored the relationships between items, and the item reliability and construct validity of the sensory profile using data from 615 adults using statistical analysis. These individuals gave sensory histories by completing their own sensory profiles. Furthermore, 20 of these adults provided galvanic skin response data, to capture the electrical conductance of skin moisture as a response to messages from the sympathetic nervous system (Martini & Bartholomew 2003). The galvanic skin response was used as an indication of physiological or psychological arousal. Arguably, respecting expert opinion and clinical reasoning is less acceptable in health science than in the management science which contributes to the researcher's background. However Brown *et al.,* felt differently and used expert judgment to categorise the items within the sensory profile into the quadrants of Dunn's MoSP. The results suggested reasonable item reliability for all subscales except for the Sensation Avoiding subscale. Furthermore, the galvanic skin response measures detected distinct patterns of physiological responses consistent with the four-quadrant model. Because of this study, a heterogeneous group of 93 adults completed a revised Adult Sensory Profile to re-examine its item reliability. The revision resulted in improved reliability of the Sensation Avoiding subscale, which had less than reasonable reliability prior to this study.

Brown et al's. (2001) series of studies supported the four subscales of the Adult Sensory Profile as distinct constructs of sensory processing preferences. Furthermore, they described emotional reactivity as a response to sensory stimulation and placed it in the sensory avoidance quadrant of Dunn's (1997) MoSP. This is intriguing, since the sensory

avoidance quadrant implies the use of active strategies to avoid stimulation, where as emotional reactivity may arguably be a passive reaction to stimulation. They described how the sensory profile is "divided into six sensory categories (auditory, visual, taste/smell, movement, body position, touch) and two behavioural categories (emotional/social, activity level)" (Brown *et al.,* 2001 p 76).

Dunn *et al.* (2002), Huebner (2000) and Zero to Three (1994) suggested that the patterns of behaviour listed in the diagnostic criteria for autism (APA 1994) such as impaired social interaction, preoccupation with special interests, preferring routine etc were reflections of sensory processing ability. However, sensory processing had not been widely accepted (in 2002) as a source of limitation by the biomedical model professions (Dunn *et al.,* 2002). To counter this, Dunn *et al.* used another convenience sample to compare the sensory processing performance of 42 children with Asperger syndrome (AS) and 42 neurotypical children using the Sensory Profile. They did this to identify the sensory processing patterns of children with AS and therefore to try to make the link between their limitations and sensory processing more explicit. This study produced results of dubious generalisability and authenticity (because it used third party data from a convenience sample). The children with AS produced data which was significantly different from neurotypical children on 22 out of 23 items. However, a frustration of this study for the researcher is that Dunn *et al.* did not evaluate the impact of these sensory processing differences on the engagement in ADL of the participants. This is relevant because individuals with all types of sensory processing patterns are living satisfying lives; arguably it is only when a pattern of sensory processing inhibits engagement and therefore life choices that it influences quality of life.

Problems with sensory gating (Ringle *et al.,* 2004; Nagamoto *et al.,* 1989; Thoma *et al.,* 2003; Wan *et al.,* 2006) and sensory processing (Brown *et al.,* 2002) occur in conditions such as Schizophrenia. Cromwell (1993) describes how individuals could experience hypersensitivity alongside over inhibition (both of which Brown *et al.* (2002) explored using the Adult Sensory Profile). Brown *et al.* (2002) hypothesised that the scores of individuals with schizophrenia (n=27) would be different from the scores of individuals with other mental health conditions such as bipolar disorder (n=30) and by 29 participants without mental illness (n=29). The sample (n=86) came from four community-based services for individuals with severe and persistent mental illness, and excluded individuals with neurological diagnoses, sensory impairments or learning disabilities. All three groups were statistically similar in terms of gender and race. However, the mentally healthy group was younger overall than the other two groups. The bipolar group demonstrated a different sensory processing pattern overall, being more sensory sensitive, and less sensory avoiding/ seeking and low registration than the schizophrenia group. Furthermore, the schizophrenia group were less sensory sensitive than the bipolar group but more so than the mentally healthy group, and more sensory avoiding, low registration and sensation seeking than the bipolar and the mentally healthy group. The researcher's therefore expanded upon the much earlier findings of Cromwell (1993) about coexisting supersensitivity and overinhibition (and their combined influence on behaviour) despite this being a small study of less than 30 individuals with schizophrenia. Brown *et al.* (2002) suggested that mentally healthy individuals and individuals with schizophrenia were equally sensory sensitive. However, they explained this based on the variability of schizophrenia, because the scores within this group for the sensory sensitivity quadrant were so disparate. Consequently, further studies would need to qualify the severity of schizophrenia symptoms and any subtypes within the diagnosis of schizophrenia, to enhance the

usefulness of the results. Furthermore, the authors suggested that individuals with low registration of sensory stimulation could also experience low self-awareness.

Pohl *et al.* (2003) conducted a cross sectional survey using a further convenience sample. The participants included 127 students aged 19 - 34 and 126 adults aged 35 - 64 and 151 adults over the age of 65. The latter group included adults grouped as 65 - 69 yrs, 70 - 74 yrs, 75 - 79 yrs and 80 plus. This study highlighted age related differences in relation to individuals with a high neurological threshold. The adults over 65 noticed sensory stimulation less than the younger groups, and in turn, the adults over 75 noticed sensory stimulation less than the 65-74 year olds, which could imply that over the age of 65 sensory thresholds rise making the individual less likely to notice sensory stimulation. Pohl *et al.* suggested that this demonstrated that older adults could develop strategies to cope with the reduced sensory acuity which accompanies normal aging. However, this study did not involve a diverse demographic group, the subdivided groups were quite small, and all were highly educated. Therefore, the results require caution.

In 2004, Ahn *et al.* explored rates of sensory processing disorders in a convenience sample of kindergarten students. The data collected was from 703 parents (39% of the local kindergarten population), using the short sensory profile. The generalisability of these results is limited due to the non-representative nature of the sample. Of the 703 children represented, 96 children (13.7%) (5.3% of 1796 of the kindergarten population as a whole) met the criteria for sensory processing disorders based upon parental perceptions. Given that Ahn *et al.,* used such a non-representative sample, It is noteworthy that children with either sensory or attention impairments or both (n =181), were evenly split between children with sensory processing symptoms only (28%; n =50) and symptoms of ADHD only (31%; n =57), suggesting that ADHD and sensory processing disorders are distinct conditions. It is noteworthy because the use of specific strategies to cope with stressful sensory stimulation is prevalent among individuals with atypical sensory processing patterns (Kinnealey & Fuiek, 1999).

However, the study conducted by Ghanzadeh *et al.* (2012) contradicted this by suggesting that individuals' with ADHD had significant olfactory deficits, and suggesting that exploring olfactory function might assist in the diagnosis and management of ADHD. On the contrary, Scheckelman *et al.* (2011) observed that olfactory deficits were not associated olfactory performance alterations among adult residents with ADHD, suggesting instead that impulsivity and hyperactivity may link to cortical olfactory processes. Then again, a study by Gansler (1998) suggested that olfactory identification is less accurate among ADHD individuals when compared to controls.

Myles *et al.* (2004) studied whether a convenience sample of children with 2 disparate syndromes on the autism spectrum exhibited distinct sensory profiles. Likewise, Asperger (1944), recognised sensory deficits in individuals with Asperger Syndrome (AS). This was the only article before theirs, about the sensory issues of individuals with AS (Dunn, Myles, & Orr, 2002). Therefore, the Sensory Profile of 86 individuals with AS and 86 with autism were paired in terms of age (range =6 to 17 years). This revealed differences in emotional/social responses, emotional reactivity, and inattention/distractibility, suggesting the influence of sensory processing on behaviour (coded as typical performance, probable difference, and definite difference), responses to stimuli, and identified sensory preferences. The study participants were members of a support

group for families of individuals with AS, and the assessments were conducted in a clinical setting and so could not represent the entire population, of individuals with ASD's.

The Sensory Profile, which underpins this study, includes subcategories such as Emotional/ Social Responses and Emotionally Reactive both of which Myles *et al.,* described as "psychosocial coping strategies," or products of sensory processing. This influenced the thesis by persuading the researcher to include both products of sensory processing (described in chapter FOUR as attributable behaviours) and observable behaviours in the signs of sensory-overload explored. Furthermore, Myles *et al.* concluded that determining the specific sensory differences of a cohort of similarly disabled individual's could aid practitioners, supporters and researcher's to understand the complexity of their needs. The limitation's of this study included the use of a convenience sample of individuals with ASD from the local area, could not be representative of the entire population. Furthermore, the use of third party data rather than by direct observation was also a limitation. It also studied a specialised group of individuals rather than a representative sample.

In 2007, Tomchek & Dunn investigated the differences in sensory processing (again using the sensory profile) among 562 age-matched children between ages 3 and 6 years with ASD's and those who are neurotypical (n=221). The inclusion criteria was that the sensory profile included no data missing facilitating a documentary review of existing clinical records. Sensory processing data collection for a national study (Dunn & Westman, 1997) involved 1,075 children from ages 3 to 10 years who were not receiving special education services or taking medication. The neurotypical and ASD participants were matched for age and gender, which given the disproportionate male to female gender ratio seen in autism was an aspiration which rendered the sample non-representative. Data analysis included, descriptive statistics, to identify the items yielding the highest reported sensory processing dysfunction. Secondly, multivariate analyses of variance investigated differences in sensory profile items and sections between the groups. Ninety-five percent of the sample of children with ASD demonstrated some degree of sensory processing dysfunction on the sensory profile, with the greatest differences reported on the low registration/ sensory seeking, auditory filtering, and tactile sensitivity sections. The ASD group also performed significantly differently on 92% of the items, total score, and all sections of the sensory profile, which confirmed the prevalence and types of sensory processing impairments highlighted in earlier studies.

As usual with Dunn's studies, a limitation of this study was the use of a convenience sample of individuals with ASD from the local area who therefore could not be representative of the entire population. Additionally, third party data was used rather than data from direct observation. Furthermore, existing clinical records produced for a different purpose could not demonstrate all the variables required by a documentary review. Therefore, this was a large study involving individuals with ASD, which used existing data. However, it reported clear trends showing differences in sensory responses between children with and without ASD within its localised study population.

According to Ben-sasson *et al.* (2007) there was uncertainty about whether a typical sensory modulation pattern existed amongst individuals with ASDs. Based on Dunn's (1997) MoSP, both sensory sensitivity and sensation avoiding represent sensory over responsiveness, whereas low registration and sensation seeking represent low sensory responsiveness (Dunn, 1997). Therefore, Ben-sasson *et al.* examined the incidence of extreme sensory modulation behaviours in 101 toddlers with ASD's. Like Brown & Dunn (2010), they compared the consistency of sensory processing measures in toddlers with ASD,

with 100 neurotypical toddlers of the same age, and with another neurotypical cohort of 99 additional infants or toddlers of a comparable mental age. To do this they used Dunn's Infant/Toddler Sensory Profile (Dunn, 2002), Infant–Toddler Social and Emotional Assessment (Carter & Briggs-Gowan, 2006), Autism Diagnostic Interview–Revised (Lord *et al.,* 1994), and Autism Diagnostic Observation Schedule–Generic (Lord *et al.,* 2002). Consequently, toddlers with ASD were suggested to experience a high frequency of low responsiveness, low seeking and avoiding behaviours. Sensory scores were amongst the data gathered on a wide range of topics within the test used and so were limited in specific detail. However Ben-sasson *et al's.,* study informed this thesis by suggesting that sensory modulation behaviours should be assessed across settings and from different perspectives. It also suggested that individual (negative and positive) behaviours in response to sensory stimulation would influence the individual's life and that of those around them. Ben-sasson *et al.* also suggested that the social and sensory aspects of social interactions are unavoidably associated.

Dunn (2007) reviewed the accumulating literature describing sensory processing stressing the importance of this knowledge for understanding individuals behaviour, whether healthy, neurotypical or living with a disability. Building upon her hypothesis about a relationship between neurological thresholds and self-regulation strategies; Dunn and her colleagues have tested it across the lifespan and in groups with and without disabilities. They found that these patterns of sensory processing occur in every age group, across the entire human race, and that individuals with disabilities have both distinctive and more intense patterns of sensory processing. Humans experience a normal distribution of sensory processing patterns, with the majority responding moderately to sensory experiences, and a few individuals responding intensely (Brown & Dunn, 2002; Dunn, 1999, 2001). The MoSP built upon the knowledge that neurological thresholds are important understanding sensory processing (Kandel, Schwartz & Jessell, 2000), because they are on a continuum that alters when an individual notices and responds to sensory stimulation. Additionally, self-regulation, determines how an individual reacts to sensory stimulation.

To determine the validity of the concepts from Dunn's MoSP, researcher's tested national samples of infants and toddlers (n =589) (Dunn, 2002; Dunn & Daniels, 2001), children (w =1115) (Dunn, 1999; Dunn & Westman, 1997), and adolescents and adults (H =950) (Brown & Dunn, 2002; Brown *et al.,* 2001). In every age group, researcher's verified the existence of the 4 patterns of sensory processing hypothesised. This Dunn (2007) suggested had heightened the validity and reliability of the MoSP, whilst adding credibility to the influence of sensory stimulation on occupational performance. This, along with the professions reawakening interest in occupations and occupational-performance in healthy individuals has opened up a new avenue for research, which will be of benefit to therapists and others.

Dunn (2007) opened a new strand of research by stressing that everyone has particular ways of responding to sensory stimulation. Portney & Watkins (2000) suggest that 2% to 4% of individuals in Dunn's research were more than 2 standard deviations from the mean and therefore would respond to sensory experiences more intensely than the majority. Dunn stressed that although it is more common for individuals in the disability groups tested to respond intensely, individuals without disabilities also experience intense responses. Therefore, she suggested that these intense sensory processing patterns are less influential than how they affect occupational performance. For example, having intense reactions to sounds could make it difficult to concentrate on a conversation when other activities are going on around them. She therefore began a strand of research to explore the sensory processing of healthy individuals. This included her 2009 book entitled "Living

sensationally", which discussed the impact of sensory processing on relationships, leisure, diet, clothing, and on work and home environments.

Dunn, Brown, & McGuigan, suggested in 1994 that behaviour responds to context. Therefore, Brown & Dunn (2010) aimed to determine the relationship between sensory processing and context (for children aged 3–11 with autism). They used data generated through the Sensory Profile - caregiver questionnaire (Dunn, 1999) (n= 49 parents) and the Sensory Profile School Companion questionnaire (Dunn, 2006) (n= 49 staff). They compared the results of the avoiding and seeking quadrants of both tests and having found significant correlations, suggested that sensory processing patterns have both universal qualities and context-specific qualities, and are related. This finding is very relevant to this thesis but should be treated with caution, given the researcher's concerns about the authenticity of third party data. This was used given the ages of the subjects, and that the aim of the study was to co-relate the two assessment tools. The researcher's avoided the bias that could have resulted from one of the researcher's being the author of the MoSP and the data collection tools used by having the questionnaires, survey instructions, and consent form distributed by an independent testing company (who anonymised the data prior to data analysis).

According to Tseng *et al.* (2011) some of the problems resulting from sensory processing dysfunction include hyperactivity, distractibility, and poor organisational skills, social and behavioural difficulties. Therefore Cosbey *et al.* (2010) used a non-experimental methodology to compare the social participation patterns (both activity patterns and social networks) of 2 groups of young children (matched for academic ability, race, gender, and socioeconomic status) with and without sensory processing problems. Unfortunately, the participants were not culturally or socio-economically diverse, which impugns the generalisability of the results. Despite this, Cosbey *et al.,* suggested that the 2 groups of children demonstrated similar activity preferences and patterns of free time use, but had significant differences in areas related to intensity and enjoyment of involvement and in their social networks, which could have limited the diversity of the participant's interactions. Recruitment of participants was via school staff who publicised the study to the parents of children who were eligible to participate. A teacher and a parent generated data about each child. Given their analysis, Cosbey *et al.* suggested that children with sensory processing dysfunction demonstrated different social participation patterns from their neurotypical peers. However because the study involved using qualitative and quantitative data collected as part of a larger study, the data may not have been exactly aligned to their research questions.

According to Engel-Yeger & Dunn (2011) humans experience life through their senses, and although most individuals have balanced sensory processing abilities, 15% of the total population has more intense sensory processing patterns (Simeonsson *et al.,* 2003, Miller *et al.,* 2007). These intense patterns of sensory hypersensitivity, or sensory hyposensitivity affect behaviour and quality of life (Parham and Mailloux 2001). For example, individuals with low neurological thresholds could show fear, negative affect and neuroticism (Kinnealey *et al.,* 1995, Hofmann and Bitran, 2007). They could also demonstrate rigid and controlling behaviours or sensation avoidance, which could lead to heightened anxiety (Kinnealey and Fuiek 1999, Pfeiffer *et al.,* 2005, Tsuji *et al.,* 2009). State anxiety is a transitory phenomena influenced by external stimuli such as an exam on top of trait anxiety which is relatively stable over time (Teixeira-Silva *et al.,* 2009) due to sensory innundation. The relationship of sensory processing patterns to low threshold and anxiety was repeatedly described by Ayres (1972), Royeen and Lane (1991) and Wilbarger and Wilbarger (1991). Furthermore, Heller (2003) emphasised that in

severe sensory hypersensitivity/sensory defensiveness, stress and anxiety could increase together with other psychological problems, even in emotionally healthy environments.

Engel-Yeger & Dunn (2011) therefore examined whether a significant relationship exists between sensory processing patterns and anxiety level of healthy adults to highlight its influence on functional abilities, behaviour, emotions and mental health. Furthermore, the coping strategies that individuals develop to deal with sensory hypersensitivity could add to the negative impact on their quality of life (Abernethy 2010). To conduct this study, Engel-Yeger & Dunn (2011) asked 135 healthy individuals to complete a sensory profile, a demographic questionnaire and Spielberger's State-Trait Anxiety Inventory in their home, having signed a consent form. The participants' had a wide range of socioeconomic backgrounds, were healthy and aged between 18-50 years. The exclusion criteria included the presence of severe systemic chronic diseases, nervous system impairments and medication use on a daily basis. All participants responded to an advertisement published in northern Israel. The results suggested a relationship between sensory processing patterns such as higher levels of low registration, sensory sensitivity and sensation avoiding and anxiety scores. Participants with sensory hypersensitivity or with low registration of sensory stimulation demonstrated significantly higher trait and state anxiety (a transitory emotional response). This includes those who are sensory hypersensitive and sensation avoiding. Kinnealey and Fuiek (1999) claimed that sensory hypersensitivity could be an unrecognised contributing or confounding factor in some individuals with anxiety. This study broke new ground because previous studies had mainly discussed the relationship between sensory hypersensitivity and anxiety among populations who develop disorders such as post-traumatic stress disorder (Morgan and Grillon 1999), pervasive developmental disorders and ADHD. Another new aspect highlighted in this study was the finding that individuals with a Low Registration pattern show relatively high trait anxiety as well. Despite the evidence presented, anxiety could be both a causative and a resultant factor of extreme sensory processing patterns leading to emotional lability (Ayres 1972). So that on the one hand, anxiety could result from perceptions of sensory stimuli resulting in increased attention and increased reactivity to them, while on the other hand, anxiety resulting from stress can amplify reactivity to sensory stimuli (Ayres 1972).

Engel-Yeger & Dunn (2011a) suggested that there is growing practical and empirical evidence of a relationship between atypical sensory processing patterns and affective disorders (Kinnealey and Fuiek 1999, Neal *et al.,* 2002, Pfeiffer *et al.,* 2005). Consequently, they studied the relationship between positive/negative affect and sensory processing patterns as expressed in daily situations among healthy adults (n= 213) aged 18-50 years. Their participants completed both a Sensory Profile and the Positive and Negative Affect Schedule (Watson *et al.,* 1988). They undertook this study because, some individuals exhibit extreme sensory processing patterns (Wilbarger and Wilbarger, 1991, Simeonsson *et al.,* 2003). These extreme patterns could negatively influence the individual's physical and mental status, alter behaviour, disrupt relationships, and affect daily living (Brown *et al.,* 1994, Ahn *et al.,* 2004, Pfeiffer *et al.,* 2005, King *et al.,* 2006).

Additionally, Engel-Yeger & Dunn (2011a) asked the same sample discussed in Engel-Yeger & Dunn (2011) to complete a Positive and Negative Affect Schedule and a sensory profile. The Positive and Negative Affect Schedule requires participants to rate their feelings concerning some affective descriptors in general. Consequently, it was possible to compare the results of both tests (using a Pearson correlation test to examine the relationship between the sensory profile and the Positive and Negative Affect Schedule scores). This showed that negative affect correlated positively with Sensory

Hypersensitivity, Sensation Avoiding and Low Registration. While positive affect correlated with Sensation Seeking. This relationship suggests that individuals could benefit from knowledge about the impact of their sensory processing patterns on participation in everyday life, quality of life and wellbeing. The use of parametric statistical tests was unusual because the scales of both the sensory profile and the Positive and Negative Affect Schedule were ordinal. This could have resulted in less accurate results the relationships between the sensory profile and the Positive and Negative Affect Schedule scores or about the generalisability of the findings. This study used a relatively small sample and used tools translated into Hebrew so that the participants could complete them and so the results could again require caution.

Engel-Yeger & Dunn (2011b) examined the relationship between pain perception, as expressed by pain catastrophising level, and sensory processing patterns among typical adults. To do this they gathered data from healthy adults (138 men and 152 Women), aged 18 - 50, using a comparative cross-sectional methodology. As with Engel-Yeger & Dunn (2011, 2011a) the exclusion criteria included the presence of systemic severe chronic diseases, pain disorders, severe impairments in the nervous system, and medication use on a daily basis. All participants completed a sensory Profile and a Pain Catastrophising Scale-Hebrew (PCS) (Granot & Ferber, 2005). The Pain Catastrophising Scale includes 13 items representing the three attributes of pain catastrophising: rumination, magnification, and helplessness. Unlike the other tests used by Engel-Yeger & Dunn (2011, 2011a) this scale was validated in Hebrew. Participants who met the inclusion criteria and who had given written consent to participate completed the questionnaires in their home in the presence of the data collector. A Pearson correlation examined the relationship between sensory profile and PCS scores. Furthermore, the significance of differences between genders and between the four patterns of sensory processing was calculated. The sample fell into two groups based on low (n-85) or high (n-205) neurological threshold.

Consequently, Engel-Yeger & Dunn (2011b) suggested that pain perception resulted from sensory processing patterns. Therefore, consideration of the individuals sensory profile when facilitating occupational-engagement was suggested. Again, this study involved a convenience sample, thus, the generalisability of the study results could be limited. To extend this study further research could examine the relationship between sensory processing patterns and additional personality traits and the way in which this relationship affects the individual’s occupational-performance and engagement.

Over the last twenty years, researcher's have tested the validity and reliability of Dunn's MoSP by conducting studies of samples across the lifespan who are with or without disabilities, using 3 age-appropriate questionnaires (i.e., the Infant/ Toddler Sensory Profile, the Sensory Profile, and the Adolescent/Adult Sensory Profile) (Brown & Dunn 2002; Dunn 1999, 2002). This has heightened the validity and reliability of the sensory profile tools. It has also added credibility to research involving the study of the influence of sensory stimulation on occupational performance. This body of knowledge has been careful to stress the use of the sensory profile in real world contexts, all of which add credence to the aspiration to study casual leisure occupations in the light of the effects of sensory stimulation. A limitation of Dunn's research is the repeated use of small and convenience samples, which may not generate generalisable results. However, researcher's have produced in excess of 800 publications using the sensory profile, and 110 that mention the MoSP, which strengthens their overall validity.

2.3 Occupational Science

Wilcock's (2001) book charting the history of occupational therapy, suggested that occupational science conceptualises in occupational rather than biomedical terms. However, Morley et al's (2011) acute practice orientated article, suggested that occupational science removed the evidence base behind occupational therapy practice. In contrast, Cole and Tufano's (2008) book suggested that practitioners should move beyond the biomedical model, using occupational science as their frame of reference. Similarly Colaianni's (2011) thesis, suggested that the philosophy of occupational therapy and the biomedical model have been in conflict for more than 60 years. Humans 'occupational needs' relating to maintaining health, can be traced back throughout human evolution (Wilcock 2006). Neurodynamic models such as the MoSP (Dunn, 1997) have portrayed human beings as the victims of external forces with little conscious control over their behaviour. However, neuro-occupation (described by Walloch (2006) as the dynamic relationship between the nervous system and occupational performance), views humans as self-organised, sentient and intentional beings who respond to their occupational needs. Lazzarini's (2004) literature review suggested that intention, meaning, and perception lead the body to react to stimuli against a background of routines, habits and occupational choices, leading to occupational performance.

Occupational science focuses on the complexity and centrality of occupation in human life. Historical, cultural, physical, social, personal, temporal, spiritual, and virtual contexts influence human beings and their occupational choices (Wilcock 2006). According to Nilsson & Townsend's (2010) questionnaire based study, occupational science is concerned with the development of humans both as a species and as individuals. Asaba & Wicks' (2010) article about their separate PhD studies, suggested that this development occurred within a social environment that both empowers and disempowers individuals. As such, occupational science offers a framework through which to explore the concept of leisure.

Sadlo's (2004) book chapter and Townsend & Wilcock's (2004) reflective article highlighted the importance of meaningful occupations, contrasting them with boring and repetitious ones. Boredom is a particular feature of Farnworth's (2004) book chapter and her (1998) experience sampling study of social occupations, which differentiated between meaningful occupation and occupational alienation. Likewise, Wegner & Flisher's (2009) systematic literature review described boredom as a lack of challenge, occupation and limited leisure resources, while Goldberg's (2012) book chapter described it as resulting from information overload. Both of these concepts are of relevance to this thesis, as many residents in this study experienced boredom, limited choice and potential susceptibility to stimulation overload. However, as Farnworth (2004) reflected, it is difficult to know whether there were greater numbers of individuals experiencing boredom or whether boredom has a lay definition, used to refer to less intense experiences.

Based on a review of research into the effects of novelty and complexity on arousal and curiosity, Berlyne's (1966) seminal study suggested that humans were motivated by structure, identity and meaning. Although, Berlyne's paper described no aims or explicit methodology, it has had a lasting influence. The results suggested a link between the under-stimulation/deprivation mentioned previously, and disability related limitations. Berlyne suggested that the nervous system preferred constant activity, engagement and exploration. He also suggested that stimulation greater than the individual can cope with could result in a withdrawal from engagement, which could in turn result in further costs (Wegner & Flisher, 2009; Goldberg, 2012; Edmund & Morris, 2000). As discussed, sensory gating deficits influence the capacity of the individual to cope

with external stimuli, rather than by the intensity of the stimuli. Therefore, there could be a link between sensory processing and engagement.

The World Health Organisation (WHO) recognised that reduced occupational-engagement influences human health (WHO, 2001). Some of the conditions that reduce opportunities for occupational-engagement include geographic isolation, idleness, and incarceration (Wilcock, 2006; Whiteford, 2009), poor health, disability, and lack of transportation, isolation, poverty and homelessness (Scaffa & Brownson (2005). However, Whiteford's (2004, 2010) book chapters focused on the restrictions to participation caused by the social and physical environment. She described the special case of occupational deprivation experienced by individuals with disabilities as being due to their social environment, rather than being a result of their limitations. This could be true up to a point, however, Bache & Derwent's (2008) case study suggested that individuals with NPC appear to remain unable to participate due to limited technological development. Such profoundly disabled individuals become dependent on assistive technology and equipment, compensatory strategies for all occupations (Fisher, 2013). However, disability related limitations, challenge the definition of occupational deprivation as being externally controlled, suggested in Whiteford's (2009) book chapter.

Toogood's (2008) experimental study suggested that enabling facilitation included (a) occupational preparation; (b) prompting/enablement; and (c) ensuring that participation is positive. McKay's (2011) thesis described the escalation from least-to-most the levels of prompting/enablement, including: (1) no help, (2) verbal instruction, (3) demonstration & verbal instruction, and (4) physical guidance & instruction.

Occupational deprivation in this context occurs against a background where acute care costs more (according to Jackson's (2010) legislative review), and consumes increasingly finite resources; resulting in reduced opportunities for improvement to the individual's sense of wellbeing (Yerxa *et al.,* 1989), and where the incidence of (Neurological Alliance, 2003), and degree of (Lakdawalla *et al.*, 2004) neurological disability are increasing. Therefore more individuals survive longer, with greater limitations, and with fewer occupational choices (according to Ganzini's, (2006) review of clinical decision-making; and Monti *et al's.* (2010) experimental study). This trend has led to a shift in policy emphasis, from escalating survival to improving life satisfaction (according to Khoman & Weale's (2006) Estimates of Life Expectancy), and health and wellbeing (Department of Health, 2010). Additionally, views exist about what is suitable for individuals with disabilities to engage in, (according to Suto's (1998) literature review, and (2004) book chapter); is sanctioned (in Pollard & Sakellariou's (2012) book chapter), and about whether unproductive individuals deserve leisure (in Lobo's (1999) literature review). Society also appears to dehumanise individuals with disabilities (according to Carlson's (2010) literature review), offering less than optimal levels of adaptation and barriers to engagement in leisure such as those described by Bundy & Clemson's (2009) book chapter and Lockwood & Lockwood's (2007) literature review among others. Society's discriminatory attitude was highlighted by the Disabled Living Foundation (2006), to lead to non-enablement, reduced opportunities, and experiencing life as meaningless and hopeless.

2.3.1 Occupational-engagement

Creek (2010 p25) defined occupational-engagement as 'a sense of involvement, choice, positive meaning and commitment while performing an occupation'. Crepeau *et al's.* (2009) book chapter suggested that occupational-engagement influenced our bodies, selves, and communities, being what Christiansen (2005) described as a lifestyle characteristic. To measure occupational-engagement, the majority of studies of leisure by Occupational Therapists have used non-standardised assessment tools, often designed to generate frequencies of involvement or types of leisure occupations (for example experimental studies by Lefrançois *et al.,* 2001; Menec, 2003; Strain, *et al.,* 2002; Wang *et al.,* 2002). The exception to this is the Nottingham Leisure Profile (Drummond & Walker, 1994). However, its applicability was limited to individuals after a cerebrovascular accident (Drummond *et al.,* 2001). This assessment was thought to lack the sensitivity to generate reliable results from profoundly disabled individuals.

Schooler and Mulatu's (2001) longitudinal study described engagement as participating in complex occupations. Additionally, Creek's (2010) book suggested that occupational-performance may be perceived differently by the individual or the observer, suggesting (as did Nilsson's (2006) PhD thesis) that it occurs amidst an interaction between the individual, the environment and their motivation, interest and wellbeing. So that the individual's engagement level both influences and could be influenced by physical and mental health (according to Bosma *et al's.* (2002) questionnaire based study). Self-reported and observed engagement enhance understanding of an individual's occupational-performance (according to Clark *et al's.* (1991) literature review and Chisholm *et al's.* (2003) resource manual), shedding light on the meaning of the occupation for the individual, and their experience. However, only the individual can truly describe his or her engagement level, their experience and its meaning (Yerxa *et al.,* 1989; Nilsson, 2006), which is problematic for this thesis given the cognitive and communication difficulties experienced.

The motor and processing skills involved in occupational-engagement are observable (according to Chard *et al's.* (2009) clinical strategy suggestions) and therefore measurable through the extent to which an individual participates (Bosma *et al.,* 2002; Hultsch *et al.,* 1999; Nicholson & Anderson, 2003; Reich & Zautra. 1989). In fact, Seekins *et al's.* (2007) preliminary study of participation, suggested that observable engagement should be the main measure of outcomes of interventions in the domain of disability and rehabilitation, which influenced this thesis.

Occupational-engagement represents both an idea and a value (Creek, 2010), requiring attention, absorption, presence or focus on the task (Rothbard, 2001). The idea involves the individuals involvement, connection with, and investment in the activity. The value being that man needs engagement in what he does (Creek, 2010), rather than just going through the motions. However, cognitive ability presents a barrier to engagement for individuals with NPC, since both attention and absorption require concentration (Rothbard, 2001) and involvement (Kielhofner 2002). Engagement has therefore been associated with motivation, choice, and meaning (AOTA, 2002). Knowledge about how and why performance occurs could influence the experience of involvement (according to the MOHO (Kielhofner, 2002)) and the experience of engagement (according to Yerxa *et al's.,* (1989) literature review). Even if the individual is unable to describe their engagement, it is observable (Suto, 1998, 2004). The demonstration of active or passive engagement can include rapt but passive attention, or it could involve physically active participation (Kishida & Kemp, 2006). Kishida & Kemp's (2010) studies of

engagement promotion, examined associated variables, and measured engagement. In 1987; Messer *et al's.,* experimental study categorised engagement in terms of object manipulation (which could be problematic for individuals with NPC) and involvement (e.g. visual attention, exploration, and perseverance). On the other hand, Bakeman and Adamson's (1984) longitudinal study subdivided group behaviour into the unengaged individuals, or those involved in passive and coordinated joint engagement. More recently Fredricks *et al's.* (2004) literature review categorised engagement into behavioural, emotional and cognitive engagement.

More recently still, occupational-engagement was suggested to influence health, support relationships, and maintain self image, by Corring's (2006) conference presentation. Lack of opportunity due to segregation, restriction, exploitation, arguably therefore has the potential to do harm (Wilcock, 2006; Yerxa *et al.,* 1989). With this in mind, Townsend and Wilcock (2004) suggested a Charter of Occupational Rights. They later concluded that all humans should be able to engage in occupations of their choice, to develop through what they do and experience independence or interdependence, equality, participation, security, health, and wellbeing (Wilcock and Townsend 2008).

2.3.2 Effects of occupational-engagement

Hammell & Iwama's (2011) literature review suggested that engagement in meaningful occupations was associated with positive health and longevity, engagement in valued occupations contributed to self-worth and to self-determination, and engaging in occupations with and for others generated a sense of belonging, and wellbeing. However to date few researcher's have generated much empirical data to support the premise that occupational-engagement contributes positively to wellbeing. According to Hammell (2009), occupations that promote interdependence contribute positively to wellbeing but models such as the CMOP-E, fail to convey the value of contributing to the wellbeing of others. Conversely, Hammell & Iwama (2011) suggested that over, under or unhealthy employment may contribute to mental ill health.

Green *et al.* (2005) surveyed 1918 older people from five countries, which reinforced the positive impact of occupational-engagement on individual wellbeing. Table 5 lists some of the effects of occupational participation. Conversely, not engaging in occupations may limit the individual's ability to recognise and express their self-identity and experience these effects. The researcher is not aware of any evidence that individuals with NPC do not derive a sense of meaning from their occupational-engagement. Fenech & Shaw-Fisher's (2012) interview findings, (see chapter six), suggested that individuals with NPC experience a sense of meaning resulting from their leisure occupations. Arguably though, individuals who do not have so many opportunities for engagement in productivity/ work or self care occupations place an extra focus on the importance of their leisure engagement and therefore on the sense of meaning derived from them. The Journal of Occupational Science includes articles about the benefits (and costs of occupational participation and engagement) as illustrated in section 2.3.3 and discussed in more depth in Appendix i. For example Lin *et al's.* (2009) phenomenological study explored the meaning of occupational-engagement for forensic outpatients, through mindfulness. The meanings suggested derived from doing the right thing, connecting with others, freedom and responsibility, and meeting challenges. This study highlighted the value of passive engagement, since some participants were reported to have enjoyed being in the presence of others who were engaged in social occupations, while they themselves were not. Equally, Nilsson & Fisher's (2006) cross-sectional study interviews suggested that learning was not given a high priority by carers, but resulted from occupational participation. This

was in contrast to Bejerholm and Eklund (2004) whose questionnaire data about the time use of individuals with schizophrenia, showed stagnation and a sense of emptiness when engaged in 'time fillers'.

Table 5 Effects of occupational participation

A sense of importance, purpose or meaning
Goal orientation
A sense of accomplishment/achievement
A sense of being fully human
Self-identity (individual/social)
Individual growth
A clear sense of the rhythm of life
A sense of belonging
Opportunities for self-expression and creativity
A sense of health, wellbeing and capability
Preventing boredom through enablement, learning and discovery
Control and choice of occupation/self-determination
Sense of engagement in the occupation
Effects of a occupational environment which was conducive
Acknowledgement or reinforcement of age/cultural/historical/gender identity
A sense of self-efficacy

Researcher's such as Hocking *et al.* (2002), Howell and Pierce (2000), Hull *et al.* (2005), Leufstadis *et al.* (2008), Scheerer *et al.* (2004), Wright-St Clair *et al.* (2004), Reed *et al.* (2010), Shordike and Pierce (2005) (in their comparative analysis), and Taylor (2008) (in her PhD thesis) have all explored the meaning of occupation. Meaning was described by Wilcock (1999) as linking doing and being, influencing the individual's sense of competence and identity. Jonsson and Josephsson's (2005) book chapter described how a single occupation could have different meanings for each member of a group engaging in it. The same researcher's linked occupational deprivation and boredom, since both were the outcomes of not experiencing meaningful occupations. They cited Whiteford (1997), who described incarceration (and its resultant boredom and occupational deprivation) in terms of experiencing a lack of occupational-engagement. Whiteford's (1997) study involved observation, semi structured interviews, formal assessments and documentary review in a prison setting. This study suggested that inmates experienced occupational deprivation, compounded by minimal contact with the outside world, which exacerbated their disorientation and psychotic episodes.

The meaning of occupational-engagement can therefore be understood from different theoretical and philosophical angles, such as the social and cultural perspectives of meaning and the experience of the individual (Jonsson and Josephsson, 2005). Chapter Seven discusses environmental factors, the meaning of occupations, and their influence on the engagement. Jonsson *et al.,* (2000) suggested that the meaning derived from an occupation could be positive or negative, whilst exploring the occupational transition from employment to retirement. These researcher's used informal, semi-structured interviews with recently retired individuals, who experienced a different rhythm of life, changes in meanings of occupations, and being in control of their time. Some of these themes could resonate with the experience of individuals with NPC, whilst others (for example, being in control of time) might not. Bakker *et al.* (2008) argued that engagement could be the inverse of burnout.

Similarly, Melamed *et al's.* (1995) experimental study, suggested that leisure congruence was associated to lower incidence of burnout.

2.3.3 Non-sensory influences on occupational-engagement

Both Dickie *et al's.* (2006) case studies and Hocking's (2000) reflective article suggested that occupational science is too individualistic in its conceptualisation of occupation. Conversely, Pierce *et al's.* (2010) literature review suggested that this was appropriate for a science and a profession linked to therapeutic practice. Individualism encompasses an ethos of equal rights, and an expectation that every human being can develop, express their personality, and pursue individual interests, putting it at odds with collective communities, where majority needs outweigh the needs of the few. If the focus of occupational science is on individuals, their uniqueness, experience and development; occupational scientists may ignore the complex social causes underpinning occupational phenomena; such as, interactions between culture, faith, economics, history and politics and the impacts these have on either supporting, or depriving people of opportunities for occupational participation. It also rejects ideological issues, and power relations, so that occupational deprivation can only be explored in relation to what happens to people who experience it, rather than the forces beyond the individual that bring it about. Whereas, arguably, the causes of occupational deprivation could be immaterial.

This concept of being self-determined is problematic because occupational-performance is influenced by the bio-psychosocial and sensory environment (according to Jonsson *et al's.* (2001) longitudinal qualitative study), in addition to an individual's preferences. Therefore, the researcher cannot believe wholeheartedly that participation in healthful occupations is a matter of individual choice and personal responsibility. Accessibility may influence engagement (see experimental studies by Verghese,2006; Verghese *et al.,* 2003; 2006), especially if being easy to access cheapens it, turning a leisure occupation into an imposed, arbitrary or easy option for supporters to provide. The level of support received and a desire to prevent boredom may influence engagingness. The timing or sense of time passing could also be a factor, since occupations are a way of using time. Another influencing factor could be the participant's sense of altruism, or the individual's interest (Yerxa, 2002), the meaning of the occupation and their sense of occupational balance. Other factors could include the novelty of an occupation, the participant's occupational capacity, and the complexity of the occupation as well as the occupational role offered. Jonsson *et al.* (2000) suggested that occupational-engagement may be influenced by internal motivations and external demands, for example the participants' ability to attend or be absorbed, and the depletion or enrichment of their physical and psychological resources through their occupational-engagement. Other facets of an occupation contribute meaning to an occupation and influence on engagement as discussed in Appendix i.

2.3.4 Occupational Deprivation and its Relevance to NPC

Occupational science is based upon the belief that humans are designed to engage in the most complex occupations (Wilcock, 2006). Consequently, being unable to engage in occupations could feel similar to the prevention of being truly human, because it is not a natural or healthy state for human beings to experience. Additionally, Rambeau's (2010) conference paper concluded that trauma and the deprivation of meaningful occupation could lead to difficulties in functional

ability. Consequently, extended periods of occupational deprivation could have a detrimental effect on health and wellbeing (Wilcock, 2006).

Arguably, the opposite of meaningful occupational-engagement is occupational deprivation. In Whiteford's (2004) illustrations of occupational deprivation, the focus was on external barriers such as a refugee camp, a prison, geographical isolation, a lack of available employment, or sexual role stereotyping. Whiteford (2009) suggested that all of these barriers to occupational participation were technically surmountable, even if unlikely. However, the researcher believes that individuals with NPC experience occupational deprivation because their disability is beyond their control, and because they depend on assistive technology, and supporter facilitation/ collaboration to communicate, or for their self-care and so forth. Occupational deprivation produces negative effects in human beings (Whiteford, 2004). Furthermore, the profound disability level of individuals with NPC means that the barriers to occupational participation are not surmountable at present, because appropriate assistive technology is not available. In the light of Wicks' (2005) suggestion that through doing, the occupational participant becomes an individual, the fact that reduced opportunities to engage in occupations could influence the individual's sense of self to the point of dehumanising them (Yerxa *et al.,* 1989; Wilcock, 2006). Hence, an earlier title for this thesis was to question whether the participants were being fully human.

Wilcock (2007) and Hammel (2008) reviewed research findings from a wide range of disciplines to demonstrate a link between engagement in meaningful occupations and health. Without describing a literature searching strategy or appraising the literature, Wilcock argued both for and against a clear link between occupations and health. She suggested that occupations provide opportunities to experience doing, being and becoming, which could be essential to survival and health. Wilcock's (1999) addition of belonging to the benefits of doing, being and becoming adds a contextual element (connectedness) to occupations (see for example Bedding & Sadlo's (2008) phenomenological study, which explored participation in art classes. This built on her previous work, which described humans as occupational beings, and upon Yerxa *et al's.,* (1989) seminal paper, which suggested that an individual was at their most human when occupationally engaged. Collins (2008) opinion piece went on to discuss the nature of being fully human based on occupational-engagement. Furthermore, O'Sullivan and Chard (2010) suggested that occupational participants discovered an awareness of their humanity through leisure engagement, supporting these ideas.

However, occupational-engagement alone could not enhance wellbeing, since it is the experience of engagement that adds meaning and satisfaction (Doble & Santha, 2008). This experience includes the facets which contribute meaning to an occupation listed in Table 5. The use of the term facet, here and by Reed *et al.* (2010) reflects an aspect, feature or element, rather than a factor, which suggests a causative attribute. Like a cut diamond, occupations are multi-faceted and have many causative attributes, seen as a whole, rather than as a set of distinct attributes.

Occupational-engagement provides a sense of purpose, without which humans could become bored, destructive and depressed (Wilcock, 2007), resulting in even fewer opportunities for occupational-engagement (Wilcock, 2006). Wilcock (2006) suggested that man's occupational nature resulted from a combination of consciousness, cognitive capacity, language and mind-body unity, most of which differentiates humans from other species. For example, a human's brain size could enable perceptions of depth, direction and space, as well as facilitating the capacity for abstraction, insight and learning,

voluntary movement, curiosity, exploratory behaviour and imitation (Wilcock 2006), all of which could be employed during occupational-engagement. By implication therefore, the limitations imposed by physical, cognitive, perceptual, communication; sensory gating and awareness limitations conspire against individuals with NPC to reduce their occupational capacity to the point of occupational deprivation. This reduction occurs despite adaptations to make the environment more conducive to occupational-engagement. Additionally, at the profound levels of disability experienced by the study population, these adaptations could be mutually exclusive, e.g. two residents trying to communicate directly, one using a Litewriter (an electronic communication device) and the other a coloured transparent letter screen. This incompatibility of communication could contribute to Martelli *et al's.,* concept of a catastrophic reaction (2008), which could be compounded by the negative effects of other forms of "being a viewer instead of a doer" because of occupational deprivation (according to Devine's (2004) much cited qualitative study).

2.3.5 Human Costs of Occupational Deprivation

O'Sullivan and Hocking (2006) and Hearle *et al's.* (2005) narrative study described how as individuals do less, they become less skilled, making participation more difficult. As they become less accomplished, their social status could decline, reducing their belief in their own self-efficacy. Being unable to engage in occupations may lead to negative effects, such as longer periods asleep, altered life satisfaction, lack of social status, diminished sense of self-efficacy, atrophied occupational capacities, loss of self-identity, social exclusion, altered patterns of time use, and imposed dependence (Wilcock, 2006; Whiteford, 2009). Turner's (2002) book chapter, and O'Sullivan and Hocking (2006) and Hearle *et al's.* (2005) studies described the insidious effects of occupational deprivation, whereby as individuals do less, they lose capacity and opportunity which could be "devastating and widespread", and therefore it becomes harder to do things. When doing requires too much effort, occupations become less rewarding and individuals are less motivated to try. However, because occupational deprivation is externally controlled, there was little research about occupational deprivation in individuals with NPC. A study conducted by Rambeau (2010) on adolescent refugees suggested that war-related trauma and being deprived of any type of meaningful occupation risks the development of significant limitations to occupational capacity. Therefore, the literature explores parallels from a refugee camp and a prison, and situations of geographical isolation, under/employment and sexual role stereotyping, to illustrate the effects of limitations to occupational experience and why occupational deprivation should be avoided.

Occupational-engagement and sleep appeared on the same continuum to Wilcock (2006). Given that humans are occupational beings (Wilcock, 2006), and are only truly human when occupationally engaged (Yerxa *et al.,* 1989), being unable to engage in occupations could lead to maladaptive behaviour such as oversleeping (Whiteford, 1997). Whiteford described time spent sleeping as wasted, or a habit to use up unengaged time (Whiteford, 1997). However the researcher believes sleep could be an avoidance mechanism at times (against negative thoughts and spiralling demotivation, boredom, lack of social status, diminished sense of self efficacy, imposed dependence and altered self-identity and so forth, which could all result from occupational deprivation). Jensen & Allen (1994) likewise, suggested that it enabled the individual to exercise some control over some part of their life, while Farnworth (1998, 2004) and Whiteford (2000) described it is a way of using time in the absence of meaningful occupations. Although arguably, sleep could reinvigorate after the effort of completing necessary

tasks or worrying about the future. Arguably, the greater effort involved in moving and the continued stress and pain of NPC are the cause of the longer periods asleep witnessed by the researcher. However, this view ignores the concept of depriving humans of opportunities to engage in the most complex occupations occurring in the animal kingdom (Wilcock, 2006; Yerxa *et al.,* 1989).

Whiteford (1995, 2004) suggested that occupational deprivation, or the absence of opportunities for occupational-engagement (Townsend & Wilcock, 2004), could lead to an inability to be fully part of the world, because it is through interaction with the environment that the individual understands themselves and their relationship to the world. Furthermore, Hearle *et al.* (2005) and Whiteford (1997, 2004, 2010) suggested that it resulted in feelings of helplessness and decreased wellbeing and life satisfaction. Although arguably, the link between depression and time spent inactive could be the result of depression, given the impact of chronic symptoms on sickness behaviour. This inactivity could have led to occupational alienation at best and occupational deprivation at worst.

Social status results from the characteristics, knowledge, ability and/or skills required to maintain a social role (Bullock, 2010). If paid employment or an occupational role is regarded as defining an individual's identity, social status (Whiteford 2009), then the converse could also be true. Wilcock (1999, 2006) suggested that individuals who are unable to "do" are at risk of losing any social identity gained through their occupational roles, their productivity and their relationships, being unable to view themselves as unique occupational beings. Although arguably, individuals lose their social status because humans dislike and are prejudiced against difference (as suggested in Brown's (2006) book).

Christiansen (1999), Phelan & Kinsella (2009) described identity in relation to occupational-engagement, suggesting that successful performance enhances self-efficacy, which in turn helps to develop a positive identity, and vice versa. On the other hand, any impediment to presenting an image of competence threatens our self-identity, which according to Sarda *et al.* (2009), Dahlbeck & Lightsey (2008) and Rinat *et al.* (2011) could influence adjustment to chronic circumstances and symptomatology (e.g. the severity of pain) as well as disease progression (Edwards *et al.,* 2001), leading to a preference for spectator occupations in response to pressure for independence rather than autonomy. Although arguably, disability could lead to a sense of reduced ability, there is also evidence that regained occupational roles lead to a sense of capability (Vrkljan & Miller Polgar, 2001).

Hocking (2006) described how as individuals do less, they lose occupational capacity and participation gets harder, less rewarding, and motivation declines. Occupational dysfunction, which leads to loss of skills and occupational capacity, could in turn lead to unfulfilled needs, roles and responsibilities (Turner, 2002). This loss of skills is what Whiteford (2000) and Wilcock (1995, 2006) called "atrophied occupational capacities" and results from occupational deprivation. Whiteford (2000) described this as a "dehumanising phenomenon". Although arguably, disability reduces engagement or performance, a lack of opportunities offered by the social and physical world is what disables, rather than limitations caused by the disability. Theoretically, this lack of opportunity is reversible (Whiteford, 2004, 2010). Another result of occupational deprivation is loss of identity.

A lack of occupational capacity could change an individual's self-identity and self-image (according to Reed *et al's.* (2010) phenomenological study). Self-identity includes a mixture of past, present and future experience of occupational-performance (Kielhofner *et al.,* 2002), including knowledge about ability, self-identity. They could also face uncertainty about their future, and could therefore have uncertain expectations of their future engagement. Kielhofner *et al.* (2002) also suggested that self-identity could alter with different levels and types of commitments – e.g. self-care occupations taking up a greater proportion of time than previously, or having free time thrust upon them because there is nothing that they can engage in. Additionally, occupational contexts could alter the meaning of an occupation (Kielhofner *et al.,* 2002). For example, being in residential care could lead to a change of occupational habits and routines similar to occupational apartheid (Phelan & Kinsella 2009) (altering the meaning of the occupations engaged in), and influencing self-identity, as part of the catastrophic reaction (Martelli *et al.,* 2008) involved in adjusting to neuropalliative disability (Kielhofner *et al.,* 2002). Especially given the feedback from a persistent lack of achievement in an occupation upon which a self-identity is based (Kleiber & Kirshnit, 1991; Tinley, 2012). The individual may attempt to engage in their previous occupations (according to Stryker's (1987) book chapter and; Kleiber *et al's.* (2008) literature review), but because of repeated failure, their self-identity could be eroded further (Whiteford 2000; Palmcrantz *et al.,* 2012). Although arguably, cognitive deficits could deprive the individual of their past and therefore impact on their recollection of who they were. However, without occupational-engagement to bolster and create an image of an occupational being, occupational deprivation could also influence institutionalisation and self-identity, since Lawton & Rubenstein's (2000) book suggested that the culture in residential homes could reinforce dependent behaviour.

Dorer *et al's.* (2009) descriptive survey, suggested that individuals with mental health problems experienced limited occupational-engagement, missing out on the social relationships built through occupations and roles – e.g. dog owners who meet when walking, or crafters who meet at exhibitions. Although arguably, social isolation could be a result of the clinical condition itself, occupational science proposes that social relationships, social identity and social roles result from and develop through occupational-engagement. Therefore, occupational deprivation could lead to limitations to development, social relationships, and social identity. Another aspect of occupational deprivation includes altered patterns of occupational-engagement.

Friendship and social interaction may be influenced by the assistive technology provided to facilitate communication (Asbjørnslett *et al.,* 2011), because it may be difficult for others to understand. Whiteford's (2004) illustrations of occupational deprivation included "prolonged isolation", e.g. resulting from the communication difficulties, and confinement, experienced by an individual with locked-in-syndrome. Prolonged isolation and confinement result in the individual becoming uncreative, unmotivated and fatigued (according to experimental studies by Connors *et al.,* 1985; Salam, 2012). Although arguably, social isolation is a result of the clinical condition itself. However, occupational science proposes that social relationships, social identity and social roles result from and develop through occupational-engagement.

The relationship between time use, sense of efficacy and identity appears compromised by prolonged occupational deprivation (Whiteford, 1997; Farnworth, 2004, Cronin - Davis *et al.,* 2004, Long, 2004) and a lack of self-determination. Consequently, Stewart and Craik's (2007) questionnaire data; Helbig's (2003) qualitative study; Farnworth (2004); and Farnworth *et al.* (2004) all suggested that time-use in residential care included personal care, passive leisure and rest predominantly, with limited engagement in active or productive occupations. Instead of choosing occupations for themselves,

residents could experience occupations that others deem appropriate (Suto, 1998, 2004), think they have earned (Scanlan *et al.,* 2010), or are available (Suto, 1998, 2004). This could influence the meaningfulness of how their time is used – i.e. killing or filling free time (Lobo, 1999; Stebbins, 2009) with former leisure occupations feeling imposed. Whiteford (1997), Cronin - Davis *et al.* (2004), Long (2004) and Farnworth, (2004) all suggested that altered occupational patterns and time use could result from occupational deprivation. Individuals with disabilities have more free time (Pentland *et al.,* 1998, Pentland & McColl, 1999, Farnworth, 2004), but less energy or opportunities to use it. Additionally, having less to do (and particularly a lack of goal directedness and challenge) could affect their perception of time passing (according to Zauberman *et al's.* (2010) experimental study.

Dependence on others could result from a lack of self-determination, resulting in atrophied occupational capacities. Physically constrained and occupationally deprived individuals (Whiteford 2004, 2010) such as prisoners (Whiteford, 1997), refugees (Whiteford, 2000) and residents in care environments (French, 2001) could share a sense of dependence or lack of control with individuals with NPC. Lack of control over occupations (Whiteford, 2000, 2004), possibly affecting their sense of time passing, could result from a timetable imposed by a residential facility (Christiansen, 1996; Farnworth, 2004; Farnworth, 2003). Zemke (2004) also suggested that humans depend on occupations to allow "being" and "doing" their self-identity (Zemke, 2004). Although arguably, imposed dependence could lead to institutionalisation because of reduced opportunities for occupational-engagement.

Disability or incarceration could restrict opportunities for occupational-engagement, e.g. as part of a prisoner's punishment (Whiteford, 1997). The effects of prolonged occupational deprivation could include a lack of sensory stimulation (according to Heuchemer & Josephsson's (2006) interview data), or were suggested by Sviden and Borrell's (1998) interview data and Helbig & McKay's (2003) literature review to result from a failure to capitalise on such stimulation when it is available. Equally, attitudes could enforce dependence through requiring permission or support for occupational-engagement, depending on what is deemed appropriate (Suto, 1998, 2004), earned (Scanlan *et al.,* 2010), or available (Suto, 1998, 2004). The individual could experience a lack of opportunity to access (even unsuitable) occupations, or a lack of access to the materials and tools required. Turner (2002) suggested that the loss of the ability to use the tools to undertake occupations was an outcome of occupational deprivation. Although arguably, profound disability limits an individual's occupational performance. However, occupational science proposes that the lack of access to opportunities for hand use leads to a 'use it or lose it' cycle, in turn leading to the atrophy of occupational capacities.

2.3.6 The Costs of Occupational Deprivation and their Links to Neuropalliative Conditions

Lazzarini (2004) described occupational-engagement as a dynamic and self-determined process, resulting in spontaneous and unpredictable patterns of engagement. She suggested that the brain reacted automatically, or relies on experience, goals and meanings to shape occupational-engagement in response to anticipated or actual sensory stimulation. Lazzarini (2004) further suggested that meaning results from actions, choices and their consequences, as well as from occupational-engagement (according to Casillas *et al's.* (2008) discussion of nonlinear dynamics and occupational learning,

meaning, behaviour, context and occupational performance). Therefore, occupations such as casual leisure could be considered in terms of spontaneous and unpredictable patterns fuelled by intention, meaning and perception, and in terms of the inputs, throughputs and outputs that result from systems theory (according to Miller & Kuhaneck's (2008) qualitative investigation of play).

Wilcock (2006) suggested that the type of limitations caused by NPC, although not external to the individual, could influence occupational performance. These effects could be a cause of occupational deprivation and the absence of opportunities for occupational-engagement (Townsend & Wilcock, 2004). Other studies have attributed occupational deprivation to mental health, orthopaedic limitations and so forth (according to Bryant et al's. (2004) comparative analysis of focus group data, Krupa *et al's.* (2009) literature review; Duncan *et al's.* (2003) questionnaire data; and Mee & Sumsion's (2001) interviews and observations based study.

Despite Whiteford's (2004, 2010) view that disability as a special case of occupational deprivation, many occupational therapists of the researcher's acquaintance around the world use the term occupational deprivation in relation to disability. This view is now more widely published. For example, individuals with hand injuries experience occupational dysfunction, whereas, Colaianni's (2011) thesis stated that if capacities are over used after a hand injury stress, fatigue and burnout with their associated risks of increased disease and injury could result in occupational deprivation. If capacities reduce after a hand injury, further atrophied occupational capacity could result (Colaianni, 2011). Both of these situations could prevent an individual from engaging in occupations (Colaianni, 2011). Additionally, Townsend *et al's.* (2009) literature review explored the links between occupation and place. In doing so, the authors suggested that occupational deprivation could result when homeless people with drug addictions have no access to safe needle exchange or addiction programs that address social influences such as education, employment, and housing, while others in the same community could live an enriched life with access to many of their desired occupations.

A very tangible example from Patomella *et al's.* (2009) article about lived experience, describes receiving the news following a stroke that the individual is no longer fit to drive as coming as a shock. They described this restraint from participating in meaningful or necessary occupations; and an inability to adapt to the disruption as leading to occupational deprivation (Patomella *et al.,* 2009), because as Townsend & Wilcock's (2004a) book chapter pointed out, occupational deprivation involves the absence of opportunities.

Additionally, Nilsson & Townsend's (2010) article suggested that very old people could face occupational alienation, imbalance, deprivation and marginalisation if they cannot participate in leisure that involve modern technologies, such as smart phones, mp3 players, and the Internet.

Alarmingly, Bryant *et al's.* (2004) focus group suggested that the threat of the removal of occupation or, enforced occupational deprivation, could convey expectations to mental health service users. Thus, undesirable behaviour(s), risked the person losing access to the service and its resources. Writing in the context of a study about fibromyalgia, Liedberg *et al.* (2012) suggested that a lack of participation or occupational deprivation leads to poor well-being. Their barriers to occupational participation included finances; their fluctuating health and occupational capacity; and others who perceived them as malingerers. Liedberg *et al's.* (2012) participants reported changed habits and roles in all areas of daily life, and because everything took longer. Brouwer *et al's.* (2008) interview data suggested that visual impairment could also lead to

occupational deprivation and isolation. Likewise, Rebeiro's (2009) literature review suggested that while engagement in occupation was supportive of health, and critical to long term well-being, there remains widespread occupational deprivation and marginalisation for people with disabilities.

According to Farnworth & Munoz's (2009) literature review, occupational deprivation has a negative impact on individuals with forensic mental health problems. Their responses included: hypervigilance, social withdrawal and decreased interaction, all of which heightened their sense of occupational deprivation.

Persson and Jonsson's (2009) book chapter about individuals with long-term pain suggested that a range of occupational experiences (including matching level of challenge with skills) was important for health and well-being. Additionally, Matuska's (2010) experimental study data suggested that if the challenge is too demanding, an imbalance arises that could become a destructive process; leading to occupational deprivation and/or overload.

When discussing voluntary work for adults with mental health problems, Farrell & Bryant's (2009) interview data, suggested that social justice could enable occupational participation (World Health Organisation, 2001). Occupational justice is a form of social justice, including access to equitable opportunities, and the means to choose, organise and perform meaningful occupations (Townsend and Wilcock 2004a). Individuals with mental health problems could be excluded from employment and leisure opportunities, leading to occupational marginalisation, while external restrictions, such as the poverty trap, could lead to occupational deprivation (Farrell & Bryant's (2009a) Literature Review). Systematic constraints and pervasive attitudes lead to individuals with mental health problems having a reduced socioeconomic status and limited occupational opportunities.

Farrell & Bryant (2009) sought the views of nine recruiters to explore factors that could motivate or support greater understanding and acceptance of people with mental health problems. A hierarchy of acceptability could exist where affective disorders are illnesses that anyone could suffer, whereas schizophrenia was on a different level, suggesting that occupational apartheid exists, instigating barriers to volunteering opportunities. The recruiters were willing participants in this research, and biased towards supporting individuals with mental health problems (Farrell & Bryant, 2009). Even so the recruiters flexibility and ability or willingness to visualise what a reasonable adjustment was (Farrell & Bryant, 2009) was varied.

Again writing about mental health, Harrison & Sellers (2008) opinion piece suggested that occupational deprivation and its opposite occupational justice could form the link between occupation and social inclusion. However, Arguably, implementation of the social inclusion agenda might reduce choice for individuals with high support needs. An example of this is the pressure to reduce benefit payments and return service users to work: individuals may feel forced to take unsatisfying work.

Watson & Duncan's (2007) experimental study based conference presentation reported on households experiencing long-term poverty and disability. The households experienced occupational deprivation due to factors beyond their control, i.e. the disability itself and their resultant social marginalisation (being unable to break out of a negative descent into difficulties). Arguably, the same lack of control exists in relation to sensory-overload in the moment and to occupational deprivation.

Wells (2009) dissertation suggested that individuals with long-term conditions such as end stage renal disease and dialysis could experience occupational deprivation which was outside their control. Wells suggested, that denial of such a condition, lack of finances, and cultural beliefs, incomprehensible medical instructions about contraindications, diminished

functional ability, time restrictions due to the treatment regime and fatigue could lead to occupational deprivation, for the individual and their carers.

Therefore, the number of writers and the number of publications that suggest that disability is a cause of occupational deprivation outweighs Whiteford's lone but authoritative voice. Additionally, Hocking's (2012) book chapter suggested that occupational science currently presents a uni-dimensional view of occupations, which has become generalised into universal views of occupational-engagement. Hocking suggests that OT's ontological standpoint is biased towards feminist and western views. Similarly, Hammell et al (2012) suggested that although the dominant theories of occupational therapy have been devised by privileged, able-bodied, urban dwelling residents of the minority world; 80% of people with disabilities live in the majority world, and 90% of these people live in rural areas, many in poverty. This links to Sherry's (2010 p 40) book chapter which observed that “in situations of poverty, environmental factors could be more disabling than impairments themselves, and entire communities could be subject to occupational deprivation”.

2.3.7 Problems with occupational science

Occupational scientists, and the subjects of occupational science research tend to be adult females without disabilities (Pierce *et al.,* 2010; Hocking, 2012). Consequently, Molke *et al'* (2004) called for studies of occupations from a male perspective, and Pierce *et al.* (2010) for research into the male perspective of minority ethnic and sexual orientation groups and from a working class perspective. In this respect, occupational science is bucking the trend, away from discrimination against women and women's values. In fact Jakobsen's (2009) interview data suggested that gender based differences were ignored altogether, to the point where Hocking (2012) suggests that children's and adolescent perspectives, and those of individuals experiencing poverty, food and personal safety insecurity are infrequent. Occupational therapy, despite its holistic vision, is constrained by western culture (according to Beagan's 2007 student data; Sakellariou and Pollard's (2008) book chapter). This generates differences in perceptions about the observable attributions of behaviours, wellbeing and the experiences of those undergoing occupational therapy (according to Park's (2008) ethnographic study).

Although Hout & Laliberte Rudman's (2010) literature review presented the refugee and immigrant perspective of occupations; exploration of antisocial and degrading occupations is infrequent, (an example being Ashforth & Kreiner's (1999) literature review about reframing of "dirty work" into a positive identity). Consequently, occupational science could be portraying an overly positivist view of occupational-engagement, avoiding oppressed, excluded, enslaved, trafficked or inescapable situations (which could fall outside the experience of white middle class occupational scientists as well as the control of the individuals or communities experiencing them). Football violence or communal drug use is challenging to understand, but for those involved they are intensely meaningful (according to King's (2001) sociological literature review and Klein's (2007) book chapter about Diaspora in Somalia). Equally self-destructive behaviours, are meaningful in the moment of their being carried out (according to Pollard & Sakellariou's (2008) discussion of questionnaire-based survey data).

Furthermore, in the case of NPC, parallels exist with the external conditions causing occupational deprivation. These include geographic isolation (Adams, 2006; Pereira, 2008; Fisher, 2008); idleness (Thibeault, 2002; Jakobsen, 2004); incarceration (Sauter-Davis, 2011; Cockburn, 2005; Provident & Joyce-Gaguzis, 2005; Butz 2010); and lack of transportation, poverty and homelessness (Scaffa & Brownson, 2005; Heuchemer, 2006; Salmond *et al.,* 2006; Duncan, 2009; Wegner, 2011).

Other causes of occupational deprivation include displacement due to being a refugee or an immigrant (Jegatheesan, 2007; Yalmambirra 2006); gender stereotypes (Min, 2008; Bergan-Gander, 2006); and perceptions of ageing (Donica, 2008; Jonsson, 2010; Ferguson & Hammersley, 2004). Individuals with NPC could experience similar restraints to their occupational-engagement, such as:

- Being removed from normal routines and roles to live with atrophied occupational capacities in residential care
- Being imprisoned by immobility, or disability
- Being isolated from others by cognitive, perceptual or communication problems which influence reciprocal understanding
- Being unemployed or unoccupied because of a lack of opportunities
- Becoming stereotyped by others' beliefs about what they are capable of, or what is suitable for them to do

Additionally, the researcher suggests that occupational deprivation (like sensory-overload) could compound profound disability by adding extra opportunity costs, because being unable has been found to lead to:

- Longer periods asleep
- Altered life satisfaction
- Lack of social status
- Diminished sense of self-efficacy
- Atrophied occupational capacities
- Loss of self-identity
- Prolonged social isolation and social exclusion
- Altered occupational patterns and time use
- Imposed dependence
- Limitations to hand or tool use

(Wilcock, 2006; Whiteford, 2009)

2.4 Summary

NPC, are therefore proposed to produce, either in their own right or as a side effect, similar restrictions to those described as the effects of occupational deprivation. These effects on individuals with NPC, in combination with the disabling nature of the disorders themselves, could be so severe that they are outside the individual's control. This imbalance in occupational participation may lead to fewer opportunities to participate in valued occupational roles (Miller Polgar & Landry, 2004). Arguably, this could be of little consequence to individuals who, if offered occupational roles, could not take them up.

The effects of not engaging in occupations include spending longer periods asleep, having lower life satisfaction, and experiencing a lack of social status. Atrophied occupational capacities lead to a diminished sense of self-efficacy, dented self-

identity and an altered pattern of activity and time use. Other effects of occupational deprivation include social isolation, imposed dependence, lack of control, and limited hand or tool use. The latter two effects result from not having tools or occupational materials to use, or to be a cause of occupational deprivation or the absence of opportunities for occupational-engagement (Townsend & Wilcock, 2004). These effects occur because the individual cannot experience the effects of participating in meaningful occupations, such as having a sense of purpose, a goal orientation, feelings of accomplishment or achievement, and being in an occupational environment that is conducive and therefore being fully human.

This in turn could influence the individual's self-identity, their opportunities for self-expression/creativity and their sense of their personal growth, their cultural and historical background, and of wellbeing. It could also affect their sense of the rhythm of life, their health, their capability and their feeling of belonging to the community. Occupational-engagement could prevent boredom through enablement, learning and discovery, and it could offer opportunities for a sense of control and self-determination. Social interaction and interaction with the activity could also have come about through occupational-engagement. Man's inhumanity to man (Sherbo, 2001) means that social, economic, environmental, geographic, historic, cultural, or political forces could have restricted opportunities for an individual to be fully human, and could thereby have influenced their sense of health and wellbeing. This soul-destroying and dehumanising experience could be the lot of prisoners, refugees, individuals who are geographically isolated, the unemployed and those who could be subject to gender based rules of behaviour, but it also appears to apply to individuals with NPC. Therefore, the challenge becomes one of limiting the effects of occupational deprivation through enabling occupational-engagement.

Additionally, sensory gating deficits have been researched in Huntington's Disease (UC *et al.,* 2003), and Head Injury (Kumar *et al.,* 2005; Arciniegas *et al.,* 1999). Damage to the RAS (a common site of brain damage), and resultant sensory gating deficits leave the individual unable to filter out irrelevant and excessive information, and consequently at risk of sensory-overload. Their inability to cope with sensory stimulation and the resultant sensory-overload could present to the observer as fatigue or shutting down. Therefore, it could be reasonable to anticipate a normal distribution of capacity to cope with incremental levels of sensory attributes.

Sensory-deprivation (resulting from under-stimulation) and sensory-overload (from over-stimulation) both influence an individual's ability to participate in occupations leading to occupational imbalance. This has resulted in the development of several similar concepts, such as the sensory diet and sensory regulation, which aim to increase physical and cognitive functioning by establishing an optimal level of stimulation. These concepts suggest the need for careful environmental management, to enhance the individual's ability to participate in occupations and reduce their likelihood of experiencing sensory-overload. These concepts aim to limit, regulate, or coordinate sensory stimulation to make the occupations appropriate for the individual.

Arguably, the domain of NPC is starting to acknowledge the fact that such individuals could have an altered capacity to cope with sensory stimulation. Whilst acknowledging the modalities used by Occupational Therapists since the 1940s, it could now be time to reflect on renewed medical research interest. The emerging nature of the knowledge about sensory gating and sensory processing to date has resulted in "new" interventions, potentially being applied indiscriminately. For

example, a group of individuals with a range of conditions being placed unsupervised in a MSE offering a biased selection of sensory stimuli depending on the range of equipment available, without first undergoing a sensory profile assessment.

Sensory-deprivation results from a reduction in the variety, meaning or intensity of sensory stimulation. The sensory-deprivation of being in a restricted or under-stimulating atmosphere, such as a home, could influence cognitive functioning. This could also be true of individuals who do not experience proprioceptive or vestibular stimulation due to their severe limitations. It could be possible to address this reduction in variety, meaning or intensity of sensory stimulation through balancing and adjusting the sensory attributes of casual leisure occupations.

Individuals with schizophrenia are described as experiencing sensory gating deficits, whilst at the same time over-inhibiting (restraining, blocking or suppressing) the reception of sensory stimulation (Brown *et al.,* 2002). Brown *et al.* (2002) also suggested that sensory processing deficits and over-inhibition can coexist, and demonstrated that sensory processing, sensory hypersensitivity, sensation avoiding, and low registration could be common in schizophrenia (Brown *et al.,* 2002). Interestingly in the context of this study, Brown *et al.* (2002) reiterated Steffy and Waldman's (1993) suggestion that individuals with sensory gating deficits could fail to respond or attribute meaning to stimuli, or perform even worse when they are offered techniques to optimise levels of stimulation.

The literature includes techniques to manage inappropriate levels of sensory attributes. However, research does not appear to propose any form of intervention to reverse or cure sensory gating deficits. Furthermore, sensory-overload is a little-acknowledged concept beyond the literature of the Allied Health Professions and Developmental Disability. Therefore, this thesis seeks to determine whether sensory-overload also affects individuals with NPC. This study will also examine whether there could be an approximate level of stimulation that maximises occupational-engagement while minimising the potential for sensory-overload. This sensory threshold can only be approximate, since each individual has a unique sensory profile of preferences and experience.

Residential care settings may present casual leisure as a group experience rather than an individualised occupation, with the staff having no insight into each individual’s sensory preferences and sensory gating abilities. This study seeks to establish whether it is possible to mark the thresholds, to create a sensory environment that participants can handle competently and enjoyably. In no way, does the study set out to establish whether one leisure occupation is more suitable for a diagnostic group than another could, because each individual has unique preferences, interests and experience.

The physical and social context around an occupation may influence engagement (Jonsson, Josephsson & Kielhofner, 2001), as could an individuals sensory preferences. The context could include the ease of access to an occupation, the level of support received and a desire to prevent boredom. The timing or sense of time passing, the participant’s sense of altruism (i.e. engaging for someone else’s benefit), and the individual's interest (Yerxa, 2002) could be a factor. Additionally, the meaning, novelty, participant's occupational capacity, and the complexity of the occupation and the sense of experiencing occupational balance could be important. Other factors could include the occupational role offered to the participants. Jonsson *et al.* (2000) showed that internal motivations and external demands including attention, absorption, depletion or enrichment of their physical and psychological resources could influence occupational-engagement.

Moving on from occupational-engagement to its opposite, occupational deprivation is one of the significant constructs of occupational science relevant to profound disability. Occupational deprivation produces costs in human beings, such as longer periods asleep, elevated rates of depression which could lead to actual or attempted suicide, reduced community reintegration, altered occupation patterns/time use, atrophied occupational capacities, lower self-efficacy and loss of self-identity, all of which (the researcher suspects) could be experienced by individuals with NPC. Occupational science proposes that occupational-engagement could counter the effects of occupational deprivation; and potentially enables the individual to act, according to our species (Yerxa *et al.,* 1989). What the literature does not appear to address at present, however, is whether the passive participation of such a profoundly disabled group of individuals influences them in the same way as active participation would, acting to counter the costs of occupational deprivation. Consequently, the field data collected during this study should document the role undertaken by the study participant during their occupational participation.

This chapter has explained the dilemma posed by NPC, and describes the less well-acknowledged phenomenon of occupational deprivation. For individuals with such profound limitations, leisure provides a major opportunity – potentially the sole outlet – for occupational-engagement. The study will therefore explore casual leisure as a way of combating occupational deprivation for individuals with NPC.

Observations of engagement could indicate whether an occupation has been suitably adapted in order for an individual to participate as much as they would wish to, rather than experiencing sensory-overload or under-stimulation. Engagement is therefore a variable to study because it is observable, and has strong links to the meaningful nature of occupations. This chapter has guided the study towards observing engagement in sensory-based casual leisure occupations. The study will therefore seek to determine whether there are any trends in the relationship between engagement and the combined number of sensory attributes during a leisure occupation. Knowledge of the unengaged behaviour and signs of sensory-overload in this group will inform this observation and collection of engagement data, and so will be required prior to the main study.

2.5 Research questions

Research questions should be smart (Meyer, 2003) (see text box 1), with a theme and a form i.e. is this a "who", "what", "where", "why" or "how" question? (Yin, 2009). The research question addressed in the chapter FIVE was 'How does engagement in casual leisure occupations (by individuals with NPC) alter with different levels of sensory attributes?' Yin (2009) suggested that 'what' questions tend to either be exploratory (in this case, many methods could be used) or about prevalence (including surveys or documentary analysis), "how" and "why" questions tend to favour the use of case studies, experiences or histories (Yin, 2009). The study proposition is that, there could come a point where increasing sensory attributes becomes more than the individual can cope with leading to a state of sensory-overload, with all its behavioural and emotional repercussions.

Text box 1 The SMART attributes of the research question

Specific matter - casual leisure occupations in relation to sensory processing

Measurable - with a standardised measure of engagement

Achievable - leisure could be the only opportunity for occupational engagement available to individuals living with neuropalliative conditions

Realistic - leisure could be relevant to study in this clinical group because other forms of occupational engagement are either not available or are conducted on their behalf

Timely - this is a contemporary rather than a retrospective study

This study proposes to explore the following research questions:

1. What are the normal and sensory-overloaded behaviours exhibited by individuals with NPC?

2. How does engagement in casual leisure occupations (by individuals with NPC) alter with different levels of sensory attributes?

Chapter THREE

Research Design Considerations

Chapter three explores the research design options used by other researcher's to gather opinions about whether the observed “shutdown” reaction results from sensory-overload and thus to indicate whether a participant involved in the main study is experiencing engagement or overload. This chapter also presents research design considerations which were considered such as the researcher's epistemological stance and the practical and ethical principles involved in studying leisure with individuals with NPC. These included gaining consent from individuals with reduced mental capacity, privacy and confidentiality, risk in relation to the benefits of research, the length of the study, the efficacy of physiological tests in this clinical group, measuring “flow” in individuals with less severe disabilities, measuring engagement and the confounding factors encountered.

An underlying issue was that the healthcare community, the recreation and leisure community favoured have their own language, goals, methodological emphases and bodies of knowledge. There is no universal research methodology. Furthermore, leisure and recreational occupations could have a therapeutic effect, and occupational therapy, diversional therapy or recreational therapy could increase an individual's ability to participate in leisure occupations (Wolfensberger, 1972; Oddy *et al.,* 1985). Therefore, occupational therapy overlaps both communities, which has influenced the methodology selection. In some fields of enquiry scientific laboratory experiments are the norm, while in others, social surveys are more common (Edexcel, 2011). The methodological options, combined with ethical considerations associated with studying individuals with NPC and with studying leisure occupations, have all informed the study design.

The complexity of NPC makes research difficult (Andrews, 1991), influencing the study design. The interprofessional nature of health care delivery and the nature of interventions make it difficult to identify the influences on outcomes in the real world, especially where the intervention is a person (e.g. a supporter). These difficulties resulted in Fleminger’s (2000) systematic review of rehabilitation for head injury, which reported a dearth of randomised controlled trials with most research using case or multiple, case methodologies. Wade (1998) reported similar findings, identifying a number of reviews and meta-analyses (mostly with a control condition) but with small samples.

Having opted for a sensory focus to the study, tensions appear when considering other factors that could influence engagement (e.g. role, personal preference, supporters who do not prioritise or value leisure and engagement), or in the context of issues such as what constitutes leisure for one individual could not be so for another (Taylor, 2008). Indeed, the anticipated normal distribution of data showing engagement reducing at higher combined sensory levels may not occur, because at the point when engagement should have declined, other factors took over the role of encouraging engagement.

3.1 Epistemological stance

The study propositions involved in this thesis include theoretical approaches to engagement, sensory processing, leisure and meaningful human occupations. The thesis uses a multiple, case methodology (Yin, 2009) developed to compare

engagement, across several cases to explore whether sensory stimulation influences engagement (Stewart, 2012). It takes the epistemological stance that man is an occupational being (Wilcock, 2006), that occupational-engagement is a human right and that occupational deprivation is harmful (World Federation of Occupational Therapists, 2004, 2006). Furthermore, occupational-engagement is influenced by the individual's preferences (including their sensory preferences), the occupation itself, and the occupational context as demonstrated by the CMOP-E (Polatajko *et al.,* 2007) and other models which have included the occupational environment, not just the person and occupation.

Carlson and Clarke (1991) suggested that authenticity and reliability were essential for the evaluation of research in occupational science, but also put great stress on non-scientific ways of knowing, allowing Occupational Therapists to alter their approach given their clinical reasoning, judgment, epistemic values, interprofessional practice, which theories they employ (Kinsella and Whiteford, 2009). Additionally, Hooper and Wood (2002) suggested that occupational therapy has two contrasting epistemologies, namely structuralism and pragmatism. Creek (2010) suggested that engagement sits within the pragmatic approach to practice, which Mitchell (2013) suggested involved contextual variables, complex problem solving, professional judgment and critical reflective clinical reasoning. Likewise, Carr's (1986) critical approach recognises that practice is idiosyncratic and contextual, developed through the multidirectional integration of theoretical knowledge and practice experience.

The occupational therapy epistemic community includes clients, managers, academics, practitioners, and those undertaking combinations of these roles. Having undertaken all of these roles it is important premise of this thesis is that, the epistemic knowledge of occupational therapy can be both domain specific and generalised (Mitchell 2013a), being based upon experience, reasoning, research, and expert opinion (Mitchell 2013), therefore transferring knowledge between basic and applied science, clinical practice guidelines, clinical knowledge, case studies, clinical reasoning, client preferences, and policy etc. (Youngblut and Brooten 2001). This view of knowledge as malleable is demonstrated in this thesis by using a children's assessment of a non-age specific phenomenon (engagement) with adults, and also knowledge of sensory processing first developed in the field of paediatric learning disabilities, with individuals with NPC.

The reductionism of the biomedical model is problematic, since OT's regard each stakeholder as unique, because of the infinite variety of human, contextual and occupational facets which make up our occupational-engagement, reinforcing an individual's unique identity and humanity (Yerxa *et al.* (1989). It is therefore important to the researcher to include a mixture of clinical experience and evidence in practice. The researcher believes that only the individual can determine the meaning of an occupation to them (Taylor, 2008; Yerxa *et al.,* 1989). The result of this is that the researcher believes that no one else can or has the right to decide what is meaningful for another individual. Therefore, data collection involved a large number of individuals who were able to choose which occupations they engaged in, to seek to find a core group who attended each occupation observed, to analyse their data.

Furthermore, Schön (1983) suggested that, scientific and technical approaches were frequently ineffective in negotiating the qualitative parts of professional practice, since few cases are clear-cut. This has influenced the researcher's epistemic values in order for me to understand that a negative result of occupational deprivation could be interpreted using

the biomedical model as its cause. She therefore, cannot see life as clear cut with linear relationships, since (linking back to my historical background) human history is often cyclical which is why trends reoccur.

She also has a special interest in continuing professional development and therefore the interaction between theory and practice. Given Carr's common sense approach to knowledge development and use, it feels sometimes, as though Occupational Therapists have sought to become more evidence based because it is expected, to allow them to appear more scientific (Kinsella and Whiteford, 2009) or because of the associated kudos and funding (Davies, 2003). However, no matter how scientific the knowledge or expertise, rehabilitation remains an interpretive practice (Montgomery, 2006). Interpretive practice was used to develop Table 7 to present a comparison of the signs of sensory-overload with engagement categories defined in the ICER.

The opposite of evidence based practice includes for example, professional artistry (Paterson, Higgs and Wilcox, 2005), professional judgement (Kinsella, 2004; Montgomery, 2006), reflective and discerning practices (Higgs and Titchen, 2001), and compassionate practices (Wright St Clair, 2001). Whilst supporting the thoughtful use of evidence to enhance practice, Kinsella and Whiteford (2009) challenged inflated views of its practical importance (Kinsella, 2007). Instead, they suggested that evidence informed practice knowledge, as well as other pluralistic ways of knowing (Whiteford, 2005) and professional judgment in context (Kinsella, 2004; Macklin, Whiteford and McAllister, 2006). One such way of knowing results from the researcher's sensory hypersensitivity, as part of the 15% of the total population who experience more intense sensory processing patterns, experiencing heightened anxiety, fear, low self-esteem, rigid behaviours, and avoiding sensations which other individuals take for granted (Engel-Yeger and Dunn, 2011). This resulted in insight into the influence of the sensory context on occupational-engagement. Additionally, She is a Presbyterian Scot (who believes as it says in the acknowledgements that "every decision comes from the Lord" (Proverbs 16:33) and therefore there is no such thing as chance and so does not believe in randomisation (Proverbs 16:33) preferring not to undertake an RCT.

There is no predominant research methodology in occupational science, although Yerxa *et al.* (1989) listed a variety of research approaches suited to the study of occupation, without offering a rationale for their selection. Their list includes commonly employed qualitative research methodologies such as ethnography, life history, naturalistic inquiry and case methodologies.

Furthermore, given the importance given to reflective clinical reasoning, Stewart's (2012) suggestion that case study research is particularly applicable to real world practice, is valuable. She suggests that case study research is practice-relevant, rather than practice-oriented, leading to the generation of theory and constituting a valuable part of an Occupational Therapist's repertoire.

3.2 Methodological options available to identify sensory-overload or any resultant behaviour

Several standardised assessments of sensory processing in children exist to measure occupational-performance through observation. However, the Sensory Integration and Praxis Tests (SIPT) (Ayres, 1989) assesses children aged 9 years or under (Ayres, 2004), is not suitable for individuals with difficulty following directions/ demonstration. The DeGangi-Berk Test of Sensory Integration (Berk & DeGangi, 1983) is used with younger children but is less sensitive to some sensory attributes than others. The Test of Sensory Functions in Infants under 18 months (DeGangi & Greenspan 1989) highlights deficits in sensory processing, functioning and reactivity. Neither the SIPT, the DeGangi-Berk Test, nor the Test of Sensory Functions in Infants describe or identify sensory-overload or any resultant behaviour, so none of these would help to address the first research question, additionally they require sustained attention and the ability to interpret verbal instructions, and so would be of limited use with individuals with limited attention and communication.

An adult test to consider is the Observations Based on Sensory Integration Theory (Blanche 2010) workbook. This norm referenced assessment of occupational performance, highlights signs of nervous system integrity associated with sensory integrative functioning and therefore by extension could highlight signs of sensory processing limitation. The publication of this assessment (after the data collection for this thesis), parallels the studies carried out in chapters FOUR and FIVE by establishing individual's sensory preferences and observing the individual whilst participating in an occupation, and so could be a usable alternative for future replications of this study.

3.2.1 Interviews

Given the unreliable communication of individuals with NPC, interviews would not be an appropriate method to collect data from residents themselves. However it could be used with staff because they allow for clarification, and confirmation that unfamiliar concepts are understood. The Functional Assessment of Sensory Integration (FSI) (Cook, 1991) documents third party criterion referenced data about sensorimotor performance, so could be used for individuals for whom formal testing is problematic. Sensory processing deficits make attending, making sense of, or surviving standardised testing difficult; therefore non-standardised measures such as interviews and checklists could be used to assess sensory processing (Cook, 1991), collecting data from third parties.

Interview assessments validated for children aged 12 or under include The Touch Inventory for Preschoolers (TIP) (e.g. Royeen's (1987) experimental study) and the Touch Inventory for Elementary School Aged Children (TIE) (Royeen & Fortune, 1990). However, these assessments do not include the range of sensory attributes required for this thesis (Dunn, 1994). The Sensory Processing Measure - School (SPM - School), assesses the occupational and sensory systems performance of children using data collected from adults in several environments (Miller-Kuhaneck *et al.,* 2007). The Sensory Profile School Companion (Dunn, 2006) highlights sensory patterns and overall sensory difficulties, based on the MoSP. The SPM - School and the Sensory Profile School Companion assess sensory preference, awareness and tolerance, using a 5-point Likert scale. These third party questionnaires raise concerns about the authenticity and accuracy of third party data. Whilst they could be

used to assess occupational-performance and therefore might identify the normal and sensory-overloaded behaviours exhibited, they are all validated for use with children.

Given that the participants of this study were all adults, it might be useful to consider other assessments of sensory processing. The Sensory Integration Inventory-Revised (Reisman & Hanschu, 1992) is used with adults with cognitive disabilities, to screen and rule out behaviours that are not due to sensory dysfunction. The SII-R collects third party data, prior to data analysis to search for dysfunction in sensory integration and to screen out non SI dysfunction related behaviours.

Because the aim of gathering opinions about sensory-overloaded behaviour is to inform a later study, and none of these highlight the behaviours exhibited as a result of sensory-overload. A unique structured interview format for this study could ensure consideration of each type of behaviour highlighted in the literature, for each third party discussed. Interview data collection is time-consuming, but could ensure a high return rate (Robson, 2002).

3.2.2 Questionnaires

Self-report questionnaires should be unaffected by altering the order in which the questions are presented (Robson, 2002). The questions and the introductory explanation should be understandable, asking the right questions to elicit the data required. To canvass supporting evidence from other sources before answering the questions, a questionnaire could be supplied in advance of the interview, e.g. to gain a team's opinion of an individual's usual response to a stimulus (Robson, 2002). However, questionnaires can be subject to response bias if participants who have difficulties understanding written text chose not to respond (Robson, 2002). A first-person self-report questionnaire was unsuitable for this study because many of the concepts were unfamiliar to the respondents, and because of the complex symptomatology of NPC.

Another way of gathering data about sensory preferences is by taking a sensory history using a standardised history-taking questionnaire. This has the benefit of identifying sensory processing difficulties, which are context specific (Kientz & Dunn, 1997). An alternative type of sensory history could involve Dunn's (1999) Sensory Profile and the subsequent Brown & Dunn (2002) adolescent/ adult sensory profile. These can identify non context specific sensory-related behaviours. Like the interviews with the Residence Manager presented in chapter Four, the sensory profile assesses a combination of sensory processing, observable and attributable; behavioural and emotional responses. For individuals who are unable to express their own opinions reliably or who have limited communication the sensory profile includes caregiver questionnaires, which highlights which sensory experiences produce positive or negative responses across contexts.

Given the communication and cognitive impairments experienced by individuals with NPC, taking a sensory history directly from the participants may not be fair or authentic. Also asking them to participate in an observed assessment which could take several hours to complete may be too challenging, therefore a lesson was learned (for the data collection for this thesis) from the adolescent/ adult sensory profile (Brown & Dunn, 2002) which includes a caregivers questionnaire. However, the sensory profile does not create a picture of the behaviours that result from sensory-overload and so cannot be used unmodified.

The Sensory Profile yields useful information about which sensory systems the individual finds challenging as well as overall information about the individual's ability to cope with the sensory environment. Brown *et al.* (2001) suggest that, these sensory traits do not vary significantly over time. Consequently, this tool may not measure behavioural outcomes following specific sensory stimulation, which is the goal of this study. Arguably, observing an individual's response to sensory stimuli to complete the sensory profile is a judgement-based process, which could therefore be open to bias such as lack of insight, scepticism, or overly positive reporting. Based on the experience of other researcher's, data collection about whether an individual demonstrates or is experiencing engagement or overload could involve interviews, questionnaires or documentary reviews, depending on their appropriateness for the participant group from whom the data will be collected (in this case, healthcare staff and individuals with NPC).

3.2.3 Documentary review

Robson (2002) described documentary review as non-intrusive, but laborious. This technique allows cross comparison of data from many sources. Documents remain available for re-analysis after their initial use, but they could also be incomplete or access to them could be limited. The investigator's lack of contact with the study participants, reduces their influence on the data gathered. Archival data could triangulate other data. However, if data collection occurred for other purposes, it may not address the research question, and the link between cause and effect may not be explicit, or its use could be unethical. Documents could include care records, minutes of meetings, letters, memoranda, or articles. However, the researcher had access to discipline-specific notes and care plans, which could be analysed using relational analysis, narrative analysis or:

- Content analysis could establish whether concepts appear within a document (Robson, 2002).
- Systematic review could synthesis of relevant results, enabling an overview of the findings of a range of studies (Robson, 2002).
- Secondary analysis could extend a previous analysis of existing data (Robson, 2002).
- Meta-analysis could combine the data into larger samples for statistical analysis (Robson, 2002).
- Conceptual analysis could quantify the presence of a concept (Robson, 2002).

Documentary review was not appropriate methodology for this study because sensory-overload was not a familiar concept to staff, and so it was unlikely to occur in care plans, because the home did not complete sensory profiles with its residents. Additionally, documents produced by the residents themselves are very rare, and their contents, when available, were unlikely to include such a qualitative subject.

3.3 Methodological options to sample experience

There are many assessments of occupational-performance (Law *et al.,* 2006; McDowell and Newell 1996). Mostly they evaluate occupational-performance in ADL (Hayase *et al.,* 2004). They do not often concentrate on leisure, due to the focus on the cost-effectiveness of rehabilitation (Fricke, 1993).

Measuring experience or satisfaction could include the extent to which the participant is engaged or expressing satisfaction, enjoyment and relaxation. Therefore, to sample experience it would be useful to establish a definition for engaged and non-engaged behaviour, to compare alterations against. An experience sampling format could be used to collect signal-contingent, interval-contingent, or event-contingent data. Methodologies could include testing hypotheses through Randomised Controlled Trials (RCT) and true experiments, (which would be hard to justify given that the central tenet of leisure is that it is freely chosen, rather than imposed as part of an experimental design). Other methodologies could include documentary review, or self-reporting of experience using standardised data collection tools applicable to engagement (e.g. the ICER (Kishida & Kemp 2006)), leisure (e.g. the Leisure Satisfaction Scale (Di Bona 2000)), MSEs (e.g. Interact) or life satisfaction (e.g. the European Quality of life Scale (McWilliam & de Kruif, 1998). However, the cognitive and communication problems experienced by the residents reduced the sample to those who are able to express their opinions verbally (but who were less at risk of sensory-overload), rendering the sample group sub-optimal and too small to be feasible. Because answering questionnaires is inappropriate for the majority of residents living with NPC, the collection of third-party data could represent their views (UK Parliament, 2005). In fact, several articles about optimal engagement have been published using third-party data. For example, satisfaction studies published by Delle Fave and Massimini (1988, 1991) which presented engagement as reported by study participants' mothers. However, the researcher had concerns about the authenticity of data, given that only the individual can define their engagement level (Yerxa *et al.,* 1989; Nilsson, 2006; Taylor, 2008).

3.3.1 Experimental testing of hypotheses

Randomised controlled trials, true experiments, or quasi-experiments, can test hypotheses. An exploration of the differences between these experimental designs follows.

3.3.1.1 Randomised Controlled Trials (RCTs)

RCTs aim to avoid selection bias by allocating participants to intervention groups randomly and comparing an intervention with a control condition (Robson, 2002). They produce data about the effectiveness of interventions (Cartwright, 2007), but risk ignoring the reasons why any findings appear, and so they do not contribute to the understanding of a phenomenon (Pawson & Tilley, 1997). Furthermore, the eligibility criteria for participants may be biased, thereby limiting the generalisability of the results (Wong, 2007). Allocating to a control or an intervention group means that for the social sciences which have a qualitative tradition of research, RCTs could result in participants being allocated to a potentially harmful (e.g. occupational deprivation) or uncertain condition (Robson, 2002), raising ethical concerns.

On the other hand, the results of an RCT are generally dependable and replicable (Wong, 2007). However, as Hippocrates (Jones, 1923) said, attention should be paid "to experience combined with reason". This is especially true in occupational science, because occupational beings have evolved illogically, so that experimental approaches to measuring occupations could be less appropriate than qualitative methods because the participants rarely produce the clear-cut definitive findings that RCTs detect (Robson, 2002). Furthermore, Robson (2002) suggests that randomisation could discourage or constrain performance in an experimental group, or enhance it in a control condition, thus artificially increasing the significance of any effects observed.

The lack of acceptability of RCTs in the evaluation of social phenomena like leisure could appear at odds with the adoption of RCTs as the "Gold Standard" within biomedical professions (in response to the Cochrane Reviews, which place the highest value on large RCTs in their hierarchy of evidence (Cochrane, 1979; Cochrane Controlled Trials Register, 1999). Robson (2002) suggested that extensive social programmes or interventions could appear ineffective, while losing touch with the individual effects of the intervention in the pressure to produce significant quantifiable results. Additionally, with a social phenomenon such as leisure, it could be difficult to adhere to the randomisation process.

Participating in an RCT could take the occupation away from being leisure, because it would not be self-determined, which would invalidate the study. Studying large sample groups should reduce the effects of random variation, using statistical techniques and presenting results based on average scores and normative responses to calculate the randomness out of the study (Drummond, 1996). Furthermore, the study population is representative of individuals with NPC across Europe, but is still a small group.

3.3.1.2 True Experiments

True experimental methodologies can highlight the differences between participants by using a matched methodology. This depends on having a measurable variable, which correlates strongly with the dependent variable and which is unlikely to influence the intervention effects. A two-group methodology could be used when an independent variable remained unchangeable and where the participants are unlikely to receive more than one intervention (unlike this thesis which will be conducted in a real world context), or where they could be affected by pre-testing or being tested with a matched variable. This may not be appropriate when studying casual leisure, because such occupations are different every time.

A factorial methodology could help where there are several independent but potentially interacting variables, such as this thesis. The selection of a parametric methodology could be appropriate when the independent variables will produce a range of values or the focus is on the relationship between independent and dependent variables. Care should be taken, when studying casual leisure, which is enjoyed in the moment, rather than having a lasting or therapeutic effect (Leng *et al.,* 2003), and where randomisation could change the character of the occupation.

Therefore, a repeated measures methodology might be appropriate if the independent variables are likely to change over time, or were several interventions occur simultaneously in a real world setting rather. The selection of a repeated measures methodology could also increase the amount of data collected, thereby increasing the reliability of the results, capturing changes over time.

3.3.1.3 Quasi Experiments

Quasi-experimentation (Campbell & Stanley, 1963) is useful if the researcher cannot conduct true experiments for ethical or practical reasons, but need's to counter threats to the validity of the study, as in this instance. Quasi-experiments use approaches such as Pre-Test and/or Post-Test, Time Series, Regression-Discontinuity, and Case methodologies (Robson,

2002), but without random allocation to intervention groups. A quasi-experimental methodology might prevent a catastrophic failure if randomisation was not possible (Cook and Campbell 1979), despite Judd *et al.'s* (1991) assertion that a lack of randomisation detracts from the quality of any study.

Case-based studies; do not seek to 'control' the variables to produce universally applicable generalisations (Yin, 2009). Clearly, there are many variables in any occupational context; therefore, any attempt to control for them would be futile. The cases used were a convenience sample of casual leisure occupations, which would have occurred regardless of the study. Therefore, an activity analysis describes the variables within each case (Simons, 2006). However, it was not until all the data collection was complete that the core group of residents who became the participants became apparent.

Arguably, cases should be selected on the basis of being either an atypical case, or a typical case (Yin, 2009), because it is the rarity or commonplace nature of the case which generates understanding. The rationale for studying these cases was that they were typical of the casual leisure opportunities available at the home, however the participants are a rare group of profoundly neurologically disabled individuals, thus offering a combination of distinctiveness and relevance to the real world (Fishman, 1999).

Arguably, observing typical leisure opportunities goes against Simons' (2006) warning about accommodating positivistic principles such as representativeness and generalisability in favour of using the uniqueness of individual cases as a way of understanding the complexity of experience. Conversely, Myers (2000) argued that a strength of case-based studies was that they occur within a real world context. According to Fishman (1999), these can be divided into three categories. These include studies conceptualising the case (within the positivist paradigm), epitomized by Yinn 2009, those conceptualising the case (within the hermeneutic paradigm), exemplified by Lincoln and Guba (1985), and those focussing on the pragmatic uses of the case, demonstrated by Bromley (1986).

The case-based methodology could use direct observation of the cases or interviews in a real world context, including groups of people (Yin, 2009). Quasi experimental research gives the researcher cannot manipulate behaviour the opportunity to use an experimental design (Yin, 2009). Here, an experimental but case-based methodology might allow the participant to respond to the case rather than consciously changing their engagement behaviour (Yin, 2009). Both Cook and Campbell (1979) and Judd *et al.* (1991) suggested that a quasi-experimental methodology, without randomisation, could be appropriate for studying leisure.

Bassey (1999), suggested that case-based research could seek out (a new) or test (an existing) theory e.g. engagement in the face of differing sensory attributes while providing descriptive data to facilitate knowledge. In Bassey's terms, this thesis is an example of both theory seeking (since sensory preferences may not be a universal consideration), and theory testing (since sensory-overload and its influence on engagement is being 'borrowed' from the domain of developmental disabilities). Arguably, it could also be described as a descriptive study, providing insight into a phenomenon about which little was previously known. Stake (2006) suggested that case studies may focus on understanding an inherently interesting issue. This study is both instrumental and intrinsic, and was based on a pragmatic desire to use the insights gained to enable occupational-engagement in a group of individuals who were at risk of occupational deprivation. Authors such as Bassey (1999) and Simons (2006) also identified evaluative case studies which focus on judging the worth of interventions.

While this research aimed to provide insight's that could inform decision making regarding leisure provision, it was not focused on evaluating; rather on exploring how engagement in casual leisure occupations alters with different levels of sensory attributes?.

In this thesis, the standardised measure used was the ICER, which captured the engagement category of the participants. As a result, non-parametric tests are used initially (see appendix vi). More importantly, pattern matching compared the results with the anticipated patterns of engagement predicted by the professional knowledge of occupational therapy (about the effect on occupational-engagement of sensory stimulation). Pattern-matching involves no precise comparisons of the significance of the differences between data but focuses on the pattern overall (Yin, 2009), therefore the statistical analysis is presented in appendix vi, rather than the main thesis. As a result, chapter seven discusses the differences between the anticipated and actual pattern and attempts explanations for the differences (Yin, 2009). However, no attempt was made to generate a hypothesis, because the results were so different from knowledge used in practice. The analysis of time series data has included a brief tracing of changes over time in Figure 6, with a view to analysis using through time and non-linear regression statistical techniques. Such analysis might have been used to refute predictions from an explanatory theory, about the effects of sensory-overload on engagement, but the data did not prove appropriate for this technique to be used.

The subject of a case study should be explicit (in this case occupational-engagement) (Yin, 2009). It is important to define the 'case' with care, as a 'case' could be one or more individual('s), a decision, project, partnership, process, or an organisational, social, or political phenomenon; with several 'cases' being included in a multiple, case-methodology (Yin, 2009). Cases studied by other researcher's have included the economy of a country, an industry, or a policy (Drucker 1986). Therefore, in case studies it is valuable to describe the real-life context (Chapter One), the participants (5.2.1), the cases (5.2.4.2.1. to 5.2.4.2.8) to enlighten those situations in which the intervention has no clear, single set of outcomes (Yin, 2009). In this thesis each case is a single casual leisure occupation. The logic linking the data to the propositions is that there could come a point beyond which increasing sensory attributes becomes overloading leading to a decline in engagement in the occupation. Consequently, data is required about the engagement of individuals during each case, which when collated may present a pattern of group engagement. Observations of the participants were conducted in 8 cases, each including a different number of sensory attributes.

Data analysis criteria usually provide some explicit criteria for the understanding and interpretation of data (Yin, 2009). This is particularly true of statistical analyses; however, the analysis in this thesis uses theoretical propositions, with a descriptive framework to identify links, and test explanations (Yin, 2009). Data analysis could therefore include pattern matching, explanation building and time series analysis. Pattern Matching compares and contrasts the anticipated pattern and actual data (Trochim, 1989), so that if the patterns match, (which does not occur in this thesis) this could strengthen the validity of the results (Yin, 2009). Pattern matching involves no precise comparisons between data, focusing on the pattern overall, highlighting the trends that occur in the results and the extent to which a pattern appears rather than statistical tests (Yin, 2009). Building an explanation on the other hand, is a higher-level skill, not undertaken by the researcher, which generates a hypothesis; with the explanation reflecting the study propositions (Yin, 2009). In contrast, analysis of time series data tends to involve a single variable, using non-linear models to strengthen the analysis (Yin, 2009).

Case-based methodologies usually focus on one class of performance i.e. occupational-engagement with the intervention (the sensory attributes) being altered, to establish the influence of the intervention on a case (Thompson, 2006), provided that the degree of change is measurable (such as an increase in sensory attributes) (Robson, 2002). This thesis measures behaviour as a response to an alteration in the intervention (Dermer & Hoch, 1999), occuring in a real-life context, or where the boundaries between the phenomenon and context are difficult to distinguish (Spaull *et al.,* 1998), which may be less rigorous than other methodologies (Noyes, 1999). Case studies can include, or be limited to, quantitative evidence, and could involve repeated measures as part of a 'time series methodology' (as in this case) which increases the amount of data collected (Barlow *et al.,* 1984).

Formative in the development of the thesis was the reduction of random variation effects through studying large data sets, and presenting results based on median data, to calculate the randomness out of the study (Drummond, 1996), using replication logic to capture data variability across 8 cases (Barlow *et al.,* 2008). So, in this thesis the focus is on a cohort of individuals with NPC compared as a group, (rather than on a series of individuals, compared as individuals).

There are several quantitative and qualitative approaches to case observation. For instance, quantitative studies may involve repeated measurements, under changing or constant conditions (Drummond, 1996). To capture experiences or opinions, Drummond (1996) suggested the use of semi-structured interviews or questionnaires. However, this would be difficult with individuals with NPC.

To demonstrate experimental control, a control phase (A) (such as the non-stimulating and non-demanding control condition observed - see 5.2.4.2.1) must remain constant, with a change in the dependent variable(s) being seen when comparing performance between phase (A) and phase (B) (Thompson, 2006). This is to highlight the relationship between an intervention and the change that results (Noyes, 1999). The main types of case methodology possible include altering the variables using systematic patterns, such as:

- An A–B methodology, where the study participant experiences two conditions (Robson, 2002).
- An A–B–A methodology includes an additional phase to return the subject to the original condition. Data showing a stable pre-intervention control, an alteration during phase (B) and a return to the control could enable the inference of a causal relationship. However, removing an intervention that appears effective could be construed as doing harm to the participants (Robson, 2002).
- An A–B–A–B methodology counters these ethical concerns by adding an additional intervention phase, allowing within-subject or between-subject replication (Thompson, 2006).

The selection of a series of case methodologies could allow comparison between a series of occupations against a control condition. However, because casual leisure occurs in the moment, the use of pre-test and post-test data would not inform the research questions.

Multiple, case methodologies allow the researcher to consider variables (such as engagement), within a case (the casual leisure occupations) (Spaull *et al.,* 1998). Yin (2009) stressed the importance of using the most appropriate case, since Boruch (2007) found that not all studies used an appropriate case (including studying individuals as the case where a group would have been more informative). Stake (2006) suggested that the definition of a 'case' results from the purposes of the study, and (2003) suggested that a case could be an example of a problem. Therefore, in this thesis each case is a casual

leisure occupation (engaged in by a cohort of 14 individuals), to detect patterns in group engagement under different sensory conditions.

While multiple, case studies are less frequently published than case studies with multiple attributes, roughly 10% of public service management articles published in the period 2004–9 were case-based comparative studies (Stewart, 2012). This is significant because this thesis started as a service evaluation conducted by an MBA. Similar to service evaluation, educational research also lends itself to multiple, case methodology, when there is a need to evaluate the factors underlying the success or failure of a specific element of practice or a whole programme (e.g. Pereira and Vallance, 2006). Research traditions such as service evaluation are closely connected with the pragmatic case study, and may involve a combination of the positivist and pragmatic paradigms, being designed to support service delivery (Fishman, 1999). Fishman (1999) differentiates between positivist (applied science) and pragmatic (disciplined enquiry) research. This thesis considers service outcomes, in this case the effects of menu-based leisure provision on a group of participants with NPC, and whether it meets its goals (Fishman, 1999).

Therefore multiple, case study may compare and contrast a phenomenon (such as engagement), through several cases brought together to explore variables that seem to have some bearing on an outcome (e.g. sensory attributes) (Stewart, 2012). The replication of experiments, may produce findings which are generalisable to theoretical propositions rather than populations, even infering causal relationships (Yin, 2009). They may not however, achieve King *et al's.,* (1994) standards of refutability, depending on the proposition under investigation (for example, that sensory-overload could inhibit engagement in casual leisure occupations) (Yin,2009).

Therefore it is important to define the "case" carefully (including distinguishing it from the contextual environment), since there are several "cases" included in this multiple-case study (Yin, 2009). In this thesis, the participants whose engagement was studied (5.2.1) have been distinguished from the residents who did not participate (the context for the case study) (chapter one). The structuring of the cases to reflect a theoretical framework relating to occupational-engagement (as described in 5.2.4.2) gives the methodology added weight. For example, choosing cases with a spread of variance of the dependent variables (i.e. incrementally more sensory attributes between the occupations) could help to avoid selection bias (thus helping to address King *et al.*'s*,* (1994) constraints about selecting variables).

Furthermore, the control condition could be similar to the cases in that it is a sensory experience, but different in terms of the sensory attributes. Nevertheless, such controls cannot account for every kind of contextual influence possible. Especially since quasi-experimental studies could include factors that are difficult to measure, and may not conform to statistically based tests of validity, reliability and significance (Stewart, 2012). Data in multiple, case study research (e.g. structured observations) should be able to generate understanding based on factual data (Stewart 2012). However, Yin (2009) suggested that data analysis is the least developed aspect of case-based research. Therefore, it is useful to note that Stake (2006) identified three sequential steps in cross case analysis:

- Identify themes in each of the cases (hence, Chapter FIVE includes an activity analysis of each occupation and the non-stimulating and non-demanding control condition)
- Identify factors in each of the cases (hence, Table 10 identifies each of the sensory attributes offered by each occupation and the control condition).

- Cross-case analysis (hence, appendix vi includes a case-ordered statistical matrix comparing the engagement categories exhibited by the participants in each of the occupations).

Yin (2009) distinguished between case studies that have multiple attributes and true multiple, case studies including replication logic across a number of separate 'experiments' such as this thesis. Consequently, Stewart (2012) suggested that multiple, case studies offered a meta-perspective on an issue such as engagement in casual leisure occupations.

In this instance the research question addressed was "Does engagement in casual leisure occupations alter with different levels of sensory attributes?". Multiple, case studies allow the researcher to consider variables (such as engagement), incorporated within a case (a leisure occupation) engaged in by a group (n=14). In this instance each case varied in terms of its sensory attributes. Previously, other studies of engagement have used time-sampling, interval recording, or recording length of engagement or frequency; focussing on an individual (e.g. McWilliam & de Kruif, 1998), or a cohort (e.g., McWilliam, 1999). Such studies have gathered data on a range of issues, such as whether an individual was engaged in the occupation (e.g. Bevill *et al.,* 2001), or the social context of engagement (e.g. Raspa *et al.,* 2001). According to Ridley *et al.* (2000), measuring individual engagement provides information about the suitability of an occupation to engage in (e.g. Sandall *et al.,* 2001).

3.3.2 Self-reporting

Self-report data collection uses question styles ranging from open-ended questions to fixed-format rating scales, e.g. Likert-type scales, and different types of experience-sampling methodologies:

- Thought-sampling (Klinger, 1978, 1979; Hurlburt, 1997) focuses on inner thoughts and excludes contextual information
- Descriptive experience sampling describes inner experience as a basis for quantitative analysis (Hurlburt, 1997)
- Ecological Momentary Assessment which includes the study participant's perceptions and the context surrounding it (Stone *et al.,* 1999)

Experience-sampling methodologies may therefore involve sufficient depth to enable the researcher to address complex questions (Scollon *et al.,* 2003). However, the cognitive and communication difficulties of the participants in this research would appear to render self-reported data collection unsuitable for an NPC population.

3.3.3 Observation

Data collection through observation involves documenting the behaviour of the participants once observed. This time consuming process collects data overtly, or by unobtrusive observation, potentially influencing both the context and the participants' behaviour (Robson, 2002). However, observation data can triangulate information obtained by other techniques. The role adopted by the investigator is as important as the structure of the data collection. More informal, less structured approaches allow the observer freedom about what information is gathered, but require the observer to synthesise and

organise the data during the observation (Robson, 2002). Alternatively, more formal and structured approaches (such as the one proposed) steer the observer's attention towards only necessary data. Reliability and validity are easier to achieve with formal approaches to observation, but come at the cost of a loss of complexity and completeness in comparison with informal observation (Robson, 2002).

Participation levels adopted by the observer can vary from full participation (becoming part of the group or context) to being an unnoticed 'pure' observer (with no interaction with the context at all). The roles undertaken depend on the purpose of the observation and the type of data gathered; for example, the complete participant role is useful where the participants are unlikely to co-operate or their behaviour would change if recorded overtly. However, this style of observation is ethically indefensible (Robson, 2002), risking the observer 'going native' and losing the research perspective. Equally, detection avoidance could distort the results – e.g. introducing a reflective bias in non-contemporaneous documentation.

Alternatively, the participant-as-observer role relies on relationships with the group to offer clarification if needed (Robson, 2002). The observer's attributes, such as age, gender, ethnic background, and the use of props could influence the group's acceptance of this style of observation; while, socially desirable responding may also occur (Robson, 2002). Observations of a pre-existing group by an established member could improve the quality of the data interpretation, but influence its objectivity (Robson, 2002). Alternatively, the marginal-participant role involves less participation in the group dynamics, and involves the researcher taking the role of a passive participant (Robson, 2002). The observer-as-participant does not participate, but is familiar to the participants in her role as an observer (Gold, 1958).

The skills required for skilled observation, include monitoring engagement and environmental features, and defining behaviours in objective, neutral and accurate terms (Cook, 1991, Dunn, 2000). When observing occupational performance, the observer should not influence the individual, the occupation or the environment (or the interaction between them). Knowing this, influenced the style of observations used in chapter FIVE (Dunn, 2000). Observation in its natural context provides opportunity to notice the occupational context, and how it contributes to, or interferes with the occupational-performance (Dunn, 2000). The AOTA uniform terminology (1994) defines the occupational context as the physical, social, cultural and temporal features of an occupation (Dunn, 2000). Some aspects of the context remain stable, while other aspects are fluid and interact with the occupational-performance (e.g. social environment) (Dunn, 2000). Observational data collection, allows the observer to record the actual behaviours that have occurred, and to review and interpret the data afterwards, whilst remaining objective during the session (Dunn, 2000). This is an important skill when working in an interdisciplinary team, because colleagues from other disciplines could interpret behaviour differently (Dunn, 2000). For example, if an individual wriggles, cries out and pushes away his caregiver when moved. The sensory processing interpretation could be that the individual has difficulties organising vestibular stimulation when moving from supine to upright. A psychoanalytical explanation could focus on the difficulty of the individual with bonding with the caregiver. A behavioural understanding could address the association of the individual's caregiver with something unpleasant. If the observer recorded "The individual is hypersensitive to movement" (i.e. the interpretation of behaviour, not the behaviour itself), and then the other options suggested by other perspectives could be excluded.

Systematic participant observation is the most likely to collect quantitative data (Robson, 2002). The captured data requires coding, and could range in complexity from noting whether a particular behaviour occurred, to the use of rating

scales, which give clarity about the observation criteria (Robson, 2002), such as that suggested for this thesis. Therefore, it will be useful to know what signs of engagement the participant population typically demonstrate, and ideally, what the signs of engagement are, as opposed to the signs of overload for each individual. The reliability of the format used depends on the (interpretation, observation and documentation) skills of the observer as well as the inter-observer reliability (Robson, 2002).

Observable behaviours could include:

1. Non-verbal behaviours (Weber, 2010)
2. Spatial behaviours (movement towards or away from others; Meaney, 2004)
3. Extra-linguistic behaviours (speaking rates, loudness and tendency to interrupt; Wharton, 2003).
4. Conversation content and its structural characteristics (Vigil & Hodges, 2005)

Observation-based data collection is useful when the data cannot be gathered through interview as in this case (Babbie, 1992; Bernard, 2006; Gall, Borg & Gall, 1996; Montgomery & Duck, 1991).

3.4 Practical and ethical principles for studying leisure with individuals with NPC

3.4.1 Consent

Profound neuropalliative disability involves a combination of limitations, which could influence the mental capacity required to consent to participate in the study and the ability to communicate it. Adults without the mental capacity to consent should participate only in research which is specific to their medical condition (which is the case here), and where data collection is kept to a minimum – e.g. by using a structured format (Andrews, 2005, 2005a). Ensuring that individuals with cognitive and communication dysfunction understand what participation in the study would involve, and the lack of compulsion to participate, requires great care (Cameron & Murphy, 2006). Valid consent involves an understanding of the study, the ability to make an informed choice, and the ability to communicate that choice voluntarily (Cameron & Murphy, 2006). Researcher's must ensure that participants are not excluded or included without their consent (Cameron & Murphy, 2006).

A core principle of the Mental Capacity Act (UK Parliament, 2005) is the assumption of capacity to make choices until evidence has suggested otherwise. Furthermore, mental capacity, being situation specific, can fluctuate over time due to illness, anxiety, fatigue, medication, discomfort, sensory impairments (Andrews, 2007). Situation-specific capacity could therefore mean that individuals have the mental capacity to make decisions about leisure occupations, but not about a treatment intervention (Andrews, 2007). Supported decision-making to decide whether individuals wish to participate can include familiar supporters, competent at communication with each study participant and are aware of the individuals' engaged behaviour. This involves using pictures, allowing extra thinking time, explaining with a family member/carer present to discuss it later, and using simple language in the individual's mother tongue (Andrews, 2007). This procedure therefore requires a greater than average time allowance. Furthermore, information sheets and consent procedures can be adapted for each individual's needs, whilst still being equivalent for all participants. In this study, situation-specific consent was therefore

an on-going process requiring continual review and occurring during each case, rather than simply at the start of the study. A diminished sense of power and inconsistent responses may have influenced behaviour and consent (Royal Pharmaceutical Society of Great Britain, 2007). The decision was taken by the Ethics Committee to limit this study to those individuals who could give consent themselves, which altered the thesis drastically. It changed the focus from studying individuals who could be at risk of sensory-overload and therefore could be liable to give inconsistent responses, to those with less severe limitations. These less disabled individuals could have had a greater capacity to gate sensory stimuli to avoid becoming overloaded, and therefore this constraint rendered the study less innovative. Voluntary informed consent involves participants being familiar with the study, and requires the use of consent forms (Marsh & Glendenning, 2005). Therefore, the options for this study were to seek formal written consent, signed by a guardian on behalf of those without the capacity to give written consent themselves, and to ask at the beginning of the activity whether the participant consents to participating in the study. The researcher assumed that this procedure would yield a more realistic impression of the participant's consent at the time. According to Cameron and Murphy (2006), the indicators of consent include engagement as well as verbal or nonverbal responses, whereas passive or ambivalent verbal or nonverbal responses could suggest a reduced level of consent. Therefore, gathering verbal witnessed consent to observation occurred at the beginning of each leisure occupation from the participants themselves, and witnessed by the staff who escorted them to the activity. A copy of each consent form remains in the participant's medical notes, with another given to the participant, along with an information sheet about the study. The Ethics Committee agreed that witnessed consent could replace written consent from those participants who could not write when given in addition to a relative's written consent on behalf of an individual with a neuropalliative condition.

3.4.2 Privacy and confidentiality

Participating in a research study is voluntary, with the right to decline to take part at any point. In this study, those participants who do not consent to observation had the right to continue to participate in the leisure occupation, but no data was collected about them. When this occurred, the observer moved out of their visual field so that the observation of other participants in the same activity did not affect them. Confidentiality concerning the information collected and the participants anonymity was honoured (Marsh & Glendenning, 2005). In line with the principles about the use of resident-identifiable information (Caldicott 1997) and the Data Protection Act (UK Parliament 1998), all personally identifiable information was removed and replaced with a code. The researcher kept the key to decoding the data in a secure location, and the data was only accessible by individuals related to the project, in line with the purpose of the project. All anonymised data was, encrypted and password protected. It was stored securely on a CD Rom in a safe at the home. Therefore, access to it was restricted to the employees of the home, such as the researcher, and the Research Governance Manager. The homes policy was for data to be kept securely for eight yearsprior to deletion.

3.4.3 Risk versus benefit

The risk of misuse or misrepresentation of the findings, could be minimised through building relationships with and active involvement of service decision makers in the study. Particular attention was required since the study participants were vulnerable adults who may not be able to speak for themselves, or express their own opinions, may find themselves to have

diminished power, have a disability, may be brought to public awareness because of the study, may be damaged by the process of or by implementation of the findings, may not have the mental capacity to make decisions (Royal Pharmaceutical Society of Great Britain, 2007). Hence care was taken to enable them to understand what was happening. It also explains why it was hard to justify gaining consent for a study from a third party, not truly be able to put themselves in the position of the participant (Marsh & Glendenning, 2005). Arguably, their engagement is the only factor that indicates their consent, since it could be hard for them to opt in or out, or to express their opinion about the occupation (Cameron & Murphy, 2006). The benefits of the research should outweigh the risks for the participants, which was taken into account when designing the study. The local research governance procedures, written with this group in mind were followed. To avoid bias as much as possible, a research assistant other than the researcher should ideally have gathered the data. However, this was thought intrusive on the participants' privacy, and so was not sanctioned. Furthermore, the DCS stipulated that clinical staff's caring duties were not to be effected by the data collection, and that the observer was a single experienced neuropalliative professional who is aware of any signs of overload and/or engagement that could be exhibited.

3.4.4 Study Length

The length of the study was influenced by Leng *et al.*'s (2003) proposal that sensory leisure at the home was enjoyed in the moment, rather than having a long-term therapeutic effect. Leng *et al.* (2003) used a two-group randomised controlled trial methodology involving behavioural, physiological and involuntary movement measures. However, overall this methodology proved ineffective at gathering data from individuals with NPC. Additionally, Leng et al, suggested that the measurement of sensory environments could be measured in terms of leisure satisfaction (or in this instance engagement) after each isolated experience, with no post-session data collection or follow-up beyond that required by the researcher's duty of care. Participants living with NPC generally have an activity tolerance of approximately forty-five minutes, which informed the length of observations undertaken.

3.4.5 Physiological tests

Physiological tests may demonstrate causal relationships (Robson, 2002). However, mood (such as enjoyment) cannot be measured using physiological tests, even if it has a physiological background and/or consequence. However, there are physiological, biomechanical and functional tests that explore stress, the absence of which could influence mood and wellbeing. Sufficient stress is required for creativity, whereas excessive stress could lead to misery (Selye, 1974). What is sufficient stress for some individuals could count as distress in others, due to the balance of demands compared with individual resources to cope with pressure (Lazarus, 1976). Stress levels can be measured physiologically using a number of indicators, such as adrenalin or noradrenalin levels in the blood, salivary oxidation, heart rate, electro-dermal activation and galvanic skin response, respiratory rate, muscle tone, electro-encephalography, or dopamine levels in the blood. However, involuntary movements, spasticity or flaccidity makes collecting samples and scanning very difficult with individuals with NPC according to Leng *et al.* (2003), who found it hard to ensure that the changes observed were due to the intervention, and not a result of the NPC. Physiological tests have not identified conclusive signs of inferred leisure satisfaction in individuals with NPC (Leng *et al.,* 2003), and are an invasive way of gathering data which does not sit comfortably with the ethos of leisure

being self-determined, fun and enjoyable. Furthermore, Leng *et al.* (2003) discussed difficulties with gathering physiological measurements, and questioned whether they were appropriate for gathering first-hand data or whether it would be more appropriate to use third-party data. However, a balance was required between authentic individual specific data such as physiological tests, which would be difficult to gather effectively, or the more complete data that third party responders could generate. Whilst it is an institution, the home is also the residents' home, and so it's philosophy had moved away from the biomedical model towards the social model of disability. Physiological tests sit within a biomedical model rather than the social model ethos. Therefore, all these factors – the difficulty of data collection, the tenuousness of the link between physiological data and the research questions, and the social model of disability in the home – meant that physiological tests were inappropriate to use for this thesis.

3.4.6 Measuring "Flow" (or optimal experience)

The Flow questionnaire includes subjective and qualitative, open-ended questions about the features of optimal experience, and the factors that contribute to the occupational context influencing the cultivation of optimal activities (Csikszentmihalyi, 1997). These open-ended subjective questions could be difficult for participants with communication and cognitive dysfunction to answer. Furthermore, Csikszentmihalyi (2002) describes sensory gating deficits as "stimulus over inclusion", which influences the capacity to experience "Flow". Thus, Csikszentmihalyi (2002) appears to suggest that individuals with NPC cannot experience a state of optimal engagement or "Flow". He also suggested that individuals vary in their reliance on the external cues necessary to accomplish a mental task, enabling less self-regulation of thought processes, autonomy and flexible attention. He implied that "Flow" experiences were impossible for individuals with cognitive dysfunction who are reliant on environmental stimuli to support their engagement. Experience sampling is a popular methodology in "Flow" research. However, although both serious and casual leisure can offer an individual the opportunity to experience a "Flow" state according to Stebbins (2006), the sensory gating deficits of the participants being studied and their dependence on external cues for their cognitive processes could impede their ability to experience "Flow" (Csikszentmihalyi, 2002). The researcher therefore chose not to rely on measuring "Flow" states in the residents at the home, but to explore occupational-engagement instead.

3.4.7 Occupational-engagement

The most common strategies for assessing occupational-performance in practice include skilled observation and interviewing (Dunn, 2000). Observation of the person (see 5.2.1.), the occupation (see 5.2.4.2.) and the environmental variables that are supporting and creating barriers to occupational-performance are frequently used as sources of assessment data (Dunn, 2000). It was felt that, as an early stage researcher a study involving the interaction between the participant, the occupation and the environment would be too complex. Instead the study focussed on casual leisure occupations in context and the need to recognise the sensory-overload amongst residents who were occupying what for them might be an overly stimulating environment. The decision not to observe the interaction between the environment and the occupation resulted from the belief that humans are occupational beings and as such observing the interaction between the environment and the occupation would not contribute to addressing the research question. In this study, therefore, observation focussed on the interaction between the occupation and the participant, to limit the complexity and

number of the variables. Dunn (2000) suggested that occupational-performance fell into three categories: sensorimotor, cognitive, and psychosocial aspects; with engagement, arguably including all three categories. This decision was taken because, asking the individual about their satisfaction with an occupation might be problematic for individuals with NPC; whereas, observing their engagement could demonstrate satisfaction in a more authentic way than gathering third person data.

3.4.8 Measuring Engagement

Data collection could involve capturing engagement, either as the individual perceives it themselves or as it could be seen through the eyes of an observer; by using self-reports, observations or documentary reviews. Parslow *et al.* (2006) suggested that engagement measures are plentiful, but McWilliam and Ware (1994), suggested that the reliability and validity of measuring such a multi-dimensional concept was problematic, while Bosma *et al. (*2002) and Hultsch *et al. (*1999) thought that its complexity gave measures limited comparability. Some measures are age group specific (e.g. Bevill *et al.,* 2001) or diagnostic group specific (e.g. Bejerholm & Eklund, 2006). However, to date no measures exist, specifically for use with adults with NPC. Additionally, casual leisure occupations are enjoyable in the moment, which implies that the same engagement and enjoyment may not be repeated if the occupation reoccurred.

Since 2002 six measures of occupational-engagement have been published (Chugg & Craik, 2002; Goldberg *et al.,* 2002; Wood, 2005; Black, *Krieshok, & McKay,* 2006; Bejerholm *et al.,* 2006; Eakman, 2007) but none of them were suitable for use with a population which could not communicate reliably, because they all rely on time use diaries or interviews. For example, Chugg & Craik (2002) used semi-structured interviews to describe the influences on occupational-engagement, without publishing the tool that they had devised. At about the same time, the Engagement in Meaningful Activities Survey (Goldberg *et al.,* 2002) was published, but again required respondents to have reliable communication and to be cognitively able to participate. In 2005, Wood published her Activity in Context and Time (ACT), observational measure. This collected data about patterns of time use, intention to engage, and mood of people with Alzheimer's Disease living in residential care, but did not measure engagement directly. In 2006, Black *et al.* created their Occupational-engagement Scale for College Students. This captured interview data about 18 items, but was not suitable for use with this clinical group. Bejerholm *et al.* (2006) published their Profile of Occupational-engagement, which involved a 24-hour subjective time log, which would have been difficult for individuals with NPC to complete. Since data collection, the Meaningful Activity Participation Assessment (MAPA) (Eakman, 2007), has been published which was designed to measure the meaningfulness of activity, however if the ICER's use with adults is questionable, it should be noted that the MAPA was validated with older adults with Alzheimer's Disease. The MAPA is a reliable and valid measure of meaningful activity, incorporating both subjective and objective indicators of activity engagement. Recently, Stav et al's. (2012) systematic review of articles reported that self-determined leisure, social and religious activities have a positive impact on health and wellbeing, but that the benefits of occupational-engagement could vary based on the person, occupation and environment.

To complicate matters, McWilliam and de Kruif (1998) identified different types of engagement, such as focused or casual attention, and persistent, symbolic, encoded, constructive, differentiated, undifferentiated, non-engaged, transitional, and uncodeable behaviours. Bagatell (2012) highlighted the tension between the behavioural and attributable aspects of

engagement and the ways that people engage in occupations, including the transactional, contextual nature of engagement. Tools such as the E-QUAL III (McWilliam & de Kruif, 1998), categorised the complexity of engagement (from less to more sophisticated) and the type of engagement (e.g., with adults, with peers, or with materials). The ICER-Revised, also includes eco-behavioural observations (Bagatell, 2012). Quantitative measures of engagement combined with qualitative data could be useful where individuals have difficulties engaging with their environment (McWilliam & Bailey, 1995) and supporters have little or no training in enabling engagement (Bagatell, 2012). Raspa *et al.* (2001) placed these engagement categories on a continuum of sophistication (including the range of cognitive skill levels (e.g. problem-solving, language). However, measures of engagement that rely on cognitive skill may fail to capture engagement behaviour (Kishida & Kemp, 2006) in individuals with NPC.

Arguably, although there are various measures of engagement available, they may not be sensitive to the engagement levels of individuals with profound disabilities. As a result, Kishida and Kemp (2006) validated a measure of engagement for use with severely developmental disabled populations, which was suitable for use by marginal-participant observers. Engagement results in unengaged, active or passive individual engagement, or passive joint and coordinated joint engagement (Kishida & Kemp, 2006; Bakeman & Adamson, 1984). This is relevant because four of the cases used by this thesis were group occupations. However, individuals with NPC do not tend to interact with each other due to their use of mutually incomprehensible assistive technology. Kishida and Kemp (2006) identified five levels of observed engagement, including active and passive engagement, undifferentiated engagement, and active and passive non-engagement, demonstrated by individuals when engaged in an occupation. Whilst NPC and developmental disabilities are very different in cause, they have some similarities in terms of executive processing, reliance on environmental cues, physical limitations and communication difficulties, all of which impact upon whether the individual can engage. Therefore, this thesis used Kishida and Kemp's (2006) definitions of engagement because they describe the categories of engagement so clearly.

3.5 Confounding Factors

The field of leisure encompasses individual and collective engagement. Leisure science studies recreation, play, games, involvement in sport and the arts, live entertainment, hobbies, socialising, sightseeing, and do-it-yourself, and doing nothing in particular etc. Furthermore, within the domain of social science there appears less capacity for experimental research than in the domain of natural sciences. Situations such as variations in the equipment used for games or sports or in management situations lend themselves to experimental study designs, whereas topics of interest to the leisure science researcher do not (Edexcel, 2011). For example, sensory, social and physical environmental factors could influence engagement in the real world. Had the overarching philosophy of this study not been one of leisure, then the participants could have been allocated to a crossover study design based upon a matrix of combinations of conditions. Data from a case study requires triangulation with other sources of data. However, the removal from the thesis of a study of the meanings of leisure study has left the data at the risk of being confounded through a lack of triangulation (Edexcel, 2011). Furthermore, the original ethical permission for the study stipulated that a less disabled group of participants was included in the study. The DCS also made a condition about which Residence Manager (with a more profoundly disabled group of residents in her care) should be the only staff member interviewed. These stipulations, in combination may also have confounded the study, by

creating a situation where the interviews and observations involved different participants. Additionally, the natural occurrence of several co-variants rendered regression analysis impossible and therefore no relationships between engagement and occupational role, between engagement and the level of support offered, or between engagement and the familiarity or novelty of the occupation could be analysed.

3.3.4 Summary

Therefore, the most appropriate way to sample experience in this instance, was the use of marginal-participant structured observation gathering data through a series of quasi-experimental case methodology studies, similar to those described by Wade (1998). Comparison of the data from a control condition and data from a time series of incrementally stimulating occupations will occur. Participant observations have a potential for bias due to previous knowledge and interpretation by the researcher, but marginal-participant observations should be less easy for the participants to influence (Robson, 2002). Ideally, observers who are blind to the research hypothesis would further reduce the potential for bias during data collection, as would using a structured observation format.

The main study captured data about engagement in leisure, avoiding the use of random allocation. Because casual leisure occurs in the moment, the use of pre-test and post-test data would not inform the research questions. Therefore, case quasi-experiments focused on the effects on engagement behaviour after the introduction of increased sensory attributes (Dermer & Hoch, 1999). A 'time series methodology' using a structured observation tool (the ICER) might generate sufficient data to conduct a series of comparisons of a stable control condition with each of the intervention states associated with a series of casual leisure occupations (Robson, 2002).

Consequently, a series of repeated case experiments established the effect of an intervention (sensory attributes), on the engagement of a cohort of participants in casual leisure occupations. The repetition of the cases (which turned the study design from a case study into a multiple, case study) ensure that the same data was collected, using the same measure (the ICER) for each case, which included incremental levels of sensory attributes.

Case-based studies offer a naturalistic exploration of the complexity of situations (Yin, 2009), collecting either quantitative or qualitative data (Zucker, 2009). In this instance quantitative data about engagement was collected, using the ICER, to consider what happens, and why (Bassey, 1999). The underlying philosophy of a case study approach fitted very comfortably with addressing how type questions such as "How does engagement in casual leisure occupations (by individuals with NPC) alter with different levels of sensory attributes?" The marginal participant role is familiar to the residents as a way of collecting data, using a standardised outcome measure. A preliminary study also occurred, to supplement the definitions of engagement behaviours that form part of the ICER (and guide their recognition). Other researchers seeking to address similar research questions have used interviews, questionnaires and documentary review. Therefore, a structured interview format gathered face-to-face opinions from a Residence Manager, asking questions in a set order, and using the same wording for each resident discussed.

Some residents were able to articulate speech clearly and understandably, but their cognitive dysfunction meant that they could have difficulty understanding any questions put to them and being able to think through and formulate their

answers. These individuals are very vulnerable to suggestion and persuasion. The small subgroup that could reliably express their own opinions were the most able residents with no awareness issues, who are able to control their environment using assistive technology, are more able to gate sensory stimulation and therefore have a wider choice of, and more control over their leisure occupations.

As demonstrated in a residential care service audit report (RHN, 2007), a comparison of leisure satisfaction data gathered from this more able group (RHN, 2006) with similar data gathered from all residents yields quite different results. This could support Csikszentmihalyi's (1990) premise that full engagement to the point of "Flow" is more likely if the individual has a sense of the possibility, rather than the actuality, of control. Reed et al. (2010) also promoted the meaning derived from the possibility of an occupational role as an important factor in identifying the meaningfulness of an occupation. Because of the first-party/third-party gap in insight about the preferences of the residents, and their own difficulties in representing their preferences, self-reporting would appear to be an inappropriate method of collecting data from the entire home population. Whilst, it could be an appropriate method of collecting first-party data from the more able group, this subgroup was less representative of the entire population. This is unfortunate because in other circumstances it would be a very appropriate way to understand what an individual really feels about a leisure occupation.

The researcher's role in many leisure opportunities at the home has been to observe engagement (see chapter six). Therefore, the residents were familiar with an observer, especially during trial leisure opportunities. This should have reduced the influence of the observations on participants who might try to please, or meet social expectations, (Robson, 2002). This artificial behaviour could be difficult to maintain over time, especially for those with cognitive dysfunction and memory impairments (Robson, 2002). Therefore, a time-sampled methodology sought to capture their natural behaviour.

Other problems concerned the generalisability of findings. It is possible that the sample of individuals might not be representative of the population (because only those who were able to give consent were observed, and these were the most able residents), or indeed the individual concerned (because they are having a bad day). Therefore, triangulating the data with a description of their normal and sensory-overloaded behaviour, sought to make the observations more reliable (Babbie, 1992; Bernard, 2006; Gall, Borg & Gall, 1996; Montgomery & Duck, 1991). Furthermore, interval contingent observation offered the opportunity to observe and record contextual data between times (Bernard, 2006).

This thesis sought to gather objective descriptive data. However, subjective variables required the researcher to make inferences about the behaviour observed during the case. For example, a neurotypical individual sitting slumped in a chair with their head bowed could look sad, withdrawn, or distressed. However, an individual with Huntington's Disease who normally demonstrates continuous involuntary movement (worsened by stress, anxiety, or depression, but decreased during uninterrupted concentration, when asleep, or with correct posture or positioning) could be very engrossed, happy and relaxed when sitting in the same unmoving posture (Nance *et al.,* 2003). Therefore, inferring the engagement level during the observation requires previous knowledge of the individual, or a description of their usual and sensory-overloaded behaviour. Then, comparison with their resting unengaged behaviour could give a reliable interpretation of their engagement. Therefore, when writing field notes the investigator included descriptive and subjective data, about everything that could influence the behaviour observed.

Participant observations have the potential for bias, however, marginal-participant observations suffer less bias since they require less previous knowledge. Ideally, observers should be blind to the hypothesis, and should use a structured observation format to reduce the amount of data collected. However, observers should be aware of the behaviours that indicate engagement or non-engagement. Any observation format should enable accurate documentation of the engagement level of the sample group for a period of forty-five minutes. Therefore, a single marginal-participant observer collected the data. This research followed the home's research governance protocols, and required consideration of consent, privacy and confidentiality and risks as related to benefits.

To inform these observations, and since sensory-overload is not well-known outside the domain of developmental disabilities, it was felt that it would be more effective to use face-to-face contact to gather data about the residents' resting and overloaded behaviour, having previously briefed the Residence Manager. The data collected to inform the observations of engagement included a staff member's opinions of the signs of sensory-overload exhibited (i.e. whether an individual was engaged or overloaded). However, having their opinion sought could influence staffs practice, and reduced the staff-to-resident ratio during data collection.

Chapter FOUR

Preliminary study: Study of resting and sensory-overloaded behaviour

4.1 Introduction

Chapter Four presents a preliminary study of resting and sensory-overloaded behaviour. It describes the methodology, the participants, and the data collection tool. It also describes piloting the questionnaire and the data analysis before presenting a reflective review of the preliminary and pilot study methodology. The results relate to the research question: what are the normal and sensory-overloaded behaviours exhibited by individuals who are living with NPC?. There follows an overview of the residents' non-engaged resting behaviour, and their observed and attributed behaviour when experiencing sensory-overload. These are discussed alongside the influence of the findings on the later observations of engagement study.

Throughout the history of occupational therapy, occupational-engagement has been valued as both a therapeutic agent and goal (Fisher 2013). Occupational Science links well-being and occupational-engagement, suggesting that well-being is achievable through occupation (Aldrich, 2011; Wilcock, 2006). For instance, Yerxa (1998, p. 412) defined health as "a positive, dynamic state of 'well-beingness'" and satisfaction in one's occupational performance. Therefore, given that humans are occupational beings (Wilcock 2006), arguably, active occupational-engagement is his natural state for wellbeing. Therefore, any thing less (such as passive, undifferentiated or non engagement) could be assumed less satisfying.

Likewise, writers such as Shearer *et al.,* 2006; Steiner & McDermott, 2009; Rose, 2011; Clare *et al.,* 2012; Williams, 2006; Richler *et al.,* 2007; Tantam 2011; Caldwell & Horwood, 2008; Bosboom *et al.,* 2004; Wolters *et al.,* 2008; Pillay & Suniti Bhat, 2012; Bellando & Pulliam, 2009; McKay *et al.,* 2009; Chen et al, 2009; Allen & Polaha, 2006; Bogdashina,2003; Richler *et al.,* 2007; Abell *et al.,* 1999; Harvey, 2010 have suggested that sensory-overload detracts from occupational-engagement. Individuals with NPC, potentially, could therefore be dis-enabled further by inappropriate sensory stimulation. The effects of inappropriate sensory stimulation may be perceived by onlookers as fatigue (see textbox 1), altering the individual's information processing, and reducing engagement, which may evolve into occupational deprivation (O'Sullivan and Hocking (2006); Hearle *et al.* (2005); Burllau (2007), Whiteford (2000); Townsend and Wilcock (2004). Furthermore, the risk of sensory inundation following RAS damage, may limit an individual's occupational choices and experience to casual leisure occupations (with all the sensory attributes involved) because they are less able to engage in serious leisure (Stebbins, 2008). Their inability to process efficiently could mean that causal leisure, by definition is too stimulating for the individual to cope with.

A combination of environment and RAS damage has been suggested to overload or deprive the individual of sensory stimulation (Howell, 1999), to the point of cognitive problems, challenging behaviour, lack of awareness of their sensory needs (Champagne & Stromberg, 2004), reduced occupational-performance and engagement abilities (Howell, 1999; Easton & MacKenzie, 1988; Geary, 1994), affecting behaviour and emotional reactivity (Parham and Mailloux, 2001). This justifies

research into the effects of sensory gating deficits in conditions such as post-traumatic stress disorder (Ghisolfi *et al.,* 2004), Huntington's Disease (UC *et al.,* 2003), Dementia, Multiple Sclerosis, Parkinson's Disease (McCarley *et al.,* 1997; Morton *et al.,* 1995), and Head Injury (Kumar *et al.,* 2005; Arciniegas *et al.,* 1999). Whereas, SI theory stresses the importance of matching the individual (and their sensory processing ability) to the occupation (and its context) (Dunn 2001).

Sensory-overload may cause an individual to try to reduce its impact (e.g. hiding the face, covering the ears, hand flapping, or by over-focusing on an object) (Chen et al, 2009; Shearer *et al.,* 2006). Healthy adults can also be affected by unrestricted and indiscriminate sensory stimulation (Engel-Yeger & Dunn 2011), while individuals with sensory processing or sensory gating problems may be overwhelmed by it. This happens because the sensory detection, processing and motor system influences our understanding of the outside world and the behaviour that results (Steiner & McDermott, 2009).

Rose (2011) suggested that sensory-overload leaves the individual achieving only the bottom rung of Maslow's (1954) hierarchy of needs, limiting their occupational-engagement according to their degree of sensory-overload. The individual may be incapable of making sense of and associating concepts, rendering them dependent on others and external sensory cues (compounding their sensory experience), without any understanding of their behaviour or of its repercussions. If experienced too frequently sensory-overload, could lead to a fragmentation of sensory impressions in an autonomic storm (Caldwell & Horwood, 2008). The emotional energy experienced is generally high, and sensory-overload is very uncomfortable, requiring symptomatic relief through antisocial or risky but stimulating, or calming behaviours (Rose, 2011). Arguably, sensory-overload could increase in the complexity of the processes used in participation, reducing the individuals occupational-engagement.

Therefore, authors have linked well-being and occupational-engagement as a positive state, suggesting that neurological damage may limit occupational-performance and engagement and that increasing sensory-overload further reduces occupational-engagement or occupational capacity. Baysinger's (2009) and Roberts et al. (2007) experimental studies, suggested that engagement may be altered in response to sensory stimulation. Baysinger (2009) based her conclusions on estimates of engagement level while Roberts et al. created their own "Engagement Level Rating Scale" and collated data without stating its criteria. Roberts et al. (2007) suggested that SI interventions could improve an individual's engagement, decreasing their level of maladaptive behaviour with significant decreases in performance upon removal of treatment. They used a longitudinal, single-subject crossover design to report improvements in self-regulation, engagement and decreased aggression following SI interventions. Therefore, the researcher was able to list the behaviours demonstrated resulting from sensory-overload. She was also able to estimate (based upon the definitions of the engagement categories proposed by Kishida & Kemp (2006) and her clinical reasoning), how significant the impact of these behaviours would be on occupational-performance and so predict which engagement level the participant might be able to demonstrate. Therefore, to create a definition of engaged and non-engaged behaviour to inform the observations of engagement, the research question considered was "What are the normal and sensory-overloaded behaviours exhibited by individuals with NPC"?. Consequently, interview data described the residents' unengaged and sensory-overloaded behaviour. This was important since the researcher's' perceptions of the signs of sensory-overload exhibited by residents would influence the interpretation of whether the behaviour observed was demonstrating engagement or not (Dunn, 2000).

4.2 Method

A structured interview format formed the basis of the discussion of each resident in turn, with the participant (n=1). Structured interview's are useful for gathering quantitative social survey data, and in this instance meant that data was collected about each resident using the same questions, in the same order to minimise variation. Standardising the questions had the advantage of potentially reducing interviewer variability, leaving differences in responses to result from 'true variation', rather than inconsistencies in the interview process, whilst reducing intra-interviewer and inter-interviewer variability. No interpretation of responses occurred before or during coding.

4.2.1 Participant

The participant (an Residence Manager) was recruited by the DCS, because her residence accommodated the most severely disabled residents in the home, who were less able to express their own opinions or consent, at more potential risk of sensory-overload, and who were likely to have had fewer opportunities to organise their own leisure occupations independently. The participant gave written consent to participate in the study, having discussed the study, a briefing presentation, the interview and the topic of sensory-overload eight days prior to data collection. The participant and the researcher both retained copies of the consent form.

The participant was an experienced Registered Adult Nurse, who had an overview of all residents under her team's care. An Residence Manager was selected to compare, contrast, and be aware of the subtleties of behaviour exhibited by the neuropalliative individuals in her care. However, to limit the impact on her workload, the participant had pre-selected nine of the most able residents in her care, and had prepared by consulting her staff about each resident's resting and overloaded behaviour. The residents discussed were the ones that she felt were most likely to participate in leisure occupations, but were unable to express their own opinions, due to cognitive and communication limitations, and so were similar to those who were originally the intended focus of the study presented in chapter five. The residents discussed were not the same residents as the ones eventually observed engaging in occupations in chapter five, who were required to give their own consent. It was not possible to interview the Residence Managers for the residents observed (in chapter five), because this would have contravened the organisational request to limit the number of and length of time staff members were involved in the study. This limitation had the potential to confound the data; however, data collection proceeded because this study collected unique data. The raw data presented in Appendix vii shows the results of the discussion of the usual behaviour of the residents discussed.

Socially desirable responding could alter the validity and reliability of the data collected, through over-claiming knowledge or responding to questions in a way that sought to influence the interviewer (Mesmer-Magnus *et al.,* 2006). Social desirability responses reflect an ability and motivation to distort responses (Mesmer-Magnus *et al.,* 2006). Arguably, having discussed the topic of sensory-overload, the participant may not wish to appear ignorant and thus might be more strongly positive to please the researcher, or negative since sensory-overload is not a concept familiar outside of developmental disability and AHP practice. However, this might not have been problematic because Mesmer-Magnus *et al.* (2006) suggested

that socially desirable responding does not automatically influence test validities. Barrick and Mount (1996) for example found applicants distorted their responses because of self-deception and impression management, but this did not influence the results overall. Similarly, using meta-analysis, Ones *et al.* (1996), and Hough *et al.* (1990) who instructed their respondents to fake responses; both found that the criterion-related validity constructs remained unchanged because of socially desirable responding.

Social desirability encompasses unconscious self-deception and conscious impression management (Mesmer-Magnus *et al.,* 2006). The participant, did not seem to be over-claiming her knowledge of sensory processing, which might have resulted from neuroticism, intelligence, or openness to experience (Mesmer-Magnus *et al.,* 2006). She appeared interested to explore and discuss it; questioning, rather than just acquiescing. Team leaders with emotional intelligence use their reasoning around antecedent and subsequent behaviour to understand their own or others reactions, and were therefore not likely to over-claim their professional knowledge, thus reducing the likelihood and influence of socially desirable responding in this case (Mesmer-Magnus *et al.,* 2006).

4.2.2 Data collection tool

Based on the signs of sensory-overload highlighted in the literature (Shearer *et al.,* 2006; Steiner & McDermott, 2009; Rose, 2011; Clare *et al.,* 2012; Williams, 2006; Richler *et al.,* 2007; Tantam 2011; Caldwell & Horwood, 2008; Bosboom *et al.,* 2004; Wolters *et al.,* 2008; Pillay & Suniti Bhat, 2012; Bellando & Pulliam, 2009; McKay *et al.,* 2009; Chen et al, 2009; Allen & Polaha, 2006; Bogdashina,2003; Richler *et al.,* 2007; Abell *et al.,* 1999; Harvey, 2010), a format was drawn up to capture the usual behaviour of a group of residents and their behaviour when experiencing environmental over-stimulation.

Self-report questionnaires could be subject to response bias (Robson, 2002). The questionnaire was therefore clearly linked to the research question, and gathered appropriate data relevant to the participant's experience. However, it was useful to pilot the questions and the introductory explanation to discover whether they were understandable, and asked appropriate questions. Appendix ix contains the data collection format used to interview the Participant.

At the time of the study, there was no standardised assessment of sensory-overload; therefore, a developmental approach similar to that used to create the sensory profile occurred. To begin with, to focus the participant's attention on any normal and anomalous behaviour exhibited by the resident under discussion, an open-ended question asked how staff identified when a resident is experiencing stress because of over-stimulation. This was followed by listing the behaviours and asking whether it occurred in non-stressful circumstances. This followed a formula by asking (for each sign of overload listed) what the resident's normal ability to**...**, or level of... was. To explore how overload was identified, a further question was asked (for each sign of overload listed) whether the resident under discussion demonstrated any signs of altered ability to..., or altered level of... when experiencing environmental over-stimulation. A useful clue to the severity of the impact of overload on each resident was to ask how long it took them to recover from an overly stimulating environment. Bryman (2001) suggested that structured interviewees may answer a series of questions on a certain direction regardless of their content. Therefore, the wording in some of the questions changed occasionally, when compared to the rest of the items.

The participant was in danger of a disparity of meaning because sensory-overload was a new concept for her, and to drawing on commonly held or collaborative meanings, rather than using "official" definitions (Bryman, 2001). Therefore a researcher may assume that interviewer and respondent share the same meanings and understanding when in fact they do not (Bryman, 2001). Bryman (2001) suggested that the problem of meaning is resolved by ignoring it. However, in this instance, the participant received the questionnaire and a briefing presentation including a brief literature review and a definition of sensory processing, via email after her recruitment. Furthermore, a discussion of the interview procedure and definition of sensory-overload occurred eight days prior to the interview during a telephone conversation. The pilot usage of the questionnaire ensured that respondents would interpret the meaning of each question in the intended way, and that they were understandable, being neither “loaded” or “leading” questions; which, although narrow were not closed questions. This occurred because this was not a topic of much familiarity to the participant and so narrowing the boundaries of the question helped her to understand the questions.

4.2.3 Procedure

Approval to commence data collection was granted by the University of Roehampton School of Human and Life Sciences Ethics Committee and by the DCS after the Heads of Clinical Services meeting, which had discussed the study (see appendices x and xi). Piloting the data collection format involved three staff who were not involved in the study.

4.2.4 Pilot Study

The purpose of piloting the questionnaire was to ensure that it would gather the anticipated data. This was required because sensory-overload was not something the Residence Manager had studied previously.

The three piloting staff members had read the definitions of sensory-overload in the literature review of the study, and discussed the definitions of each of the signs on the questionnaire together in a group briefing session to achieve a common level of understanding. The researcher anticipated that the signs of sensory-overload described in the literature would be familiar to staff specialising in neuropalliative rehabilitation.

Piloting the questionnaire involved three staff members who witnessed and completed data collection during a mock interview between the researcher and another staff member about a resident who was not involved in data collection for any part of this thesis study. All five staff involved in the pilot used the questionnaire shown in appendix ix. The staff members involved in the pilot were a Music Therapist, a Nurse Manager and the Creative Activities Coordinator.

After the pilot, a comparison of the data collected for similarities, differences and inter-rater reliability occurred. A Cohen's kappa reliability score of 0.70 or over suggested consistency of data gathered by the raters (De Wit et al 2007). There was a high level of agreement (k =0.88) between the piloting raters.

4.2.5 Data Collection

The participant's lack of education about sensory-overload, meant that she had little insight into the hypothesis. However, face-to-face interviews ran the risk of an interaction between the characteristics of interviewers, the respondents, the data generated and even the concept under discussion (Bryman, 2001). In this instance, prior to conducting the interview the participant and the researcher had spoken on the phone but never met, and so had very little rapport built up. This helped to maintain neutral and professional boundaries. The participant was asked the questions about each resident in turn, completing each questionnaire about a single resident before moving onto the next. Bias and rapport building could have been limited (because to have no rapport would have had equally influential consequences) by conducting an interview over the phone (Bryman, 2001). There is evidence that emotionality and rapport building may reduce when communicating through technology (Silver and Oakes, 2001); due to limiting the social/ non verbal cues. However, explanation and rapport were the considerations felt to contribute positively to the veracity and validity of the findings.

4.2.6 Data Analysis

Analysis of the 405 data points considered whether individuals with NPC demonstrated the signs of sensory-overload highlighted in the literature. A spreadsheet including the answers to each question in the interview highlighted themes and trends in the data. No statistical analysis of the results occurred because the study sought to establish the presence (rather than the frequency) of a sign of sensory-overload.

4.2.7 Reflection on the study methodology

Arguably, the researcher tutored the Residence Manager (by answering questions and offering her a literature review), potentially pressuring her to give the answers that she felt the researcher wanted to hear. The researcher's influence in tutoring the respondent is undeniable, which made the avoidance of socially desirable responding a priority. The researcher's influence was defensible given that sensory processing is not an acknowledged concept beyond the domain of the allied health professions. Consequently, it was unfamiliar to the respondent and her team. However tutoring eliminated any disparity of understanding caused by the new concept (Bryman, 2001). On reflection, the learning disability branch nurse could have tutored the Residence Manager on the topic, however, the researcher was under pressure not to further reduce the clinical staff to resident ratio.

Arguably, Kishida & Kemp's (2006) definitions of the engagement categories were so clear and explicit that this preliminary process was not required to highlight engaged and non engaged behaviour. Especially, since they had standardised their assessment for use with individuals who had developmental disabilities and therefore were vulnerable to the influence of the sensory environment. However, the DCS stipulated that the observations of engagement involved an amalgamation of individual inventories of which behaviours could represent sensory-overload in individuals with NPC, hence the preliminary study. The University of Roehampton ethics committee's insistence that the observations involved a different, less disabled group than those discussed by the Residence Manager hindered this plan. However pragmatic studies such as this, address naturally occurring phenomena, in all their complexity, including a context that requires or prohibits stipulated factors, as in this thesis (Fishman, 1999). In ideal circumstances, i.e. when the wishes of the DCS and the University Ethics Committee were not contradictory, the interview and the observations would involve the same residents. However, the

dichotomy between their positions meant that this was not feasible. Equally, it would have been easier and more fruitful to have used an assessment of sensory-overload, which had been standardised for use with individuals with NPC; however, such a measure was not available at the time of the study. Furthermore, ideally an observation or engagement measure, which has been standardised for use with individuals with NPC, would be, used thus rendering superfluous the preliminary study.

However, based upon the requirement for only a single observer (experienced in NPC); a preliminary study was required to inform the observations of engagement. It would have been useful to record the interview, so that several data collectors could verify the results. Other options for establishing the overloaded behaviour of a group of individuals would have been to ask them; although they may have had little insight, and their communication, and cognitive problems might have influenced their ability to recognise such an unfamiliar concept in themselves. Physiological tests such as skin conductance, or saliva pH could have identified stress in the participants of the observation study; however, Leng *et al.* (2003) suggested that physiological tests were not reliable with this clinical group. Furthermore, the Residence Manager's responses about a sign of sensory-overload could have reflected earlier discussion, involvement in other studies or responses about a different behaviour in the same interview (Bryman, 2001). However, rather than gather the opinions of someone who had no idea about the topic it was decided to risk biasing her, in an attempt to broadcast knowledge which could have enhanced quality of life, preventing challenging behaviour and enabling occupational-engagement. Consequently, the Residence Manager received a briefing upon which to base preparatory information gathering about her residents.

Structured interviews risk an imbalance of power with the researcher collecting information and giving nothing in return (Bryman, 2001). A qualitative methodology may have avoided this (Bryman, 2001). Therefore, the briefing presentation offered some knowledge to enhance team practice whilst allowing for clarification (Opdenakker, 2006), and potentially influencing the participant. Had the participant felt threatened, there was a danger that she could have obfuscated due to feelings of inadequacy (Wimmer & Dominick, 1997). As it was, data collection was constrained by limited understanding, so that briefing facilitated the production of informed data, but was insufficient to enable prediction of the anticipated answers. Biasing influences could include over representing her new knowledge, or matching it with pre-existing knowledge, experience, interests, and attitudes (Robbins, 2004). Additionally underestimating the influence of external factors and overestimating the influence of internal factors could also have biased her answers (Robbins, 2004). Consequently the researcher offered referenced definitions to aid her understanding (Robbins, 2004). Discussing several occasions when a behaviour could have occurred, and framing the discussion towards non demonstration of behaviour meant that each resident was opted in rather than opted out of a behaviour, avoiding creating meaning out of coincidence (Robbins, 2004). The interviewer was not blinded but adopted a 'persuade me to opt the resident in' approach (Robbins, 2004), by asking 'what does that look like' for each sign of sensory overload discussed. Ideally the Residence Manager would have described all her residents to give a larger sample, or to interview each Residence Manager about all 14 residents observed. An alternative method of enhancing the reliability of the results would have been to cross code the data with another observer or another data set (but no such data set was available). However, the DCS did not permit the reduction of clinical staff: resident ratios for long, multiple raters or recording equipment. Furthermore, no statistical testing of the data occurred, because percentages and raw data are descriptive and contributed to a binary occurrence contingency table.

Frequency data was not appropriate to present in table 7. This table compares the influence of sensory-overload on engagement category and so arguably frequency could be less influential on an individual's engagement category than the presence of an experience. In turn, intensity of experience could depend on the individual's reception of the stimuli (consequently, of their threshold of responsiveness, sensory profile and preferences) just as much as the intensity of the attributes offered. Intensity of experience, like meaning could be something which only the individual can describe, although arguably, reaction to it could be witnessed by an observer.

Additionally, frequency data was not suitable to present because it would have been based on the Residence Managers opinion (biased or otherwise), the size and representative-ness (or not) of the sample, or interpretation of the data by the researcher. Furthermore, frequency data requires a sensitive data collection tool to rule out false positives and negatives. Data production sensitivity was also influenced in this case, because of the Residence Manager's lack of exposure to sensory-overload. The advantages of frequency sampling are that it is objective, repeatable, and simplistic. Frequency data requires no estimation or subjective evaluation, and is relatively rapid and easy to collect. However, the observer should be aware of less concrete responses such as could be or sometimes as opposed to yes/ no. Furthermore, if the signs of sensory-overload were easy to recognise, frequency data could be very rapid and simple to collect, allowing a comparison of data between engagement categories. However, the intensity, density and dispersion of data could be a disadvantage as well as an advantage, making it difficult to determine the cause of changes observed without triangulating data. Though often correlated, frequency does not necessarily relate directly to the degree, intensity or level of the concepts influence, due to explicit or implicit causes. Furthermore, little training is necessary to collect frequency data, which can be easily summarised and evaluated. Binary occurrence contingency data on the other hand, merely reflects the presence of the concept amongst the entire sample. No judgement about the degree, intensity, strength to which it was present occurred, and there is no need to distinguish individuals. The theoretical background of the researcher includes a knowledge of leisure, occupational science and sensory processing. A different researcher with different theoretical and professional experience could have interpreted the data in a different way. The results could have been more robust if the significance of the data from the interview with the Residence Manager was justified; or better still, to collect the data from several Residence Managers who were conversant with sensory processing.

4.3 Results in relation to the research question: what are the residents normal and sensory-overloaded behaviours?

4.3.1 Overview of the residents' non-engaged behaviour as a group

Several residents were described as non-verbal but could laugh, make noises or express themselves non-verbally. In fact, most were very expressive, e.g. one demonstrated relaxation by coughing less. The residents discussed were all aware of their surroundings, with their levels of awareness ranging from low, to being able to concentrate if supported. Most had poor coordination or no upper limb movement. All but one resident was able to make and maintain eye contact. Several residents were uninhibited, but most were able to control their behaviour and speech without outbursts.

The non-verbal residents used non-verbal communication, to get attention, while verbal residents could call out. Residents were described as having either no perceptual deficits or being unable to demonstrate perception. Several residents required constant reminders, but were able to make their own decisions; while others had a normal level of orientation and memory. The residents' usual sensitivity to light and sound ranged from "normal" to not liking touch, or being sensitive to light and/or sound. The residents' information processing varied from "normal" to very slow. The residents' usual tones of voice were described variously as expressive or "normal" if they were able to vocalise, or not applicable if they were not able to verbalise. Word-finding abilities amongst the residents was effective, "with difficulty" or not applicable. The resident's usual level of understanding written text ranged from normal to not applicable. The resident's usual level of understanding spoken words were described as ranging from normal to "likes voices but doesn't understand them". The following section will summarise the participant's description of the residents' behaviour when experiencing an overly stimulating environment.

4.3.2 Overview of the residents' observed and attributed behaviour when experiencing sensory-overload

Initially, (during the phone call eight days prior to the interview), the researcher and the participant had a conversation about the differences and similarities between fatigue and sensory-overload, which may appear similar in behavioural outcome, but have different causes. It became easier to distinguish between the two when the researcher suggested that the participant kept reporting that a particular resident was sensitive to light, noise or touch, and became distressed when experiencing an MSE. The raw data presented in Appendix x results from the discussion of the signs of sensory-overload exhibited by the residents.

The participant repeatedly described examples of sensory defensiveness (Heller, 2002) such as stress, and withdrawal from sensory stimulation, which corresponded to Dunn's (1997) sensory avoidance and sensory hypersensitivity. The flight-or-fight systems of individuals who are sensory defensive are perpetually active, triggering a continuous stress response, leading to fatigue and depression, sleep difficulties, headaches, increased tone, and so forth (Heller, 2002). The raw data collected from the participant (presented in Appendices vii and ix) describes residents exhibiting several of these responses.

Some behaviour occurs directly in response to a cause, whilst other behaviour could only be attributed to a cause. Attributed behaviour expresses the individual's wishes and emotions in the moment (Watson 2004). For instance, Pfeiffer & Kinnealey (2003), Kinnealey *et al.* (1995) and Pfeiffer (2002) all suggested that sensory processing could have a social–emotional impact. They suggested that sensory defensive adults could feel anxious and uncomfortable, adapting or eliminating activities in response to the sensory environment, which could interfere with functioning, extending beyond observable social–emotional behaviours (Kinnealey & Fuiek, 1999; Pfeiffer & Kinnealey, 2003). Sallee and March (2001); Lane *et al.* (2002) and Pfeiffer & Kinnealey (2003) suggested that the emotional-processing circuits in the limbic system and RAS control arousal and attention levels, linking sensory defensiveness and RAS dysfunction, and emotion and sensory processing/ gating dysfunction with anxiety.

Myles *et al.* (2004) suggested that SI dysfunction results in (a) low endurance and tone, (b) poor registration of stimulation, (c) tactile challenges, (d) fine motor/ perceptual problems, (e) self-regulation problems, and (f) oral sensory sensitivity. Sensory defensiveness was described by Lane *et al.,* (2000) as the behavioural manifestation of a dysfunction in sensory processing/ gating which causes problems in the individual's capacity to regulate and organise the quantity, quality, and type of response to sensory stimulation. Engel-Yeger & Dunn (2011) suggested that the literature around sensory processing emphasises its possible impacts on functional abilities, behaviour, emotional aspects and mental health. These are measured using the Sensory Profile which measures problems with sensory processing and concomitant behavioural and attributed socio-emotional responses which Myles *et al.* (2004), described as "psychosocial coping strategies," or products of sensory processing.

Therefore, the researcher has chosen to highlight in the fourth Column in table 6 whether a physiological behavioural, cognitive or affective response to sensory attributes could be directly observed or attributable to an individual based on the participant's clinical reasoning and the literature about sensory processing. Bagatell (2012) also collected data about the behavioural and attributable aspects of engagement. Furthermore, in the second column the researcher has categorised the signs of sensory-overload into Beck and Emery's (1985) categorisation of the social–emotional impacts of sensory processing dysfunction:

1. Attributable e.g.
    - cognitive (i.e. difficulty with reasoning or concentration),
    - affective (i.e. edgy, fearful, or uneasy),
2. Observable e.g.
    - behavioural (i.e. avoidance, restlessness, or inhibition), or
    - physiological (i.e. heightened reflexes, increased heart rate, or insomnia).

Combining the data from all the residents reveals an emerging pattern, as shown in Table 6:

Table 6 Behaviours reported compared to the number and percentage of residents

Topic	Beck and Emery (1985) category	Alteration reported	How decided? observable/ attributed	% of sample	Raw data
Sensitivity to light and sound	Behavioural, physiological	increased sensitivity or defensiveness to light or sound	attributed based on attempts to avoid the stimulation	88	8
Vocalisation	behavioural	reduced ability to vocalise	observable	88	8
Eye contact	Behavioural	reduced ability to maintain eye contact	observable	77	7
Gaze direction	behavioural	less able to direct their gaze	observable	77	7
Meaning deafness	Cognitive	reduced understanding of speech	attributed based on apparent lack of understanding of previously understood words	77	7
Tone of voice	Behavioural	monotone tone of voice	observable	77	7
Anxiety	Affective	increased anxiety	attributed based on attempts to avoid the stimulation	66	6

Mood	Affective	lower in mood	? Observable but more likely attributed	66	6
Muscle tone	Physiological	reduced muscle tone	observable	66	6
Speed of processing	Cognitive	slower information processing	attributed based on response time	66	6
Concentration	Cognitive	reduced concentration	? Observable in terms of changing position when concentration ceases but more likely attributed	44	4
Limb eye coordination		reduced coordination	observable	33	3
Orientation and memory	Cognitive	reduced orientation to time place and person and poorer memory	attributed based on apparent lack of understanding / apparent disorientation	33	3
Sense of time passing	cognitive	less accurate sense of time passing	attributed based on surprise at the actual vs. perceived time	33	3
Muscle tone	Physiological	increased muscle tone	observable	22	2
Perception	Cognitive	less accurate perceptual ability	attributed based on apparent lack of understanding	22	2
Self-regulation	Behavioural, cognitive	reduced self-regulation	attributed based on response to environment compared to usual behaviour	22	2
Meaning blindness	Cognitive	demonstrate reduced understanding of the written word	attributed based on apparent lack of understanding of previously understood words	11	1
Perseveration	Behavioural, cognitive	increased perseveration	observable	11	1
Word finding difficulties	Cognitive	increased word finding difficulties	observable	11	1

Key:

Blue background over 2/3 of participants

Green background between 1/3/ and 2/3 of participants

Yellow background less than 1/3 of participants

Table 6 demonstrates the behaviours reported to result from an overly stimulating environment. Two residents (22%) demonstrated increased muscle tone, and six (66%) showed reduced muscle tone. Seven (77%) showed a reduced ability to maintain eye contact. Four (44%) demonstrated reduced concentration. Three (33%) were seen to demonstrate reduced concentration. Eight (88%) were described as showing a reduced ability to vocalise. Two (22%) demonstrated reduced self-regulation (e.g. displaying outbursts). One (11%) exhibited increased perseveration (repeated movements or vocalisations). Three (33%) were described as demonstrating reduced orientation to time, place and person. A further three (33%) were described as having a poorer memory. Six (66%) exhibited increased anxiety. Seven (77%) demonstrated reduced understanding of speech. One (11%) showed a reduced understanding of written text. One (11%) exhibited increased word-finding difficulties. Seven (77%) were described as demonstrating a monotone tone of voice. Six (66%) were described as exhibiting slower information processing. Eight (88%) demonstrated increased sensitivity or defensiveness to light or sound. Three (33%) were described as showing a less accurate sense of time passing. Two (22%) displayed a less accurate perceptual ability. Six (66%) were described as being lower in mood. Seven (77%) were described as being less able to direct their gaze.

4.4 Discussion

Over two thirds of the residents demonstrated sensitivity to light and sound, alterations in vocalisation abilities, eye contact, eye gaze direction control, meaning deafness and tone of voice. Over a third of the residents demonstrated

alterations to anxiety level, mood, muscle tone, information processing and concentration. Under a third demonstrated alterations to limb eye coordination, orientation and memory, perception, and self-regulation. Similarly, under a third demonstrated meaning blindness, perseveration, word-finding difficulties and an altered sense of the passage of time.

The signs of sensory-overload suggested by the interview participant appear very similar to Kishida and Kemp's (2006) definitions of passive non-engagement and passive engagement – i.e. they render the individual fairly passive and unable to participate. To recap, Kishida and Kemp (2006) define passive engagement as interacting with the environment without handling or discussing the material. Kishida and Kemp (2006) describe passive non-engagement as not interacting with the environment and not presenting as anticipated. However, there is a difference in terms of the degree of engagement between passive engagement and passive non-engagement. This difference could relate to their degree of sensory-overload (Rose, 2011); with those who were participating passively appearing less overloaded than those who were passively non-engaged.

4.5 The findings influence on the observations of engagement study?

Table 6 demonstrates the behaviours resulting from sensory-overload. By adding columns for each of the categories of the ICER to table 6, it is possible to cross tabulate these behaviours onto the engagement categories defined by Kishida and Kemp (2006). This cross tabulation reflects the impact on occupational capacity that a symptom might cause to align each sign of sensory-overload with the engagement categories in the ICER. This comparison assisted the transition of the ICER from the original clinical group i.e. individuals with profound and multiple developmental disabilities into the domain of neuropalliative rehabilitation, and is presented in Table 7. Richardson *et al.* (2004) argued that practitioners continuously engaged in this kind of knowledge creation through clinical reasoning, professional judgement, reflective practice and experiential learning. The assumptions and decisions required to do this followed reflection upon whether an individual displaying a particular sign of sensory-overload would be inhibited from active engagement, in what way and how that could appear to the observer in relation to the ICER categories. This reflection following Kolb's experiential learning cycle (1984) drew upon the researcher's clinical experience of individuals with NPC, and upon the sequelae of sensory stimulation across the range of conditions encountered throughout her career. The data collected from the Residence Manager contributed current examples/ experience. Associating the signs of sensory-overload with the categories of engagement following a period of clinical reasoning fell into the practical experimentation part of the reflective cycle.

An expert practitioner uses clinical reasoning to connect concepts (Unsworth 2004). Unsworth's (2004) figure showed the conceptualisations of clinical reasoning, including the constituents of pragmatic reasoning and a therapists values, beliefs, views and ideas about her skills in relation to the person, occupation and environment. Clinical inductive reasoning cross-references experiential learning from one situation with a theoretical model from another e.g. engagement categories from a standardised observation tool with the signs of sensory-overload. Galileo's theory of motion, Faraday's concept of the magnetic field, and Einstein's theory of relativity are examples of creative theory formation, although how theory formation occurs may be problematic (Clement 2009). For example Darwin's theory of natural selection could have been the result of a gradual building up of empirical evidence or of clarity when threatened that a competitor would publish first, which enabled him to link concepts together (Clement 2009). How this new knowledge results is a source of controversy between the

rationalist and empirical traditions (Clement 2009). The rationalist tradition values reasoning based upon experiential learning and prior knowledge. As already mentioned, Unsworth (2004) suggests that occupational therapy is conducted under the influence of the therapist's professional knowledge and experience, ethics, personal motivation, and context, which all influence clinical reasoning. Whereas, the empiricist tradition values observation and repeatability of experimental procedures (Clement 2009) impossible in the real world given the occupational therapy belief that all humans are individuals, and interact with the occupation and the environment (Polatajko *et al.,* 2007).

Table 7 Tabular representation of the linkage between passive engagement/ passive non-engagement and an individual's behaviour when experiencing sensory-overload in tabular form

		Category of the ICER this sign of sensory-overload could present as:				
		Active engagement	**Passive engagement**	**Undifferentiated engagement**	**Non-engagement**	**Active non-engagement**
Level of rational or emotional engagement (Tseng & Ho (2011)/ behavioural alteration could result from signs of sensory-overload such as:	**Increased sensitivity or defensiveness to light or sound**	0	0	1	1	1
	Reduced ability to vocalise	0	1	1	1	0
	Reduced ability to maintain eye contact	0	1	1	1	0
	Less able to direct gaze	0	1	1	1	0
	Reduced understanding of speech	0	1	1	1	0
	Monotone tone of voice	0	1	1	1	0
	Increased anxiety	0	0	1	0	1
	Lower mood	0	0	1	0	0
	Reduced muscle tone	0	0	1	1	0
	Slower information processing	0	0	1	1	0
	Concentration reduced	0	0	1	1	0
	Limb eye coordination reduced	0	0	1	1	0
	Reduced orientation to time place, person and poorer memory	0	0	1	1	0
	Less accurate sense of time passing	0	0	1	0	0
	Increased muscle tone	0	1	1	1	0
	Less accurate perceptual ability	0	1	1	1	0
	Reduced self-regulation	0	1	1	1	1
	Meaning blindness	0	1	1	1	1
	Increased perseveration	0	1	1	1	1
	Increased word-finding difficulties	0	1	1	1	1

Inductive reasoning synthesises findings, within the context of the researcher's professional knowledge and practice experience. It is a progression from particular/ individual instances to wider generalisations. Inductive reasoning requires the

inferring of general principles from facts. Table 7 is the result of just such inductive reasoning resulting from expert clinical reasoning. As such it demonstrates expert practice, by cross referencing the signs of sensory-overload and Kishida and Kemp's engagement categories the researcher is actually relying on clinical reasoning and years of experience which have contributed to a data bank of likely outcomes, similar to computer modelling. The researcher is not claiming that sensory-overload happens for the same reasons in developmental disabilities and NPC, or that the same processes in both types of condition affect that engagement. Rather, table 7 seeks to demonstrate that the signs of sensory-overload and Kishida and Kemp's engagement categories appear to vary together (supporting Rose's (2011) assertion), which could have clinical applications. Consequently, table 7 explores whether this phenomenon is sufficiently credible to inform the observations of engagement presented in chapter five.

As Kinsella & Whiteford (2009) suggested, practice results from evidence based reflective, wise and clinically reasoned practice and human judgement based on experience and context. This occurs in a reality that can be approximated, measured and studied, but never completely understood (Denzin and Lincoln 2000). Furthermore, clinical reasoning may build on patterns, hypothetical-deductive or diagnostic reasoning and narrative reasoning (Could *et al.,* 2008). The patterns allow the practitioner to associate the problems of the moment, with those previously experienced, adopting a precedent-based resolution. An information based hypothesis, allows the practitioner's hypothetical-deductive reasoning, to reflect, generating supplementary hypotheses about how to deal with a problem. The process of inquiry, reflection and management involved in narrative reasoning allows the practitioner insight into both problem and context (Jones and Rivett, 2004). Narrative reasoning demands collaboration between patient and practitioner, and ongoing reasoning about how to proceed (Edwards and Jones, 2007).

4.5.1.Clinical Reasoning underpinning the linkage between passive engagement/ passive non-engagement and an individual's behaviour when experiencing sensory-overload

Clinical reasoning is the thinking that guides clinical practice (Unsworth 2004) and includes collaborative reasoning and empowerment of patient's (Resnik and Jensen 2003). The clinical reasoning cycle (Levett-Jones *et al.,* 2010) considers the patient, new and existing knowledge, to define the problem, plan interventions, evaluate the outcomes, reflect and learn (Hoffman, 2007).

Therefore, the researcher considered the situation of the residents as individuals with NPC. Recent research about sensory gating in NPC, and knowledge about sensory processing suggest that these individuals could be further dis-enabled by inappropriate sensory stimulation. The knowledge around this topic including the demographic information presented in Chapter ONE, shows these individuals to be part of a small but highly dependent population. The average Barthel score of the residents was 7/100, whilst the average Katz score was 1/6. Onlookers may perceive as fatigue (see textbox 1) or shutdown, the effects of inappropriate sensory stimulation. Furthermore, this group appeared passive; sleeping when not stimulated. Sensory processing influences occupational capacity (Bar-Shalita et al, 2008, Lane & Schaaf, 2010, Miller et al., 2007; Pfeiffer et al., 2011). Sensory imbalance reduces cognitive functioning making occupational-engagement more difficult (Howell, 1999;

Easton & MacKenzie, 1988; Geary, 1994). Indeed, Hahn's (2012) and Cascio *et al's.* (2008) literature reviews suggested that sensory stimulation felt exaggerated and invasive when overloaded, overriding all thought processes, resulting in automatic behaviour. Additionally, Williams' (2006) book and Majic *et al's.* (2011) experimental study suggested that slower information processing resulted, with the individual being present but not participating actively, similar to Kishida & Kemp's (2006) definition of passive non-engagement. Pfeiffer et al. (2011) also stressed the link between sensory-overload and engagement behaviours. Furthermore, Olson's (2011) PhD thesis used behavioural observations similar to those presented in chapter five to suggest that the occupational-engagement of individuals with sensory gating deficits was altered by sensory stimulation, to the point of reduced functioning. Olson also noted that individuals in different quadrants of the MoSP respond differently to sensory stimulation. She suggested (like Bundy & Murray, (2002)) that low registration and sensation seeking individuals require more stimulation than most, seeking activities with more sensory attributes (Dunn, 2001).

Therefore the researcher reasoned that sensory-overload, whether temporary (because of a change to the occupation or its context) or longer-term (because of an NPC) may lead to reduced occupational capacity and therefore reduced engagement which may evolve occupational deprivation. This mirrors O'Sullivan and Hocking (2006) and Hearle *et al's.* (2005), suggestions that as individuals do less, they lose capacity making doing more difficult. When doing gets harder, occupations become less rewarding and reducing the individuals motivation to try, so they do less which would appear similar to passive engagement or passive non-engagement. It also reflects Burllau (2007), Whiteford (2000) and Townsend and Wilcock's (2004), suggestion that becoming physically disabled involves a transition from being able, to occupational disruption or dysfunction which could then evolve into occupational deprivation. Furthermore, the risk of sensory inundation following RAS damage, may narrow an individuals occupational choices and experience to casual leisure occupations (heightening the sensory attributes involved), due to a reduced engagement in serious leisure (Stebbins, 2008). Their inability to screen out or process efficiently either normal (or in the case of casual leisure occupations high) sensory attributes could mean that the leisure opportunity, by its very nature is too stimulating for the individual to cope with. Evidence of neurologically disabled individuals doing less came from O'Sullivan and Chard (2010) and MS Society (2009).

Howell (1999) linked the occupation and its context to neurological damage by suggesting that a combination of care environment and health condition (with a damaged RAS), could overload or deprive the individual of sensory stimulation; leading to hallucinations, reduced concentration, anxiety and confusion which could influence the individuals engagement. Thus, making the individual ever more vulnerable to further inundation (Howell, 1999; Meyer *et al.,* 2010). Furthermore, in the context of NPC, individuals who have experienced trauma, have cognitive problems, or exhibit challenging behaviour, may not be aware of their sensory needs or stress responses (Champagne & Stromberg, 2004). This may lead to negative behavioural consequences such as reduced occupational-performance and engagement abilities (Howell, 1999; Easton & MacKenzie, 1988; Geary, 1994).

4.5.2. Demonstrating the linkage between passive engagement/ passive non-engagement and an individual's behaviour when experiencing sensory-overload in tabular form

Lane & Schaaf (2010) suggested that the sensory environment influenced brain functioning, and in turn behaviour. While, Berlyne (1966) suggested that the nervous system needed "just right" stimulation to promote engagement and exploration. Whereas, sensory-overload resulted in a withdrawal from engagement (Wegner & Flisher, 2009; Goldberg, 2012; Edmund & Morris, 2000), because an individual became passive and floppy or it led to challenging behaviour (see 4.6.1 - 4.6.5). Whiteford (2004, 2010) did not delineate between temporary disruption, and long-term preclusion from occupational-engagement in terms of their effects. Neither did she quantify the occupational loss to result in deprivation, disruption, or alienation thus backing up the researchers decision to note binary occurrence contingency but not frequency data in table 7.

The data presented in chapter four (table 6) suggests that the residents could be at risk of sensory-overload, and that this could contribute to an explanation of their mainly passive state. This reinforces experimental research into the effects of sensory gating deficits in conditions such as post-traumatic stress disorder (Ghisolfi *et al.,* 2004), Huntington's Disease (UC *et al.,* 2003), Dementia, Multiple Sclerosis, Parkinson's Disease (McCarley *et al.,* 1997; Morton *et al.,* 1995), and Head Injury (Kumar *et al.,* 2005; Arciniegas *et al.,* 1999).

Processing this information to come to an understanding of the problem involved considering table 6. The signs of sensory-overload suggested by the interview participant appear to render the individual fairly passive and unable to participate, being very similar to Kishida and Kemp's (2006) definitions of passive non-engagement and passive engagement. To recap, Kishida and Kemp (2006) define passive engagement as interacting with the environment without handling or discussing the material. Kishida and Kemp (2006) describe passive non-engagement as not interacting with the environment and not presenting as expected. Therefore a normal distribution in engagement with under or over-stimulation decreasing engagement was anticipated in the data presented in chapter five. There is a difference in terms of the degree of engagement between passive engagement and passive non-engagement, which could link to the degree of sensory-overload. Those engaging passively appearing less overloaded than those who were passively non-engaged. However, a lack of awareness of sensory processing could mean that the effects of inappropriate sensory stimulation was perceived by onlookers as fatigue (see textbox 1) rather than sensory-overload.

Inconsistencies in the data to consider include the different ability levels of the Residence Manager's residents and the observation participants which was beyond the control of the researcher. Other problems with the data include the lack of triangulation data so that consideration focussed on the sensory rather than meaningful context of an occupation. So, given that humans are occupational beings (Wilcock 2006), active occupational-engagement is their natural state. Therefore, passive engagement or non-engagement may be less satisfying or even stressful. O'Sullivan and Hocking (2006) and Hearle *et al.* (2005), suggested that as individuals do less, they lose capacity, making engagement harder and less rewarding leading to reduced perseverance, which could appear similar to passive engagement or even passive non-engagement. Therefore, the researcher hypothesised how significant the impact of the overloaded behaviours would be on occupational performance, suggesting which engagement category the participant might consequently demonstrate.

Cross tabulation is the process of creating a matrix of data to allow comparison of nominal and ordinal data (Thames Valley University, 2008). The categories representing one variable (e.g. definitions of engagement level) are presented in columns, and categories representing another variable (e.g. signs of sensory-overload) are presented in rows. A contingency

table such as table 7 allows the reader to see the proportion of behaviours reported as the signs of sensory-overload when compared with the engagement categories defined by Kishida & Kemp (2006). The ICER categories contain categorical data which allows each category to be ranked. The same would not be possible for the signs of sensory-overload since the positivism and negativity of each sign could be subjective. If one or both variables are nominal, (as in this case) a Cramer's V test could determine the significance of the difference between the proportions, provided that they represented individuals sampled from the population randomly (which these data were not).

Whereas a frequency table displays numbers and percentages for each value of a variable, table 7 does not show exact quantities of variables. Instead table 7 (a binary occurrence contingency table) displays the relationship between one categorical variable and another. It therefore allows the reader to examine a hypothesis that the values of one variable are contingent (dependent) upon those of another. Contingency tables can be used, for purely descriptive purposes, as in this case. For example, it could include several variables thought to measure a belief (California State University, 2011). In binary categories, there are only two variables (in this case present or absent). If the variables measure the same underlying concept, there should be a relationship between them, without one being dependent upon another. Table 7 therefore presents which definitions of engagement the researcher felt that each sign of sensory-overload could represent, and avoids quantifying the association between these two sets of variables. This was done because the researcher was not concerned about the strength of the relationship, merely that there could clinically (rather than statistically) be such an association occurring. This is similar to Darwin's occurrence table about finches on the islands he encountered presented by Bezáková (2008) who suggested that an effective statistical test for binary contingency tables remains elusive. Cross-tabulations can be analysed on two levels; either to determine whether any patterns appear or to test the relationship between the two variables using a chi-square test or a correlation coefficient (Thames Valley University, 2008). Table 7 shows the patterns that emerged.

Under different circumstances, this translation of the ICER for use with participants living with NPC could have involved validating the ICER (or its definitions) for use with individuals with NPC, to use an engagement measure designed for NPC from scratch, or to use a measure of casual leisure satisfaction and engagement that was adapted for use with individuals with a profound level of disability. A group of participants who were able to express their opinions reliably and consistently could have described their engagement. However, a group of individuals with NPC such as this may, have been experiencing sensory-overload to the point of disengagement and if they were, might not have been aware of, in control of, or able to describe it.

4.6 The influence of sensory-overload on engagement

Rose (2011) suggested that sensory-overload may leave the individual in a state of only achieving the bottom rung of Maslow's (1954) hierarchy of needs and reducing their occupational-engagement according to their degree of sensory-overload. This occurs because the individual is incapable of making sense of and associating concepts, rendering them dependent on others and external sensory cues (compounding their sensory experience), without any understanding of their actions or of their repercussions. Consequently they could demonstrate behavioural and emotional outbursts, being unable to break the task into manageable parts and associate between the parts.

4.6.1. Active engagement

As can be seen in table 7, none of the signs of sensory-overload appeared in the active engagement column, because by definition if someone is overloaded their engagement reduces. Kishida & Kemp (2006) define active engagement as appropriate active participation in the occupation involving manipulating materials or vocalising. Prior to undertaking the interview proposed with the Residence Manager the researcher's expectation was that this might be demonstrated by residents:

Attention
Accepting/ using props e.g. playing instrument
Eye contact
Joining in
Laughing in response/ seeming to be enjoying it/ clapping/ smiling/ grinning
Looking animated
Nodding in time or response to activity
Responding to speech from others
Singing appropriately
Spontaneous action/ speech (appropriate with audience or performer)
Eye tracking
Use of initiative/ problem solving/ overcoming challenge
Using tools

4.6.2. Passive engagement

Kishida & Kemp (2006) define passive engagement as interacting with the environment without manipulation or vocalisation. The signs of passive engagement demonstrated include many of the signs of sensory-overload, the difference with active engagement being the resulting level of physical ability (Rose, 2011). Therefore it is important to understand the normal resting behaviour of the individual against the individual's limitations. For this reason, it is valid to combine the passive and potentially active engagement statistics when reporting on the engagement level of individuals with NPC. Prior to undertaking the interview proposed with the Residence Manager the researcher's expectation was that this might be demonstrated by residents:

Watching/ attention
Eye contact/ tracking
Head pointing to listen
Looking animated
Nodding in response to activity
Responding appropriately to speech / audience/ as prompted by the performer
Smiling

Passive engagement could be the result of elements of sensory-overload such as reductions in: ability to vocalise, maintain eye contact, direct gaze, and understanding of speech. Furthermore, many of the residents exhibited a more monotone tone of voice, altered muscle tone, less accurate perceptual ability, reduced self-regulation, meaning blindness, increased perseveration and increased word-finding difficulties. Arguably, a reduced ability to vocalise could present as passive engagement because Kishida and Kemp (2006) defined it as interacting with the environment without handling or discussing the materials, resulting because their sensory-overload rendered them silent when spoken to; or when those about them are singing or laughing but the expectation is to join in, despite demonstrating attention (Clare *et al.,* 2012). Equally, a reduced ability to maintain eye contact could have influenced the resident's ability to demonstrate active engagement because eye gaze was an important non-verbal cue to interest especially for individuals with communication impairments (Tortora, 2011). Such residents could demonstrate mild engagement or toleration rather than active engagement, influencing the choices offered. Similarly, being less able to direct gaze could have influenced the individual's ability to demonstrate active engagement because eye gaze was an important non-verbal cue to interest and to communication especially for individuals with communication impairments (Tortora, 2011) thus in turn demonstrating mild engagement or toleration rather than active engagement, thus influencing the choices offered. Reduced understanding of speech and sounds could have left the individual without comprehension of what was going on around them, after a while the individual could appear to be present without participating (Williams, 2006). This could have influenced an individual's engagement through supporters making assumptions that the activity was not of their preference, thus reducing their choices as each occupation leads to the same reaction. Additionally, having a more monotone tone of voice could present as passive engagement by appearing bored, less animated, unemotional and therefore disinterested. Equally, altered muscle tone could present as passive engagement because the individual could be unable to grasp the objects and withdrew, therefore appearing passive, whilst displaying attention and interest. Likewise, a less accurate perceptual ability could reduce their understanding of how to participate, appearing physically passive, while maintaining their attention. Similarly, reduced self-regulation could present as passive engagement because Kishida and Kemp (2006) defined passive engagement involving interaction with the environment without handling or discussing the materials. Instead, exhibiting automatic behaviours such as mannerisms (Richler *et al.,* 2007), absently overeating comfort food (Tantam 2011) to maintain coherence and keep agitation in check (Caldwell & Horwood, 2008), making them appear distracted and present in body, but not attending. Meaning blindness could present as passive engagement, because all their effort goes into information processing and understanding themes and trends such as safety and fight and flight rather than fine detail (Williams, 2006), influencing engagement through not understanding what their role is. Equally, increased perseveration could give the impression of being present but distracted. Furthermore, individuals with brain injury experience word finding difficulties (Candeloro 2010), which could present as passive engagement by reducing their ability to discuss the occupation, being monosyllabic, speaking less or not at all.

4.6.3. Undifferentiated engagement

Undifferentiated engagement is defined by Kishida & Kemp (2006) as interacting with the environment in an automatic or repetitive manner (McWilliam & de Kruif, 1998). This group of behaviours include symptomatic behaviours which are outside the control of the individual. Prior to undertaking the interview, the researcher's expectation was that this might be demonstrated by residents:

Jumping or kicking feet/ chorea form movements/ clonus/ extensor thrust as a startle reflex

Perseverating actions or speech

Bruxism

The researcher felt that because undifferentiated engagement involves interacting with the environment automatically, all the signs of sensory-overload could occur. Arguably, increased sensitivity or defensiveness to light or sound could present as undifferentiated engagement. Distractibility, poor pattern recognition or abandoning an occupation could also result from an inability to understand an occupation which is too much for them (Rose 2011). Furthermore, engagement could have been reduced because they were unable to avoid, or gate sensory stimulation, becoming inundated to the point that they could only respond automatically. Perseveration is the repetition of a particular response such as asking the same question or making rhythmic movements, humming and grunting (Stewart *et al.,* 2009), which could influence engagement by distracting others, or taking over from verbal communication, which may become untenable (Pillay & Suniti Bhat, 2012). For example, in Parkinson's disease, there is evidence of immediate reward seeking behaviour and/or stereotyped behaviour as well as impulse control disorders such as compulsive internet use, skin picking, gambling, binge eating (Bosboom *et al.,* 2004). Furthermore, undifferentiated engagement could present as hyper-sexuality, or apparent apathy (Bosboom *et al.,* 2004) resulting from a lack of modulation of behaviours (Wolters *et al.,* 2008). Equally, a lack of eye contact could be an automatic way to stave off over-stimulation (Bellando & Pulliam, 2009), which could feel aggressive or threatening to the overloaded individual. Avoiding eye contact could however, reduce the ability of the individual to engage in a social context, giving the appearance of resentment, boredom or disapproval (McKay *et al.,* 2009). Being less able to direct gaze could have influenced an individual's engagement because through altering where and upon what they could focus could blur the objects, or faces being viewed, or an eye gaze controlled computer may function less effectively. Reduced understanding of speech or sounds could leave the individual disorientated, more liable to overload or unable to discriminate speech from background noise, thus appearing to lack mental capacity, or as being awkward (Williams, 2005). Similarly, having a monotone tone of voice perhaps without facial expression, making emotion detection difficult (AllPsychologyCareers, 2010), could lead to the assumption that the individual was bored or disinterested, limiting future choices offered. They could appear hard to build a rapport with, making others less willing to keep trying to engage them in future. Equally, having slower information processing could have influenced engagement by stimulating reactive, rather than thoughtful, planned responses. Rose (2011) suggested that "An individual in sensory-overload could experience anxiety, developing an aversion to similar occupations". Increased anxiety could have influenced engagement because the individual becomes engaged in repetitive hand flapping which stops him using his hands to participate in the occupation or using the same repetitive actions and words whilst playing with objects (Chen et al, 2009). Anxiety or lowered mood during an occupation could be interpreted by supporters as active dislike, wishing to be elsewhere, or doing something different, leading to removal and not being offered this choice as a consequence (Rose, 2011). Additionally, distractibility and poor concentration could have resulted from the increased energy expenditure resulting from sensory-overload, consequently reducing performance when the individual became tired, had a shorter activity tolerance or had been concentrating for too long (Rose 2011). Equally, reduced orientation to time place, person and poorer memory could have influenced engagement because they appeared disorientated, or not understanding others expectations. Furthermore, a less accurate sense of time passing could have influenced engagement because the occupation appeared to go on forever, and therefore appeared boring, or to be passing more quickly so that the individual felt time pressured.

Altered muscle tone and the resultant loss of coordination and movement could also have influenced engagement because they appeared clumsier or not trying to participate. As could a less accurate perceptual ability, leading to a repeated failure to participate, based on their lack of understanding of how to participate and use objects. Also, reduced self-regulation could influence perceptions of an individual's engagement, distracting others, because of bruxism or stuttering (Allen & Polaha, 2006), repetitive use of objects (such as banging, humming), hand and finger mannerisms (Richler *et al.,* 2007), hyper-sexuality, repeatedly disassembling objects, overeating comfort food, and emotional detachment (Tantam 2011) to calm themselves (Caldwell & Horwood, 2008). Furthermore, meaning blindness could have influenced the individual's engagement, distracting others because their perseverative actions (Richler *et al.,* 2007) could be the only thing that they can do, with the repeated stimulation becoming familiar and therefore comforting in a fragmented and confusing world (Williams, 2006). This could have influenced the individual with Parkinson's disease's engagement because compulsive behaviours (Bosboom *et al.,* 2004) could result from a lack of modulation of behaviours in the basal ganglia (Wolters *et al.,* 2008) could interrupt or over take the actions required to participate. Equally, whilst word finding difficulties are experienced by individuals with brain injury (Candeloro 2010); increased word-finding difficulties could have exacerbated the individual's communication difficulties still further or could have interrupted social interaction through making communication disjointed (Candeloro 2010).

4.6.4. Passive non-engagement

During non-engagement an individual may be present but is isolated or neutral and not part of, participating in or involved in the occupation. Kishida & Kemp (2006) split non-engagement into active and passive categories. They defined passive non-engagement as not interacting with the environment or responding as anticipated during the activity. Prior to undertaking the interview the researcher's expectation was that this might be demonstrated by residents:

Eyes not tracking

Responded to touch only

Self-stimulation/ rocking/ fidgety/ foetal position/ humming to self

Yawning

Head down/ holding head/ eyes open/ staring straight ahead/ away

Staring at the ceiling/ no obvious engagement/? Asleep/ snoozing? / not tracking

Startled/ puzzled

requiring stimulation to arouse attention

Looking around at distraction

Embedded occupational involvement

Because some individuals with NPC do not interact with their environment in a demonstrable/ observable way in a group situation, the passive non-engagement category also included the behaviour of these apparently non-interactive individuals. An example would be individuals who were physically present during an occupation but were doing something else e.g. reading a magazine, or fidgeting (Richler *et al.,* 2007), overeating comfort food, (Tantam 2011). This is an active choice on their part, but is not disruptive or demonstrating inappropriate behaviour. It is therefore difficult to locate this behaviour in Kishida and Kemp's (2006) observation format. One could argue that they are actively but not disruptively non-engaged, whilst being loyal to their fellow residents by attending. In the context of occupational science this would be

described as an embedded occupation (Bateson 1996) and as such they are not interacting with the occupation being observed, and so for the purpose of this study should be categorised as passive non-engagement.

Arguably, a reduced ability to vocalise could have reduced engagement because reduced communication may have resulted in inappropriate assumptions about preferences or mental capacity (Clare *et al.,* 2012) and therefore the choices offered. Equally, the avoidance of or difficulty with maintaining eye contact, directing eye gaze, or peripheral perception (Bogdashina, 2003) may distort understanding, influencing engagement and giving inaccurate non-verbal cues (Tortora, 2011), suggesting boredom or lack of interest, may influence the choices offered by supporters. Additionally focussing elsewhere could alter what the individual is able to attend to, drawing them away from the occupation. Also, a reduced understanding of speech or sounds could reduce understanding per se, giving the impression of being disinterested, bored or awkward (Williams, 2005), disorientated, dissenting or distressed. Furthermore, altered muscle tone could reduce coordination and movement and thus manipulation, appearing awkward on purpose and because it is not their usual behaviour. Reduced orientation to time, place, person and poorer memory, or slower information processing or concentration could appear as passive non-engaged due to reduced understanding and lead to withdrawal from the occupation. Similarly, a reduction in limb eye coordination could make individual's appear unwilling or unable to "behave", the task being too challenging or complex and requiring adaptation. Equally, less accurate perceptual ability could reduce their understanding of acceptable behaviour, object use or how to participate to the point where they become passive. Also, having a monotone tone of voice could be perceived as demonstrating negativity, boredom and lack of interest influencing how supporters perceive the individual's engagement and their preferences for and limitations to future choices (Richmond and McCroskey, 2004). Reduced self-regulation could present as being present but appearing more interested in something else such as self-stimulation, repetitive use of objects, fidgeting (Richler *et al.,* 2007), overeating comfort food, (Tantam 2011). Furthermore, meaning blindness and increased perseveration could present as over focussing on something that they can understand or being more interested in the repetition of the repeated word(s), noise or gesture than the activity. Equally, increased word-finding difficulties could detract from interaction with those about them, making the individual appear disinterested or distracted.

4.6.5. Active non-engagement

Kishida & Kemp (2006) defined active non-engagement as interacting with the environment in an inappropriate manner by manipulation/movement and/or vocalisation. Prior to undertaking the interview proposed with the Residence Manager the researcher's expectation was that this might be demonstrated by residents:

Challenging/ disruptive/ attention seeking behaviour
Grumpy/ cross/ irritated/ negative mood
Agitated
Causing disruption to other residents

In the pilot stage of the observation study, observers had perceived active non-engagement as an attempt to "sabotage" the performance for other residents, and presenting in a similar manner to challenging behaviour. In particular, this category could have included signs of sensory-overload such as reduced self-regulation, meaning blindness, increased

perseveration, increased word-finding difficulties, increased sensitivity or defensiveness to light or sound, or increased anxiety. Brod *et al.*'s model (2000) suggests that the social and physical environment of people with cognitive deficits influences their behaviour strongly. Problematic behaviours could be indicative of distress and include aggression, perseverative movement or noisemaking, among other behaviours. Rose (2011) suggested that sensory-overload caused intense discomfort forcing the individual to seek relief through a release valve, such as hyperactivity and emotional outbursts. Therefore arguably, increased sensitivity or defensiveness to light or sound could present as active non-engagement, e.g. a tantrum in a noisy, smelly, crowded over stimulating environment (Miller, 2010). Equally, reduced self-regulation such as vocal disinhibition, hyper-sexuality, repeatedly disassembling, or smashing objects, (Tantam, 2011), could distract others and prevent the individual from engaging in the case.

Furthermore, meaning blindness could present as active non-engagement because behaviours such as aggressive outbursts, self-harming, destruction of property; or oppositional, socially inappropriate or prejudicial behaviour could result from the frustration of too much going on around the individual, which they do not understand. Equally, increased perseveration could result in challenging behaviour such as loud outbursts, self-harming, crashing and trashing of objects; or oppositional, socially inappropriate or prejudicial behaviour. This could prevent the individual's engagement (and that of those about them) by taking their attention away from the overloading activity, while giving the individual an opportunity to gain attention, avoid demands, increase sensory feedback, gain control over their own body, activities or life, calm themselves by reducing their arousal and anxiety (Centre for Developmental Disability Health, 2005). Furthermore, word finding difficulties could increase (Candeloro 2010) during sensory-overload and leading to frustrated outbursts and inappropriate social behaviour, self-harming, or destructiveness which could prevent the individual's engagement (and that of those about them) by capturing their attention. Arguably, each of these behaviours could present in combination as challenging behaviour or as active non-engagement.

Breaking down Kishida & Kemp's (2006) definitions of engagement through the signs of sensory-overload may be counterproductive, since each sign would appear to negatively and globally influence engagement. However arguably, the greater the sensory-overload, the greater the impact on engagement. Therefore, table 7 demonstrates the effects of sensory-overload mentioned in 4.6.1 - 4.6.5. Both at an individual behavioural level (demonstrated in the rows of table 7), and at a more global level (demonstrated in the columns in table 7).

4.7 Data validity and credibility

Leisure or occupational science research throws up difficulties with validity (reflecting the phenomenon studied), because research is concerned with the behaviour of human beings and their attitudes, which are so complex. One such experiential social science concept is the question of what engagement is, and why it occurs (Edexcel, 2011). Methods of data collection designed to capture experience are prone to imperfections, producing data that is less reliable than data collected in areas which are more open to experimentation.

In the case of this study, the validation of the findings included checking that the data reflected the Residence Manager's recollection of the interview. Validations of the findings also occurred at research or audit seminars and ward

feedback sessions presented for staff. Reflecting on the lives of such profoundly disabled individuals, by visiting the organisation studied, or by viewing video clips broadcast by the BBC, on the home's website, or by watching the film "*The Diving Bell and the Butterfly*", based on the 1998 book by Bauby (McCammon, 2008) may reinforce the plausibility of the findings.

Because there was no suitable measure of occupational-engagement specifically for use with adults with NPC, the ICER was used because it was simple and well defined, but was not ideal. The ideal situation would have been to create and validate a measure of occupational-engagement designed specifically for use with a population of adults living with NPC, before conducting the study. To do this it would be necessary to develop or locate a validated measure of severity of impact of sensory-overload on individuals with NPC, although there could also be a use for such a measure in the field of developmental disability. Table 7 was an attempt towards this by merging two sets of variables into a new (more focussed) tool for use only during the study presented in chapter five.

4.7.1. To validate Table 7 for use in the future

To validate any new tool a clear vision of what the expectations of it were and an appropriate methodology for merging the data before finally conducting a correlation analysis to establish the validity of the new tool would be necessary. This would provide an assurance that the tool produced valid, reliable and repeatable results, even if using a different technique to reach the same result. Such a validation could validate the new tool as it is developed, or validate it after development. Dunn (1997, p 56) faced a similar dilemma and proposed a series of studies to identify the nature of the items on her sensory profile. She compared their frequency, within different populations and conducting factor analyses to examine patterns of performance. On the basis that many heads are better than one, the first step in the validation process for the data presented here would be to suggest and hone a tool such as Table 7 with several other individuals during either a brainstorming session (Wang *et al.,* 2010) or using the Delphi technique (Hasson & Keeney, 2011) followed by an options appraisal (Cox, 2011). The second step in the validation process could be to design the validation methodology, and validation verification process (Kane, 2013). Having undertaken the methodology and confirmed that the outcomes have met the acceptance criteria the results should be published, including the validation process, so that it could be repeated, reviewed and updated.

Having developed or located a measure of severity of impact of sensory-overload, data collectors should be trained to criterion to collect data about engagement with occupations designed using a matrix (of sensory attributes), to offer the full range and combination of sensory attributes. To avoid extraneous environmental stimulation, these tests should be conducted in video recorded laboratory conditions. Using both the ICER and the measure of severity of sensory-overload, it could ensure the comparability of each engagement category and each manifestation of sensory-overload across the tests. This depends on cross-tabulating the anticipated influence of each sign of sensory-overload with each engagement category.

It would then be necessary to compare the cross-tabulated influence of each sign of sensory-overload statistically, to provide the foundation for a measure of sensory influenced occupational-engagement. Had Table 7 not been a binary contingency table, statistical methods could have validated the results e.g. a chi square analysis of the raw frequency data vs. the engagement category anticipated. Such an analysis could include raw categorical or summarised data. Table 7 includes

summarised data, since the two variables were categorical. If presenting frequency data, the signs of sensory-overload in the binary contingency data could have suggested the degree to which engagement could alter. However, a chi square analysis is not a suitable test to use in this instance. To validate Table 7 statistically, if such a comparison were repeated, frequency data could be collected and subjected to a chi square analysis. This would require clinical judgement about the level of influence on engagement. Using a large group of blinded and appropriate individuals with a theoretical understanding and practical experience of sensory-overload to cross tabulate the two sets of data in isolation, could have been more effective. Additionally higher level expert opinion could be gained by asking the authors of sensory based OT intervention models, measures and research to cross tabulate to two sets of data. This could eventually lead to a validated measure for use with individuals who are influenced most by the sensory environment e.g. those with developmental disabilities, dementia, neurological disabilities, mental health problems, etc. Options appraisals conducted to assist in determining which option to select (Cox, 2011), could evaluate the suitability, acceptability and feasibility of the options for validation (Johnson *et al.,* 2005) as well as ranking them (Cox and Rawlinson, 2009). Johnson et al (2005) suggested three aspects to the evaluation of such a measure– suitability, acceptability and feasibility. Table 8 presents a ranking table, incorporating the use of the suitability, acceptability and feasibility of the tool.

Table 8 Options appraisal based on the key factors the validation could be aligned to

options	suitability	feasibility	acceptability	Ranking
Option 1 - repeat the interview with several Residence Managers and using frequency data conduct a chi square analysis.	**Y-** This would be more suitable than the current data collection because it would gather opinions from several people.	**? -** The feasibility of this could be problematic because it would still require a degree of familiarisation with the concept of sensory-overload before hand. Furthermore, involving more Residence Managers was not the DCS preferred option	**Y/?-** This would me a more acceptable methodology since it would be suitable for statistical analysis, but less acceptable in terms of service disruption if carried out at the same home.	Low/ Medium - consider using, revising or abandoning
Option 2 - using a large group of blinded individuals with a theoretical understanding and practical experience of sensory-overload to cross tabulate the 2 sets of data in	**Y -** This would be possible with the current data, if a call for volunteers appeared in OTNews, Inspire or the journals of appropriate special interest groups of the COT.	**Y -** This would be feasible with the current data, or if option 1 were undertaken, this option would be possible using the new data.	**Y -** less biased raters i.e. blinded to the hypothesis. Calling for volunteers would not put any OTs under pressure to participate although it runs the risk (as the researcher has previously experienced) of getting no respondents.	High - adopt

isolation.				
Option 3 - using higher-level expert opinion to cross tabulate to two sets of data.	**Y -** This would be possible with the current or with new data.	**? -** It would require the tracking down of suitable experts (perhaps based on the authors or articles discovered in a literature review.	**Y -** Methodologically, this would be even more sound than option 2; however, whether the experts would be prepared to participate could be more uncertain.	Medium - consider using
Y, fits with key factors; N, does not fit with key factors; ?, uncertain/irrelevant				

Cox (2011) proposed the tool for ranking options. Having carried out the option appraisal and evaluation, -Option 2 (using a large group of blinded individuals with a theoretical understanding and practical experience of sensory-overload to cross tabulate the data (either the current or new data) in isolation was chosen. Arguably, this could also validate the data in table 7 retrospectively. A call for volunteers could be placed in an appropriate journal, or a group of local staff, who work with sensory-overload on a daily basis could be approached. Blinded raters should be less biased towards the hypothesis. Calling for volunteers would not put any Occupational Therapists under pressure to participate although it runs the risk of getting no volunteers. To further validate the reliability of the signs of sensory-overload listed in table 7 an additional study could involve factor analysis of each of the signs comparing the likelihood of each occurring across a range of different populations (age, diagnoses) using factor analysis procedures similar to Dunn & Brown (1997).

4.8 Reliability and transparency of the data to inform the study of engagement

Reliability is how replicable the results are, if repeated to re-examine the findings, either at another time or with a different sample of individuals. This is seldom possible in the social sciences, which deal with human beings in differing and ever-changing social contexts. Changes over time, to behaviour, to the constituents of the group, or to the built or social environments could all produce different results. Therefore social scientists, including the researcher of leisure or occupational science, must be very careful about attempting to generalise their findings, since they can only relate to the individuals involved, at the time and place that the research occurred. That said, the approval process undergone prior to data collection increased the trustworthiness of the study. Additionally, the methodology and findings would be transferable to other settings or to another clinical group, since they have been made explicit in this thesis and published (including the data collection tools) in peer-reviewed journals. The data's repeatability is more problematic, because of the specialised nature of the host organisation and its residents; this transferability will therefore depend on the imagination of the reader. The study could be transferable and repeatable, but it could not be generalisable. Presentation media for the results of this study have included the internet, verbal presentation to the participant, the residents and their carers, presentations at international conferences, articles in peer-reviewed publications and organisational reports, all of which have refined the information presented.

4.9 Summary

Over two thirds of the residents presented by the participant were described as demonstrating sensitivity to light and sound, alterations in vocalisation abilities, reduced eye contact, reduced ability to control eye gaze direction, meaning deafness, and changes to their tone of voice. Over a third of the residents demonstrated alterations to anxiety level, mood, muscle tone, information processing and concentration. Under a third demonstrated alterations to limb eye coordination, orientation and memory, perception of the world about them and self-regulation, meaning blindness, perseveration, word-finding difficulties and an altered sense of the passing of time. The residents could be experiencing sensory-overload which not only exacerbates their level of disability (making them fairly passive and unable to participate), but could lead to fatigue and depression, sleep difficulties, headaches, tense muscles, decreased memory and ability to concentrate (Heller, 2002).

Chapter FIVE

Observational study of engagement in leisure occupations

5.1 Introduction

Chapter Five presents a description of the case methodology used. The data collection tool (the ICER) is discussed including its first published use with adult neuropalliative participants. The cases (and their sensory attributes experienced during the casual leisure occupations) are described, and also how the data will be analysed. This chapter presents the data produced about residents as a group (not as individuals), as well as an occupational analysis of each case-based on the Hersch *et al.* (2005) format (see appendix xi). It demonstrates how engagement alters with different levels of sensory attributes. This involved a comparison of engagement between the passive and the potentially physically active occupations, a comparison of supporter-to-participant ratios with engagement, the reliability of the time-sampled observation data and the validity, credibility, reliability and transparency of the results.

5.2 Method

A) Approval from the University of Roehampton School of Human and Life Sciences Ethics Committee and DCS was received prior to the study data collection (Appendices x and xi). Potential participants were approached and consent to participate was sought using procedures described in 5.2.3.

B) The ICER was piloted with three staff who would not be part of the study (see 5.2.3), prior to its commencement. The data collection format was piloted, to determined the appropriateness of the measure for use with individuals with NPC, because it is difficult to define engagement behaviours (Kemp *et al.,* 2012) and, therefore, judgments about whether the individual is engaged relies on the perception of an observer. These judgements were enhanced in this case by the knowledge gained from conducting the preliminary study, and from the ICER definitions of engagement.

The staff involved in the pilot included the researcher, and two Leisure Service staff who were experienced in supporting leisure engagement among individuals with NPC. (These staff did not pilot the behaviour questionnaire presented in chapter four). The three staff members read Kishida and Kemp's (2006) article, participated in the ICER training package and then observed the residents' engagement in a single occupation using a signal contingent methodology to ensure that the same behaviour was observed at the same time intervals. Following this, the data underwent inter-rater reliability tests. Generally, a Cohen's kappa coefficient reliability score of above 0.60 (Casey, 2004) or of 0.70 (De Wit et al., 2007) is indicative of consistency of results between observers. The pilot demonstrated a high level of agreement (k=0.94) about the engagement coded. The reliability test achieved a significance level of p<0.05. Therefore the researcher decided that the information offered by the preliminary study (chapter four) and the definitions of engagement offered by Kishida and Kemp (2006) were informative and clear enough to guide the coding of the behaviours witnessed, and usable with individuals with

NPC. Consequently, the only alteration to the ICER was the addition of information generated in chapter four about what behaviours could result from overload.

The variations in engagement categories came from a resident who was being "disruptive" during the performance, which one observer scored as undifferentiated engagement and the other observers scored this as active non-engagement. This difficulty with the undifferentiated engagement code was vindicated when Kishida *et al.*'s (2008) findings suggested that undifferentiated engagement was a difficult behaviour to code at a specific moment in time, because coding it required contextual information. Kishida et al., therefore eliminated the undifferentiated engagement code from the ICER-R.

C) Gaining informed consent from the participants involved 3 stages, guardian consent, understanding of the project, and in situ consent.

1. Consent from each resident's guardian was collected in accordance with the Mental Capacity Act (2005) and the home's policy on obtaining consent (see Appendix xiv). The appointed person took a decision based on an understanding of the individual's preferences, rather than making decisions in their 'best interests' (Bach & Kerzner, 2010; Amnesty International, 2012).
2. The participant's capacity to consent could fluctuate over time and between situations. Therefore, supported decision-making prepared residents, allowing extra thinking time, explaining with a family member/carer present to discuss it later, and using simple language, whilst keeping the procedure equivalent for all participants (see Appendix xiv).
3. In situ and at the beginning of each case, a supporter and a witness asked each participant whether they were happy to be observed, recording the individual's responses onto a consent form (see Appendix xiv). A copy of each consent form and the information sheet about the study was kept by the participant, and placed in their medical notes. Furthermore, supporters made ongoing enquiries about continued consent, taking consideration of indicators such as engagement and verbal or nonverbal responses.

D) Data was collected by a single marginal-participant observer, who made signal contingent observations of engagement every five minutes for the duration of the forty-five-minute case, with field notes being taken in between times. The methodology included multiple cases replicated (with different sensory attributes) eight times. The observer sat (as still and unobtrusive as possible) where she could see the participants rather than the occupation. Coding the observations relied upon the findings of the earlier study (see Chapter Four), to inform Kishida and Kemp's (2006) definitions of engagement (see section 4.5). A vibrating (but silent) alarm clock indicated the time of each observation. When the alarm signalled, the observer coded each participant's behaviour in turn, making field notes in case there was a need for further contextual information during the data analysis. The number of sensory attributes in each case was not pre-specified, but was determined as part of the occupational analysis completed by the researcher about each case retrospectively (see appendix xi).

The observations were made in accordance with the home's philosophy of non-intrusion and safeguarding, which limited the number of observers, and precluded the use of video recording for research. All the cases apart from the control condition appeared on a menu of leisure opportunities advertised from the beginning of the preceding month. Having

requested to attend, transport and an escort was arranged to ensure that the resident arrived in the right location and at the right time.

5.2.1 The participants as a group

Mackenzie (2011) and Hersch et al (2005) suggested that an occupational analysis should include a description of the participant(s), and the occupation. Such a systemic analysis dissects an occupation and its biopsychosocial attributes (Harris, 2004), evaluating them in relation to the participant (Duncan, 2009). Therefore, the following paragraph presents an occupational-performance capacity analysis of the participants as a group, while sections 5.2.4.2.1. to 5.2.4.2.8, include an occupational analysis of each of the cases. Therefore the cases and the participants have been presented in a systematic manner (based upon Hersch et al's (2005) format for occupational analysis). Because sections 5.2.4.2.1. to 5.2.4.2.8 includes occupational analyses, the occupational-performance capacity analysis of the participants as a group has been placed separately here to avoid the repetition anticipated by including it with the occupational analysis of each case; and because the residents capacity for occupational-performance is so limited.

This section describes the participants through an analysis of their occupational-performance capacity as a group. The participants (n=14) were not undergoing rehabilitation, but all had profoundly disabling NPC, and were described by their Residence Manager as being able to respond to questions consistently. All gave their consent to participate in the study at the beginning of each case. They were aged between 22 and 74; five were men and nine were women. Five of the participants had brain injury/damage, four had Huntington's Disease, one had Multiple Sclerosis, two had Friedreich's Ataxia, one had Athetoid Cerebral Palsy and one had Autosomal Dominant Cerebellar Degeneration. The average mRS score of the study participants was 6, their average BI score was 7/100, and their average Katz score was 1 out of 6, all of which were lower that than Gupta *et al.'s* (2004) description of severe disability.

Presenting an occupational-performance capacity analysis of the participants describes their capacity to cope with the demands of the cases. This may enable those readers who are unfamiliar with the Barthel Index, Katz Scale, Modified Rankin Scale, Glasgow Outcome Scale and the Clinical Dementia Rating Scales to understand their profound level of disability. Hersch et al (2005) suggested that occupational-performance capacity could be listed in areas of occupation such as ADL**,** instrumental ADL (IADL)**,** undertaking education, work/productivity, play/leisure and social participation. Their ADL such as bathing, showering, bowel and bladder management, dressing, eating, personal hygiene and grooming, and sleep/rest all enable, prepare for and facilitate the resident's engagement in leisure occupations. They are occupations for which the participants required support from staff. The care staff made every effort to support the residents in their maintenance of relationships and roles with friends, pets and family. However, the residents' high dependency levels meant that they did not usually engage in the physical care of others, apart from the non-disturbance of other residents. Financial management, affording transport costs, acquiring a swimming costume, materials, entry tickets or equipment, was usually the responsibility of the residents' carers. However, none of the cases involved any financial commitment on behalf of the residents, which could have skewed the participants towards those with less financial resources available. To have energy left for meaningful and purposeful leisure occupations, care staff carried out all health management and maintenance for the residents. The home provided necessary items such as food and furniture; therefore, shopping and home management could become leisure

occupations. The home also encouraged residents to personalise and “own” their own room, while meal preparation and tidying up were left to staff. Learning participation or interests were a formal or informal process involving learning about themselves and others or about the topic and was reliant on the occupation, communication and cognitive abilities. Overall, individuals with such high dependency needs tend to engage in productive occupations such as arts and crafts as leisure occupations, since paid employment opportunities are not available to them. Enjoyment, diversion, and the topic of the occupation may influence their interest (encouraging the participant to pursue the interest further), performance, and subsequently adjustment to their disability, whilst also being enjoyable in the short term. Most of the cases (apart from the isolated listening and the Aquability session) were group events, offering topics for discussion with supporters during and after the event. Therefore the participant's occupational-performance capacity is very limited.

5.2.2 Recruitment

5.2.2.1 The sample size

The sample size (n=14) reflects the number of data points required, the resources available, a target variance or target statistical power to make the results meaningful, valid and reliable, or convenience and availability. Calculating this is important for a study aiming to make population wide inferences from a representative sample. The residents of the home offered a larger than necessary convenience sample, but the eligibility criteria and consent giving process reduced the number of participants. Larger sample sizes might lead to increased generalisability, but there comes a point beyond which any increase in accuracy gained through using a larger sample size is not cost or effort effective (Robson, 2002). To test the difference in median engagement categories across the occupations, a sample size of at least ten participants per case was required to provide an analysis of variance with a power of 0.80. This assumes a moderate effect size, or statistical and clinical difference between the groups compared (Cohen, 1988). However, caution is required when using statistical analysis in clinical settings, since what is statistically significant, might not be clinically significant.

5.2.2.2 The effect size

Cohen's d was used to estimate the size of sample likely to produce accurate, reliable and statistically significant results for this thesis. A moderate effect size was required because a low effect size might not be clinically significant. Without effect size calculations too much data could be collected, wasting the researcher's time and resources; or insufficient data could lead to unreliable results. Cohen (1988) suggested that calculating the effect size was unnecessary unless using entirely novel variables, such as the very small population of individuals in the UK with such profound and complex levels of disability.

The participants were part of a larger group of residents who regularly attended all of the cases. Guardian and in situ consent were obtained in relation to residents engaged in these occupations (see section 5.2.3); to enable data collection. All residents were free to choose which leisure occupations they engaged in; therefore, the cases observed had some common and some unique members (see 5.2.2). Locating a core group was possible, therefore the data presented here refers to fourteen core group members who attended each case and consented to the observations each time. Usually the leisure groups included more residents; so it was possible to identify a core group of the same fourteen participants undertaking all seven occupations and the control condition, to give a valid comparison between leisure occupations. When the data was

analysed some non-core participant data was excluded, because these additional residents had attended some but not all the occupations and the control condition, or had withdrawn from the case before the end of the forty-five-minute observation period, or had not consented to participate. In recruiting participants, the following inclusion / exclusion criteria were considered:

- Inclusion criteria

  Residents whose guardians had given consent to participate in the study

  Residents who consented to participate in situ

  Residents who were able to participate in all the chosen occupations and the control condition, for 45 minutes.

- Exclusion criteria

  Non core residents who attended some but not all the occupations including the control condition

  Residents whose guardians had not given consent to participate in the study

  Residents who were unwell or under the age of 18

  Residents who withdrew from the case before the end of the forty-five-minute observation period

  Residents who did not consent to participate in the study in situ

5.2.3 The Individual Child Engagement Record (ICER)

In 2006, Kishida and Kemp (2006, 2006a) were the only researcher's using the ICER other than the researcher. However, after the data collection for this thesis, Kemp et al (2012) used the ICER (see appendix v) to study the engagement of 37 children with disabilities; comparing the results from 3 different cases (self-determined play, routine, and group activities). Their methodology although similar in comparing engagement in different situations, involved the collection of observation data by two observers (reinforced by the use of video). Consequently, the gathering of two sets of engagement and interaction data occurred for a ten minute period for all three activities. An inter-rater reliability analysis compared the data collected by two observers, this reinforced the validity of the ICER by suggesting an inter-rater reliability of k=0.77, p <.001. Consequently, they suggested that self-determined play was more engaging than routine and organised group activities. They reported a significant influence on active, and passive engagement, caused by the type of activity experienced with participants being more engaged in self-determined play and routine activities than group activities, suggesting that passive engagement was more commonly observed during group activities. Kemp et al (2012) supported many of the findings of Kishida and Kemp (2006), including the influence of activity type, the length, size and composition of groups. Despite being

published after the data collection for this thesis Kemp et al's. (2012) findings suggested that (a) sufficient adaptation, (b) the role of supporters in promoting engagement, and (c) the occupation itself were all important for influencing engagement. The ICER is simple to administer in practice contexts, and includes a training package to ensure standardisation. The ICER includes five engagement codes including; active engagement, passive engagement, undifferentiated engagement, active non-engagement, and passive non-engagement. Active engagement is defined as active interaction with the environment (Kishida and Kemp, 2006). Passive engagement involves interaction with the environment without exploring or discussion with others. Undifferentiated engagement involves interacting with the environment automatically or repetitively (McWilliam & de Kruif, 1998), which in the context of NPC could include symptomatic behaviours, outside the control of the individual. Passive non-engagement involves not interacting with the environment or responding as anticipated (Kishida & Kemp, 2006). Active non-engagement could include interacting with the environment in an inappropriate manner (Kishida & Kemp, 2006).

Following Kishida *et* al's. (2008) pilot study, the ICER was revised (ICER-R) and its reliability and validity were investigated by comparing results recorded using the ICER-R with those recorded using the E-Qual III (McWilliam & de Kruif, 1998). Using a Pearson product-moment correlation, statistically significant relationship agreement ($r=.976$ $p<.001$) was found between the data gathered with the E-Qual III, and the ICER-R.

In addition to using an appropriate data collection tool, the reliability of the data for this thesis depends upon the consistency of the results across cases. Conducting the observations over a limited period ensured consistency of each engagement category and its definition, by the researcher. In addition to the ICER, the observation format used included the signs of sensory-overload and the usual behaviour for each resident. This backup was necessary because Kishida *et al.* (2008) suggested low levels of inter-rater agreement for the undifferentiated engagement code. To investigate where observers disagreed, agreement for engagement versus non-engagement was examined for each of the five categories, using Cohen's kappa coefficient to report 91.4%, acceptable mean levels of agreement (k=0.73) by coding grouped engagement and grouped non-engagement. Therefore, the inter-rater agreement across engagement categories (using the ICER-R) resulted in comparable data to that collected using the E-Qual III (an already validated measure of engagement) (Kishida *et al.,* 2008), indicating that the ICER-R and the E-Qual III were measuring similar constructs (Kishida *et al.,* 2008). Validation data from Kishida *et al.* (2008) is copied in its entirety and presented below in table 9.

Table 9

	ICER-R			E-Qual III							
Engaged	AE	PE	Total	PB	SB	EB	CP	DB	FA	CA	Total
	44.0% (2.6–87.2%)	31.1% (2.6–86.8%)	75.1% (31.5–100%)	0.0%	0.0%	1.7% (0–5.1%)	0.0%	42.7% (0–85%)	21.7% (0–84.2%)	9.6% (0–29%)	75.7% (30–100%)
Non-engaged	AN	PN	Total						UB	NB	Total
	14.3% (0–48.7%)	10.6% (0–47.5%)	24.9% (0–68.4%)						4.2% (0–25%)	20.1% (0–55%)	24.3% (0–70%)

Notes.

For ICER-R: AE=active engagement; PE=passive engagement; AN=active non-engagement; PN=passive non-engagement

For E-Qual III: PB=persistent behaviour; SB=symbolic behaviour; EB=encoded behaviour; CP=constructive play; DB=differentiated behaviour; FA=focused attention; CA=casual attention; UB=undifferentiated behaviour; NB=non-engaged behaviour

Kishida *et al*. (2008) also examined the level of agreement for each engagement code. When combined the reliability for active and passive engagement was adequate when calculated using both percentage agreement and kappa agreement, but this was not the case for the undifferentiated engagement code. However, they reported that the frequency of use of this code was less than 15%, and therefore the impact of disagreement was high. This presented a further methodological consideration for data collection in this thesis, because when analysing the reliability for low frequency behaviours, Kishida *et al*. (2008) re-categorised the engagement codes so that active engagement and passive engagement combined into an engagement category, and active non-engagement and passive non-engagement combined into a non-engagement category. Inter-observer agreement for the two combined categories was higher than 90%, *k*=0.70, i.e. at acceptable levels of reliability (Kishida *et al.,* 2008). This re-categorisation could have enabled regression analysis tests to occur. It is interesting to note that revision of the ICER into the ICER-R (Kishida *et al.,* 2008) involved removing the category of undifferentiated engagement. This category had proved unnecessary with individuals with NPC. However, the ICER was used for this study because when the data collection occurred, only Kishida and Kemp (2006) had validated the ICER.

5.2.3.1 Using the ICER with adult neuropalliative participants

Arguably the enforced dependence of institutionalisation and occupational deprivation (Carey, 2011; Barton, 2005) give individuals a powerless, childlike aspect (Barton, 2005). This increases the suitability of using a children's measure of engagement with an occupationally deprived group. Pool's (1993) pilot study concluded that care practices could enforce dependence by performing tasks for residents. Similarly, Green and Cooper (2000) suggested that only 10%-20% of residents were encouraged to engage in occupations. Observational studies by Pittaoulis (2004) concluded that occupations may also be selected by carers for their own enjoyment, allowing for passive participation by the resident. Studies have examined whether or not a participant was engaged (e.g., Bevill *et al.,* 2001), or the sophistication and the social context of engagement (e.g., Raspa *et al.,* 2001). However, since the focus here is on the engagingness of the case rather than the sophistication of the individual's engagement, the former type of assessment was preferred.

Another point in favour of using the ICER is that it measures engagement with individuals, individuals in groups (as in this thesis) and with groups (Kishida and Kemp, 2006), unlike other tools which collect data about an individual only (for

example, Casey & McWilliam, 2007). Furthermore, active and passive engagement and non-engagement could be concepts that are applicable across the lifespan because Wilcock (2006) did not differentiate the human need to be occupational based on age. Therefore the ICER could be regarded as applicable for use in determining occupational-engagement regardless of age, which was the main reason for its use. The ICER is simple to administer, is appropriate for use in practice and has a training package to ensure standardisation (Kishida and Kemp, 2006). It was developed to measure engagement using a time-sampling method similar to the one used in this thesis (Kishida & Kemp, 2010). Furthermore, the engagement category definitions are understandable and unambiguous, having been designed for use with participants with cognitive, physical and communication challenges.

The World Health Organisation (2008) has suggested that children may experience restricted opportunities, powerlessness, and be vulnerable to exploitation, similar to vulnerable adults. Furthermore, Temple's (1997) book suggests that there are similarities in cognitive and behavioural functioning between individuals with developmental disabilities and individuals with NPC which involve cognitive deficits. For example, the higher than average rates of dual diagnoses, encountering traumatic events, experiencing neglect, abuse or harassment (Martorell & Tsakanikos, 2008), the restrictions imposed by their disability (such as limited job opportunities, fulfilling relationships, boredom) or biological factors (such as injury, epilepsy, addiction) (Chaplin *et al.,* 2011). Co-existing mental health issues (with developmental disabilities see Royal College of Nursing, 2007; with NPC such as brain injury see Ouellet et al., 2009) or Martelli et al's (2008) suggested "catastrophic reaction" could exacerbate reduced occupational capacity. Furthermore, Thomas and Karmiloff-Smith's (2002) literature review argued that the atypical development found in developmental disabilities patches of typical and atypical development, and so like an NPC brain may have areas of normal cognition and areas of impairment (Ahn *et al.,* 2011), assuming typical development prior to the onset of their disability (Thomas and Karmiloff-Smith, 2002). Shallice's (1988) book about acquired brain injury argued that comparing behavioural impairments with neurotypical behaviour is informative, since independent cognitive processes can highlight the patterns of impairment present, although Karmiloff-Smith (1997, 1998) argued that direct inference from observed behaviour to brain structure was too simplistic without consideration of the context. However, this is only comparable where a damaged structure in a fully developed brain is isolated from the entire developing cognitive system (Thomas and Karmiloff-Smith 2002). An example could be where an identical effect results from damage both before and after development or where structures develop independently, reducing the possibility of mutual influence. Thomas and Karmiloff-Smith (2002), suggested that behaviour generated by developmental or acquired conditions may appear similar enough to be assessed in a similar way, using for example the ICER. A major difference between them is that acquired damage causes cognitive deficits in neurotypical adults, against a background of previously normal functioning. Therefore, Anderson et al's (2001) textbook, described recovery from brain damage as a dynamic process including neuroplasticity, and relearning etc, which may not be a feature of developmental disorders (Thomas and Karmiloff-Smith 2002).

Areas of normal development differ between an individual with a developmental disorder and neurotypical individuals who acquire brain damage because the developmental process exaggerates the effects of an early developmental fault, whereas acquired damage remains static unless a further insult occurs (Thomas and Karmiloff-Smith 2002), because the insult occurred when development was complete. In the developmental disorder the insult occurs prior to or during the

development process. Therefore, assuming that an experience would have the same effects on individuals with NPC as those with a developmental disability is problematic.

The ICER was designed for use with children with movement, balance, coordination, stability and mobility, as well as having cognitive, physical, behavioural, communication issues. Individuals living with NPC, could experience alterations to attention, arousal, activity levels, coordination, muscle tone, mood, levels of anxiety etc, also experience these. Furthermore, all the participants experienced a mix of cognitive, sensory gating/ processing, perceptual and arousal problems physical, behavioural, communication issues (Turner stokes *et al.,* 2007), which influenced their occupational capacity.

Common health issues related to both developmental disabilities and NPC include; balance, coordination, stability and mobility. Additionally, some developmental disabilities have inherent health issues, such as the heart disease associated with Down's Syndrome. While, individuals with communication or cognitive limitations may have difficulty with articulating their health needs or recognising their own ill health. Therefore, sensory impairments, obesity and poor dental health are common amongst individuals with developmental disabilities (Kerr et al., 2009).

The World Health Organisation (2008) suggested that children have different needs to healthy adults, but compared to profoundly disabled individuals, may experience a similar degree of powerlessness and lack of control. Compared to adults, children could be vulnerable to physical, mental, financial, social hazards that could impair their development (World Health Organisation, 2008). They could be at risk because they could not recognise danger, or are unable to respond with appropriate caution (World Health Organisation, 2008).

Katz (2011) highlighted the influence of cognitive ability upon occupational opportunities, performance, and engagement. Individuals with NPC, or developmental disabilities, and children are all regarded as potentially vulnerable, requiring safeguarding policies similar to Walsall Community Health NHS Trust (2009). Consequently Safeguarding adults with disabilities and children against abuse requires alertness to and avoidance of abuse, restraint, or neglect (Brown 2003). Additionally the cognitive or communication limitations of adults with disabilities and children may result in a lack of self-esteem and self-advocacy skills, a lack of understanding of social norms and appropriate behaviour which may exacerbate their sense of frustration, powerlessness (Hemmings et al., 2008)

The ICER was designed for use with children with profound and multiple developmental disabilities (Bellamy *et al.,* 2010) with or without challenging behaviour, and sensitivity to the sensory environment. Adults living with NPC, may also demonstrate sensory sensitivities (Arcinegas, 1999) and challenging self-injurious, aggressive, inappropriate sexualised behaviour; property focussed and stereotyped behaviours (Kelly *et al.,* 2008; Bellamy *et al.,* 2010). These may result from internal or external cause or be a means of communication (Kelly *et al.,* 2008; Bellamy *et al.,* 2010).

To date the ICER is not validated for use with adults, let alone those with NPC. Arguably, the engagement categories defined by Kishida & Kemp (2006) are a stable state, which makes the ICER appropriate for validating for use with other age and diagnostic groups in the future. Additionally, differences exist not only between the stages of childhood development from pre-natal to late adolescence; but also between the stages of adulthood from early adulthood to the super-elite (85 onwards) (Giddens, 2009). In early adulthood, for example intimate relationships reduce isolation (Biordi & Nicholson, 2009). Middle-aged adults could experience a conflict between a sense of contributing to society and a sense of stagnation (Crain,

2011). Differentiation being necessary between healthy aging and pathological conditions associated with aging, so that adult assessments should arguably also undergo generation specific validation.

The weaknesses of using the ICER with adults living with NPC, include the difference in developmental stage between children and adults. However, arguably, individuals with NPC had developed and then lost skills because of their condition. Conversely, it could be patronising to liken adults to children by using a measure of engagement designed for children. Arguably however, engagement has stable qualities whatever the age of the engager, so that what differs is what adults and children engage in. This could lead to exciting opportunities such as validating an adult engagement and an NPC engagement measure. This is necessary, because since 2002 six measures of occupational-engagement have been published (Chugg & Craik, 2002; Goldberg *et al.,* 2002; Wood, 2005; Black *et al.,* 2006; Bejerholm *et al.,* 2006; Eakman, 2007), none of which was suitable for use with a population with unreliable communication and cognition. This is problematic given that Stav *et al.'s* (2012) systematic review of longitudinal studies suggested that self-determined leisure, social and religious engagement influence health and well-being. Another idea could be to extend the sensory profile so that it measures sensory influenced engagement. Another opportunity could be to create an extension for the Canadian Occupational-performance Measure (COPM) (Law *et al.,* 2005) for individuals with NPC who have difficulty with physical performance, communication and cognition.

Arguably, just as other measures such as the activPAL and ActiGraph (Ridgers *et al.,* 2012), sensory profile and the Wechsler Intelligence Scale's are applied across the lifespan albeit having been validated for use with different chronological groups in the latter two, so could measures of engagement. Especially as until recently in the researcher's experience, some diagnoses of adults with conditions which up until then were associated with children had been made (in adults) using children's assessments e.g. Attention Deficit Hyper Activity Disorder, until the realisation that adult tests should be developed. Barth *et al.* (2006) used the same assessment to study object tracking, and individuation in adults, college students and preschool children. Tests such as the Glasgow Coma Scale, MRI, Xray and CT scans, EEG and angiograms are applicable across the lifespan (The Children's Trust, 2012). Furthermore, the Functional Assessment of Care Environments (Clifford & Wolfson, 1989) uses an initial screening tool regardless of age before focusing on specific needs. Adults with NPC, and children may experience the same power imbalance, limited sense of danger, safeguarding needs given their ability deficits. However, engagement is not age specific and it is more likely that it is what is engaged in which changes across the lifespan, rather than how much engagement results (Csikszentmihalyi & Schneider, 2000). Behavioural engagement across disciplines and in other species has also been measured through observation which resulted in data being categorised into meanings and intensity in a similar way e.g. Fossey (1972).

Having considered measures of occupational-engagement ; several occupational-performance measures can be used across the lifespan (Meta-OT, 2009). One such, the Allen Cognitive Level Screen (Allen, 1996) estimates cognitive function to triangulate with observations of performance. Originally developed for use with adults with psychiatric disorders and with dementia, it has been used with children, adults and elderly (Shapiro 1992, Penny *et al.,* 1995, Wu 2008) who have experienced both physical and psychosocial ill health e.g. emotional disturbance, traumatic brain injury or a cerebral vascular accident and dementia. Furthermore, the COPM (Law et al. 2005,) is a measure which detects change in self-perceptions of occupational-performance over time. This too can assess children, adults and elderly individuals (Keren-Capelovitch *et al.,* 2010; Larsen & Carlsson 2012; Colquhoun *et al.,* 2010). Another example, validated for use with specific age groups is the

Sensory Profile. This has Adolescent/ Adult (Brown & Dunn 2002) and Infant/ Toddler (Dunn, 2002) versions to ensure that it is applicable across all ages. Whereas the Dressing Loop (NHS Innovations, 2007) removed the influence of meaningfulness, occupational context, gender, age all together.

Mackenzie (2011) describes eight leisure assessments used by Occupational Therapists, published in the 1980's and 1990's. These include the leisure satisfaction questionnaire, the leisure attitude scale, the activity index, the meaningfulness of activity scale, the leisure motivation scale, the leisure diagnostic battery, the occupational questionnaire and the leisure competence measure. However, their data collection methods were not suitable for use with individuals with NPC. The Nottingham Leisure Scale (Drummond *et al.,* 2001) measures leisure participation in less disabled individuals than the residents of the home studied, following stroke. Occupational Therapists use several leisure related outcome measures across the lifespan such as the Leisure Competence Measure, the Leisure Satisfaction Scale and the Leisure Boredom Scale (Meta-OT, 2009), which are Recreational Therapy measures. One which is discussed by Mackenzie (2011), is the Leisure Competence Measure (Kloseck *et al.,* 1996), which Meta-OTs database of assessments (Meta-OT, 2009) suggested as suitable for use with individuals of all ages. This measure captures outcomes such as leisure awareness, attitude, and skills, cultural/social behaviours, and community participation. It captures changes in leisure functioning across the lifespan (e.g. Marsden's 2010 sample with an age range of 81 years) with a variety of diagnoses (Kloseck *et al.,* 2001). The Leisure Competence Measure is consistent with the Functional Independence Measure (Hamilton *et al.,* 1987); but it captures data about independence as opposed to overall leisure functioning (Kloseck *et al.,* 1996). This is crucial to the argument for using the ICER because it measures engagement rather than specific skills or attributes which could a) vary with age and b) influence participation satisfaction as a whole. Definitions of levels of active and passive engagement and non-engagement could translate into observable behaviour between children and adults given the similarities in Aguiar & McWilliam's (2012) engagement categories in toddlers, Kemp et al's. (2013) engagement categories in young children, Gross's (2012) engagement categories in high school students, and Bakker's (2011), engagement categories amongst employees, and Timonen et al's. (2011) engagement categories in adults aged over 50.

More significant (than the age of the individual's observed) in the researcher's decision making process about which measure of engagement to use, were the similarities in sensory related behaviours demonstrated, between developmental disabilities and NPC (see chapter four). Arguably, the cognitive and communication limitations experienced by individuals with NPC appear similar to the experience of children, since both groups require simplified language and so assessments should be observational rather than interview based. Additionally the adult scales of engagement sometimes rely on non observation data, which would be difficult to capture and to rely on (leng *et al,* 2003), with individuals with NPC. So it was decided that because Kishida & Kemp's (2006) engagement categories were phrased suitably for study participants of any age that this would be the measure of choice.

The link between childlike aspect, powerlessness, occupational deprivation and enforced occupations, makes a study into the engagement of individuals with NPC desirable. The ICER measures engagement with individuals in groups which makes it suitable for this study, where communication and movement limitations can isolate an individual within a group situation. The ICER was designed for use in a real world, such as practice. The ICER was designed for use with profoundly disabled participants with similar cognitive, physical, behavioural and communication challenges to those on individuals with

NPC, all of which may influence occupational performance. Occupational therapy has a history of building its evidence base and beliefs on theories built out of reflective observation and reflection on action e.g. MOHO, Bobath, sensory integration, rather than the reflection occurring prior to action. Therefore, it has not been uncommon for concepts to move from one clinical domain to another e.g. the sensory profile (Dunn, 1997), and the use of MSEs. Therefore, transferring a concept such as sensory influence and a measurement tool from developmental disabilities to NPC may be possible (which this study could help to determine). Furthermore, the really clear and unambiguous definitions of the Kishida and Kemp's (2006) engagement categories felt appropriate for use with observable behaviour demonstrated by children or adults. The cognitive, physical, communication and awareness limitations experienced by individuals with NPC reduce the range of measurement tools that could be suitable for use in this thesis. Therefore, in lieu of creating a specific leisure measurement tool for such a small and specialised population the researcher built the study around the use of the ICER.

5.2.4 The sensory attributes of the cases

A case should be focused and circumscribed (Hitchcock & Hughes, 1995) suitable to offer an understanding of the issue without including unnecessary data. The cases considered in this study were typical and naturally occurring casual leisure occupations offered to individuals with NPC, each of which:

- involved different numbers of sensory attributes
- where two cases had the same number of sensory attributes and were attended by all 14 participants the first to occur was used in the study
- were engaged in by the same 14 participants, who had consented to being observed
- produced time series data collected using the ICER every 5 minutes by a single participant observer

The cases included a listening activity, watching a film, spectating at a live performance, interacting with an interactive video installation, a making music group, an interactive drama performance, and an Aquability session. For an in-depth description of the cases, see sections 5.2.4.2.1 to 5.2.4.2.8. Taking into account that the sensory categories included in the sensory profile include visual, auditory, taste, smell, touch, vestibular and proprioceptive processing; the researcher elected to mirror these sensory attributes in the variables selected for use in this study. Consequently eight cases (including the control condition) were observed. The number of sensory attributes in each case was not pre-specified, but became clear during post hoc occupational analysis. This is a real world study and so observation data collection occurred during many casual leisure occupations, each was analysed afterwards to determine the sensory attributes represented during the case (see appendix xi).

A range of cases was accrued, each with an incrementally larger number of sensory attributes. Due to the anticipated influence of each participant's personal sensory preference (unidentified since the home did not use sensory assessments), no attempt was made to select a combination of sensory attributes according to Gestalt Laws of Perceptual Organisation (e.g. grouping) (Wen et al., 2010). This was because the SI Pyramid adapted from Williams and Shellenberger (1994); does not prioritise one sense over another. However, Spence (2002) had attempted to identify a priority order of sensory importance when sensory messages coincided. For example, visual stimulation having more weight than other senses (Mugge *et al.,* 2009)

whereas Synnott (1991) suggested that hearing had greater weight. Furthermore, the 'modality-appropriateness' hypothesis (Welch and Warren, 1980) suggests that vision is most useful in locating the individual in the environment and so dominates hearing and touch whenever the individual makes spatial judgments, while hearing is best at judging events in sequence and so dominates chronological judgements (Guest & Spence, 2003; Shimojo & Shams, 2001). Therefore, a definitive order of sensory precedence has not been identified. However, Alais and Burr (2004) disagreed by suggesting that following degradation in stimulus quality, corroborating information might be sought from other sensory modalities to maintain the perception. This decreasing effectiveness requiring supplementation from the other sensory modalities therefore suggests that which sensory attribute was present is less important than the number present to reinforce (multi) sensory integration. Therefore, perceptual coherence or grouping was irrelevant, since this was a study of engagement, rather than perceptual and sensory discrimination. Furthermore, this thesis represents a preliminary study, where all the participants experienced a mix of cognitive, sensory gating/ processing, perceptual and arousal problems, all of which could have confounded their ability to organise any sensory data into patterns.

Therefore, the number of sensory modalities represented in each case was more important to study than the combinations of sensory attributes presented during the cases observed. The number of sensory attributes was determined using a binary contingency table approach to recording presence (present/ not present), whatever its intensity, location, or duration. These considerations require exploration in more depth in a future study, but since they could involve invasive or intrusive testing, which had proved unacceptable to the home staff during previous studies. Observations of engagement occurred in accordance with the home's philosophy of non-intrusion, and its protection of vulnerable adults' policy (POVA) (as described in section 3.4). These limited the number of observers, precluded the use of video recording and physiological testing for research related to leisure, since leisure was not offered with a therapeutic effect as its primary goal. Instead, the participant-focussed stance taken by sensory profile was adopted when considering this, rather than any biomedical measurement of the intensity of the sensory stimulation. This decision acknowledged that the subjective meanings of occupations depend on the individual's preferences.

Table 10 illustrates which sensory attributes were presented during each case. The sensory attributes were identified from an occupational analysis after the live performance, interactive video installation, and interactive drama performance. It was then possible to determine which sensory combinations remained unobserved. In response to a gap analysis (conducted by the researcher), the lower level occupations were selected for observation, from the menu of casual leisure occupations provided by the home. This happened naturally and so no leisure occupations were "manufactured" with the study in mind. The non-stimulating and non-demanding control condition was the only contrived situation, and so for those residents with better hearing or sight there could have been some background sensory stimulation to disturb the busy real world care environment (unlike a laboratory situation).

Table 10 estimates the lowest and the highest sensory attributes level in each case. However not all participants noticed all the sensory attributes available. For example during the live performance, some participants held props, whereas others did not. During the listening case, the lighting in some rooms was less dim than in others or the residents sight was such that they were able to see more than other participants were. During the interactive video session, some residents were able to move their arms around to influence the projection whilst others were not, experiencing less proprioceptive

stimulation. Equally, during the making music group some participants chose to bang or wave musical instruments while others did not. The widest variation occurred between residents during the interactive drama performance. This resulted from the role that each resident played, with those who were more actively involved holding and using props, moving their heads and tasting the "wine" offered during the ballroom scene. A limiting factor to the experiencing of taste was whether the participant was at risk of aspiration, and so was not offered a drink.

The identification of each sense involved was part of the occupational analysis because the occupations were naturally occurring events, in the lives of the residents, (not arranged for the research project). A more precise environment to control the level of sensory attributes experienced would have been to remove the study from its natural environment, into experimental laboratory conditions. However even then each individual's sensory preferences could have dictated what senses where noticed or screened out, affecting the level of attributes noticed. Those individuals who were low registration could have missed stimuli, which to a sensory sensitive individual were prominent. To counteract this, the inclusion and exclusion criteria for the study could have limited participation only to individuals who were predominantly in one of the four quadrants of Dunn's (1997) MoSP, i.e. only low registration individuals. The danger of conducting the study under strict experimental conditions was that the participant behaved less naturally, because they were more conscious of the observations. Table 12 (see section 5.3.1) demonstrates a comparison of the minimum and maximum combined sensory attributes presented, the supporter to resident ratio (and therefore the potential for positive collaboration available), and whether the case could potentially be active or passive in the role it demanded from participants.

Each of the cases had the potential to stimulate a number of senses. SI involves noticing sensation, combining it with prior experience, interpreting it into something meaningful and responding appropriately (Dejean, 2008). Whereas, individuals who have difficulty processing or gating stimuli could experience atypical brain activity (Miller et al, 2009). The following occupational analysis clarifies the demands placed upon participants during engagement in the case.

5.2.4.1 Touch

The tactile system informs the body about its relationship to the environment (Dunn, 1997). The reticular activating system modulates between arousing and calming, but may be disrupted in individuals with damage to the RAS. An individual with a high threshold of registration could be unaware of a stimulus, whereas individuals with a low threshold may be trying to avoid it. In the case of casual leisure occupations, tactile stimulation occurs because during the non-stimulating control condition and the listening case, the film watching case each resident was physically isolated as part of the case. They may have felt the furniture and their clothing; potentially becoming habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). During the live dramatic performance, the performers could have touched the participants in passing. There was no expectation the participants would have to hold or touch any props as part of the performance. During the interactive video installation experience, only one or two participants were using the projection floor/mat at a time, therefore it is unlikely that they would have experienced touch other than the furniture and their clothing. During the Making Music group and the Interactive Drama Project, each participant had musical instruments to bang or play, or had props to hold or use, which could have generated tactile when instruments or props were moved. During the Aquability session, each resident entered the pool using the hoist, so that they could have felt the sling, their swimming

costume; however, again there was a potential for habituation unless updated (Parent, 1978, Hutchinson, 1990). They would also have felt the sensation of the water and the tides and ripples generated. Furthermore, the balls, water pistols and games used would have generated tactile stimulation if held, and when banged against the side or a supporter. The pool also offered quite a hard atmosphere since the floor; walls and pool sides were all tiled and a little chilly.

5.2.4.2 Proprioceptive Stimulation

The brain receives information from proprioceptors located in muscles, tendons, and joints to provide a body position map. When individuals tire easily, they may have a high threshold for noticing proprioceptive stimulation. Whereas, those with increased muscle tone may have a low threshold for noticing proprioceptive stimulation. During the control condition, most residents remained passive and still therefore not experiencing much if any proprioceptive stimulation. During the control condition, listening activity, film watching and live dramatic performance most residents remained passive and would have experienced little proprioceptive stimulation. During the interactive video installation experience, some residents could propel their own chair or wave their arms if they were able. Those participants who could move their arms and legs would have experienced proprioceptive stimulation. During the Making Music group, banging and playing the musical instruments, moving to the rhythm of the music, nodding their heads could have led to the participants experiencing proprioceptive stimulation. During the Interactive Drama Project, participants using the props and costumes could have experienced proprioceptive stimulation. During the Aquability session, using the games and the movement of the water, moving to the rhythm of the music, nodding their heads, feet and arms, could have led to the participants experiencing proprioceptive stimulation.

5.2.4.3 Vestibular Stimulation

The vestibular system informs the brain about movements made in relation to gravity. Preferences for or against movement tend to be demonstrated emphatically (Dunn, 2000). For instance, an individual with a low threshold of responsiveness could be disoriented after intense or repeated stimulation, whereas someone with a high threshold could seek out any movement to satisfy their need for stimulation e.g. hanging out of a moving car window. The cases offered different levels of vestibular stimulation for example during the control condition, the listening case, the film watching case and the live dramatic performance, the participants were on the whole passive and still, and so may not have experienced vestibular stimulation. During the interactive video case, the Making Music case, Interactive Drama case, the wheelchairs were moving around the floor and so the participants would have experienced vestibular stimulation. Furthermore, participants could have been responding to sounds, nodding their heads, and thus experiencing vestibular stimulation. During the Aquability session, the participants could have been moving their heads, feet and arms, and thus experiencing vestibular stimulation.

5.2.4.4 Visual Stimulation

The visual system maps the environment influencing hand use if the individual cannot see their hands (Dunn, 2000). Visual stimulation may result from the cases because the control condition was conducted in a gloomy but not completely dark room, to reduce visual stimulations. The listening case was provided in the participants own room, with closed curtains blocking out visual stimulations. This was a modern room with four walls and windows on one side, with

blackout curtains to facilitate circadian rhythms. The film showing occurred in a large public room, laid out like a cinema, with a screen at one end and the residents sitting in a row facing the screen. The blackout curtains were used to reduce visual stimulations therefore the room was really quite dark once the lights were turned out which drew attention to the film showing in the screen. The live dramatic performance occurred in a large room with four walls and windows on one side and open curtains to allow in the sunshine. Consequently, the residents could watch the performance, and be attracted to the actor's movements. The interactive video installation experience occurred in a dark environment, with closed curtains, late in the evening. The residents watched the projection and could have been attracted to the movements, special effects and patterns that it created. The Making Music group occurred in a sun drenched room. The residents may have seen the Disk Jockey, the equipment, each other, their supporters and the musical instruments. The Interactive Drama Project occurred in a day room with opened curtains to let in light. The residents may have seen the performers, each other, their supporters, the costumes and the props. The Aquability session occurred in the pool located in a light and airy hexagonal room. The residents could see their supporters, the stained glass in the ceiling and the patterns that this made in the water and the toys available to engage with.

5.2.4.5 Auditory Stimulation

Sounds can provide an auditory background for activity or may interfere with performance, so could influence engagement (Dunn, 2000). Shams & Kim (2010) suggested that sound and touch influence visual perception, stressing the influence of sounds on both visual perception, and learning (Shams & Kim, 2010). Indeed, Seitz et al's (2006) experimental study found that multisensory stimulation could enhance visual perceptual, with individuals receiving audiovisual stimulation showing greater accuracy and learning, than those who did not (Seitz et al, 2006). Similarly, the Listen and Learn Centre (2008) suggested that an individual with auditory processing problems may have trouble processing auditory information alongside poor motor skills and balance. In the cases, auditory stimulation occurred because during the control condition, the nursing staff were busy elsewhere, therefore, the atmosphere was quiet. The listening case happened in the participant's own sound proofed room, with notices on the door, asking passers-by to keep quiet. However, for some residents with very good hearing the occasional accidental noise could have been heard e.g. a Fire Engine. Consequently, the only noise heard was the recording, played a comfortable level for the participants but not loud enough to interfere with adjacent rooms and corridors. The film show and live performance happened in a large public space but with the door closed and bearing "keep quite" notices, so that the majority of auditory stimulation was from the film, the performers and the audience. The participants could hear the performers, to follow the story. The interactive video projection and the Making Music Group happened in a large public space but with the door closed to reduce external stimulation. The participants could hear the sounds and music of the video projection in response to their movements, or could hear the music and singing and musical instruments. The Interactive Drama performance happened in the day room of the residence. The participants had the opportunity to hear the speaking, music and singing which the performance entailed. During the Aquability session, the residents had the opportunity to play their own music. Furthermore, the pool atmosphere appeared to amplify the noise of voices when the participants and the supporters spoke, sang, laughed or shouted.

5.2.4.6 Olfactory and Gustatory stimulation

Taste and smell are the first steps of ingestion and inhalation, respectively, and the last chance for acceptance or rejection (Spielman et al., 2007). The sense of smell detects odours in the environment (which could be pleasant or potentially harmful), thus keeping the body safe and enhancing wellbeing (Spielman et al., 2007). Likewise, the sense of taste can dictate selection or avoidance of food (Spielman et al., 2007). These chemical senses influence each other (Spielman *et al*, 2007). Individuals with a high sensory threshold could crave more because it is associated with a memory, while those with a low threshold could feel irritated by them (Spielman *et al*, 2007). The respiratory and digestive systems have some common structural features, for example cilia which detect, absorb or expel chemosensory information e.g. within the oral cavity, the nasal cavity (Spielman et al, 2007). Olfactory stimulation may result because the pool used for Aquability had a smell of chlorine. Care was taken so that no novel or unfamiliar smells pervaded the rooms used for the observations. Gustatory stimulation was limited because participants did not eat or drink outside the dining room and so apart from regurgitation would not have been experiencing any tastes during the control condition. The participants were not given any food or drink during the listening case, the film watching case, the live dramatic performance, the interactive video installation experience and the Making Music group. During the interactive drama project, some participants had "wine" to taste, and participants in the Aquability session may have inadvertently tasted chlorine.

5.3 The cases

Table 10 The sensory attributes of each case

Occupation	Control Group	Listening activity	Watching a Film	Spectating at a live performance	Video Interactive Installation	Making Music Group	Interactive Drama	Aquability
Smell								?
Hearing	?	✓	✓	✓	✓	✓	✓	✓
Taste							?	?
Touch/ temperature				?		✓	✓	✓
Seeing	?	?	✓	✓	✓	✓	✓	✓
Proprioceptive					?	?	?	✓
Vestibular					✓	✓	?	✓
Minimum senses	0	1	2	2	3	4	3	6
Maximum senses	2	2	2	3	4	5	6	7

Note: (key ✓ =definitely/for all, ? =possibly/for some)

The following sections describe the occupational-performance attributes of each case, based on Hersch *et al.*'s (2005) occupational analysis, to provide a description of each case observed. All the casual leisure occupations had common factors, such as the care taken by domestic staff to reduce rather than masking smells. Consequently, the automatic odour neutralisers were turned off for the duration of each observation since they made a regular noise. Each resident was sitting in their own wheelchair, or on their own bed and could feel their furniture and clothes however touch may habituate unless it is changed and so their very limited movement could have made this form of stimulation rare. Each room maintained a comfortable temperature for non-mobile residents. No food or beverages were available to residents when unsupervised, and were not available during the observation unless specifically requested, to reduce the experience of taste during the study. On the other hand some of the sensory stimulation experienced could have resulted from their being more than one individual in the room at the time, which would also have occurred in a laboratory situation if the data was collected from a group. A way to deprive them of all unwanted stimulation would have been for data collection to occur singly, by a covert observer sitting behind one-way glass giving the impression that there was only one participant in the room at each time. Since data collection was about occupational-engagement, in a real world context, this was inappropriate and so the whole study includes the cases occurring in their natural contexts.

5.3.1 Control case

This case was set in a large day room in the early afternoon, with the curtains closed, and before a live performance was due to start. There were no staff present due to handover meetings. The residents tended to sleep when not actively engaged, and there was no background noise coming from other rooms. The dayroom was on the first floor, and so there were no sounds from outside the windows. The only person present other than the residents was the researcher who was purposefully moving very slowly and quietly so as not to disturb the residents. None of the residents were moving; many could not move or eat and drink without assistance. There were no novel or unusual smells. Those in the day room could have habituated to the touch from clothing or equipment. Occasionally a resident would move their head to look around if they were able and this would offer some vestibular stimulation however most resident's chairs included headrests, which limited movement. Proprioceptive stimulation was limited due to poor motor control. The room was not in total darkness and so residents with good eyesight would have been able to make out items in the room.

In summary, the participants sat in the dayroom for 45 minutes with no direct sensory stimulation, and with no performance demands made of them. This "waiting mode" was a state of occupational vacuum. The participants experienced this 'waiting mode' on a regular basis due to their inability to seek stimulation without assistance. Therefore, this case reflected the way many participants spent much of their time. In effect any sensory stimulation experienced could have resulted from their being more than one individual in the room at the time. Despite the low engagement from staff, special consideration was given to those who were at risk of fitting, choking or respiratory distress, even when doing nothing. No resources, tools, materials or equipment were required during the control condition. To collect the data during this activity the researcher sat where each participant was observable unobtrusively.

5.3.2 Listening case

This case was set in the participant's own room with the curtains drawn, the lighting dimmed and doors closed to reduce external stimulation, with a 'do not disturb' notice on the door. The only person present other than the participant was the researcher who was purposefully moving slowly and quietly so as not to disturb the participants. The participant was sitting or lying in a chair or bed, depending upon their pressure care regime. The participants were encouraged to relax and be still to reduce stimulation. Any remaining food was removed whenever it was no longer required to reduce olfactory stimulation that could distract the participant. The only sound, once the observation had started was that of the recording. In some cases this was a reading from a holy text (1x bible, 1x Qu'ran), an audio book n=3, music n=6 or a radio programme n=3.

This case involved listening to an audio programme of choice as a primary (rather than an embedded) occupation. Supporters could regard this as an accessible occupation for even the most severely disabled participants. However, it has been suggested that it is over-used (RHN, 2007). The participants experience this regular real world situation. However, in a laboratory situation this case would have probably involved the group being in a darkened, sound proofed room similar to the one offered here.

The performance attributes of the case included turning on/off and tuning the audio equipment, placing a tape or CD in the machine, checking the volume and clarity (both of which were completed by the observer), and listening and concentrating to understand what was heard. The precautions and contraindications for the case included controlling the sound level, which should be loud enough to hear but not loud enough to interfere with others or be uncomfortable for the participant. Other participants' noise should not block out the sound of the programme. The chosen listening material was the participant's own, and varied according to their preference. There were no physical demands on the participants during the case. The communication demands placed upon participants included agreeing or requesting to listen, the selection of programme or topic, communication with supporters facilitating the case and later discussing what had been heard with others. The behavioural demands of the case included sitting or lying still, being isolated to facilitate concentration on the programme without disturbing others. Concentration, attending to, understanding and following the programme and visualising the context of the programme were included in the cognitive demands placed upon participants by this case.

The resources required for the case included supporters, audio equipment, and a CD. The spatial demands of the case included being somewhere quiet, near enough to the audio equipment to hear it, in dimmed lighting to reduce visual stimulation, at a comfortable temperature, with positioning supported to help the participant keep alert and able to concentrate. A physically stable, aligned and supported posture was required to maintain a sitting or lying position. Maintaining concentration throughout the case required sufficient attention to sustain concentration. The choices and the discussion of the listening material could have enhanced the participant's knowledge. The listening case occurred against a background of habits, routines, and roles. The participants' role during the listening case was that of a physically passive absorber of sound, which required processing to understand. During the listening case, the participant could have attempted to link interests and roles – e.g. understanding something said to them on a previous occasion, or continuing a previous interest in music. The participant could have listened routinely to a radio programme, or carried on listening to a further chapter of a book, with the consequence that what they hear could continue from past experience and into the future. Their listening habit could orientate them and link them with the outside world, e.g. by listening to current affairs or news programmes. Some participants occasionally needed reminding about the fictional nature of the recording or programme.

Because this case could be less engaging, the participants each selected what they wished to listen to in order that it was appropriate for them as an individual. The researcher located herself to see the participant but across the room/ far enough away to minimise intrusion.

5.3.3 Film show

The room used to watch the film was a large public space, with no discernible odours, and a large screen at one end. The lighting was low, similar to a cinema, enabling participants to concentrate on the film whilst reducing stimulations from the movements of those about them. Participants had voted for which film to watch the month before. Supporters accompanied participants to facilitate their engagement with the film. The participants experience this real world experience on a regular basis. In a laboratory situation this case would have probably involved the group being in a darkened cinema setting, similar to the one offered here. The case offered hearing and visual stimulation. The performance attributes of the case included tolerating and maintaining a sitting position, watching and listening to the film, understanding the film and following the plot, and non-disturbance of others. The precautions and contraindications for the case included selecting films that did not have the potential to cause epileptic fits. The "cinema" door was closed to reduce external stimulations, and bore a keep quiet notice. Therefore, the only noise and sights were from the film, which was played at a comfortable level for participants, but without being audible outside. Each participant was sitting in his or her own chair, and required a stable, aligned supported posture to maintain this position. They were probably aware of furniture and clothing prior to habituation. For this study, participants sat further apart than usual to isolate them. Most of the participants remained stationary while watching the film show, thus they experienced very little vestibular or proprioceptive stimulation.

The film show occurred against a background of habits, routines, and roles. The participants' role during the film was that of a physically passive absorber of stimulation, linking interests and roles, e.g. understanding something said to them by a visitor, or continuing an interest in classical music. The participant could have attended the film show routinely, or be continuing to watch part of a series of films, and so what they experienced could continue from the past and into the future. The film could orientate or disorientate participants, depending on the topic and their ability to distinguish fact from fiction. Each participant watching the film varied in his or her personal, cultural, spiritual and clinical context. However, the film chosen was as appropriate as possible for the group with consideration given to gender, age and cultural beliefs. Some participants required reassurance that the film was fiction and not reality.

The occupational demands placed upon a participant included having sufficient sitting tolerance for the duration of the film, and the journey to and from it. Participants generally tried not to talk during the film so as not to disturb each other, but communication was required to express a preference for future film selections, to discuss the film with others, or if they needed assistance. Socially acceptable behaviour, involved sitting still and quiet whilst watching the film. Participants required sufficient cognitive ability, attention and concentration to understand the film and follow the plot. The spatial demands of a film show included having space to manoeuvre wheelchairs. The room was at a comfortable temperature for non-mobile participants. Their choices and discussion of the film could have enhanced the participant's knowledge. The film ("*Die Hard 2*") lasted for two hours and ten minutes. However, the average length of concentration and sitting tolerance of

the participants was about forty-five minutes once the case was underway, so the observations ceased after forty-five minutes. The researcher was seated (facing the group) approximately 3 feet higher than the participants to see them all.

5.3.4 Live performance

This case involved performers undertaking the roles of two nineteenth century characters. The performance occurred in a large public room, laid out in the round. The case offered opportunities to experience auditory, visual, tactile or temperature stimulation. Each performance lasted for approximately forty-five minutes, to maximise opportunities for concentration and sitting tolerance of the participants. The participants experience this real world situation occasionally. However, in a laboratory situation this case would have probably involved data collection within a theatrical context similar to the one offered. Given that watching a live performance is usually, a social activity this could have raised issues such as the audience member being embarrassed, aware of being observed and therefore not behaving naturally.

As in the other cases there were no ambient smells, the regular hiss of automatic air fresheners was absent, and the room was at a comfortable temperature for non-mobile participants. The performance occurred in a big public space but with the door closed (and bearing a keep quiet notice) to reduce external stimulations. No food or drink was available during the case, and so apart from regurgitation would not have been experiencing any tastes at this time. Participants were sitting in their own chair, but may have experienced tactile stimulation as the performers passed by, or from clothing and furniture. There was no expectation during the case that the participants would have to hold or touch any props as part of the performance. The open curtains admitted day light, and the temperature was suitable for non-mobile participants. Accordingly, the participants could watch and hear the performance, and could have been attracted to the performer's movements. Most of the participants remained passive during the performance and would therefore have experienced little if any proprioceptive or vestibular stimulation.

The performance attributes of the case included tolerating and maintaining a sitting position, watching, listening and understanding the performance to follow the plot. Precautions and management included managing participants who confused the performance with reality. The physical demands of the case included sufficient sitting tolerance for the period of the performance. The behavioural demands of the case included an expectation of socially acceptable behaviour such as minimising disturbance to others, whilst responding to the performers appropriately. The resources required included supporters, stage space, performers, and costumes. There were no props for the participants' use, nor were there any stage sets involved. Using a large room enabled the participants to move around if they wished or needed to.

Communication was required if the participant needed assistance or wished to discuss the performance. The participants' role during the performance was mainly that of a physically passive absorber. During the performance, the participant could have attempted to link interests and roles, e.g. understanding something said to them previously or continuing an interest in drama. The live performances stood alone rather than being part of a series, but the choice about whether to attend could have depended on the participants' liking for drama. Watching the performance could have orientated or disorientated participants at times. Special considerations included a gender, age, and culturally appropriate choice of performance. Each performance lasted 45 minutes to maximise opportunities for concentration and sitting

tolerance. The performance chosen was as appropriate as possible for the group. On the occasion that the observations were conducted the researcher was seated (facing the group) to see them all without detracting from the performance.

5.3.5 Interactive video installation

The interactive video installation detected movement, enabling participants to interact with images projected on the floor and wall. There were two layers to each projection, one being a static image and the other being a selection of small images that responded to movement. The projections used led to a trail of sparks exploding in the participant's wake, autumn leaves scattering when touched, or ripples which move outwards from a point of impact as if in a pool of water. Crucial to the installation for the participants' use was a wall projection which enabled participants who could not see the floor to join in. On arriving, participants became aware of the reaction of the projection to movement on the floor screen. This installation offered participants the potential for auditory, visual and vestibular stimulation, and for some, proprioceptive stimulation. The case occurred in a big public space but with the door closed to reduce stimulations from other rooms and corridors. The participants could hear the sounds and music generated by the video projection in response to their movements. The participants were without food and drink during the case. There were no ambient smells, or noises and the room was at a comfortable temperature for non-mobile participants. Furthermore, the likelihood of detecting touch sensation in response to movement with in wheelchairs and clothes was reduced by the participant's limited mobility. Only one or two participants used the floor at a time, therefore it was unlikely that they experienced touch. The interactive video projection occurred in a darkened environment, during the evening with the curtains closed. The projection of their movements, special effects and patterns was shown on the wall and floor screens. Some participants could propel their own wheelchair or move their arms and legs to experience proprioceptive or vestibular stimulation. This case brought with it the opportunity for intergenerational leisure (Downs, 2008) since it appeared to interest not only the participants but also their visitors, which could also have influenced engagement. Because this was a novel case, removing the social element to this case could have greatly influenced engagement. In a laboratory situation this case would have probably involved the projection happening in similar context to reduce extraneous visual and auditory stimulation. The case was not offered in a socially isolated or laboratory context because data was being collected about occupational-engagement in a real world context and so the whole study reflects the occupations occurring in their natural context.

The performance attributes required included the participant moving across the screen or mat, watching the floor or wall screen and making suggestions about what movements to make if they were attendant-propelled. The precautions and contraindications for the case included selecting a projection that used no strobe lighting effects, and therefore would not cause a participant to fit. The selected projections were age and gender neutral. The behavioural demands of the case included behaving in a socially acceptable but playful manner. The cognitive demands of the case included realising that their movements caused the alterations to the projection. Supporters, projection equipment and software, screen/mats and an audio system were required.

A room was required that was large enough for several participants to use the projection at once, with dimmed lighting to enhance the projection, and an audio system to portray the auditory reactions of the software to movement. A stable, aligned supported posture was required to maintain a sitting position. All the participants observed were able to

influence the installation e.g. by directing supporters about how to move the wheelchair. Attention to the projection assisted the maintenance of concentration throughout the case. Their choices and discussion of the case could have enhanced the participant's knowledge. Communication could be required to direct wheelchair attendants or discuss the case. The participant's role was to stimulate the projection to react to their movements. For some, the installation linked to their interest in or experience of other large celebratory events, computers, fireworks, autumn leaves, and/or water. The selected projection was as appropriate as possible for the group and the individuals who made it up.

The installation was available to participants for ninety minutes in total, on a drop-in experimental basis, with some participants staying longer than others. As the installation was one of many leisure opportunities provided during a sensory spectacular event (Stonier, 2008). Observations took place for the first forty-five minutes once the participant had understood how to engage with the case. The rejection of data from participants who used the installation for fewer than forty-five minutes enabled comparison of occupations and engagement of equal durations. On the occasion that the observations were conducted the researcher was seated (facing the group) approximatley 3 feet higher than the participants to see them all.

5.3.6 Making Music group

The Making Music group was a regular weekly event, facilitated by a volunteer who used a record deck and some simple musical instruments which participants could shake or bang. Well-known music encouraged participation, which included wheelchair dancing with their attendant or humming along. Participants (either at the observed session or at a previous session) had requested the music selected. It was therefore a mix of music genre. Although the choice of music was generally age appropriate, occasionally there were requests for music from a stage show or a television show.

Participants could experience auditory, visual, tactile, vestibular or proprioceptive stimulation. The case was presented in a big public space but with the door closed to reduce stimulations from other rooms and corridors and to contain the noise emanating from the room. Participants had the opportunity to hear the music, sing and play musical instruments. The conversations between supporters and participants, added to the noise. As in the other cases there were no ambient smells, the automatic air fresheners were silent and the room was at a comfortable temperature for non-mobile participants. The likelihood of detecting touch sensation in response to movement with in wheelchairs and clothes was reduced by the participants' limited mobility. Furthermore, participants were able to sing, or to play musical instruments, or to wheelchair dance. The music group occurred in a light and airy room with the temperature adjusted to suit non-mobile participants. The participants could see the disk Jockey, equipment, the other participants, their supporters and musical instruments. Banging the musical instruments, nodding, or swaying could have caused proprioceptive and tactile stimulation. Wheelchairs of participants who danced moved around the floor and therefore these participants could have experienced vestibular stimulation as well.

In a laboratory situation this case would have occurred in a context similar to the one offered here to reduce extraneous visual, tactile and auditory stimulation. It could also have been possible to collect data about a single participant interacting with a disk jockey or even to have the music provided by a source outside the room so that there was no one with whom the participant could interact. However given that the making music group was a social activity this could have raised issues such as the participant feeling embarrassed, aware of the observation and therefore not behaving naturally. This case brought with it the opportunity for intergenerational leisure (Downs, 2008) since it appeared to interest the participants visitors, which could have influenced engagement. The performance attributes of the case included singing, shaking or banging instruments, moving around the dance floor with their attendant, and chatting to others. The avoidance of music with sudden loud bangs reduced startle reflex reactions.

The physical demands of the case included limb movement, while others remained physically passive. The communication demands placed upon participants included singing or chatting. The behavioural demands of the case included using musical instruments and directing wheelchair dancing. Socially acceptable behaviour included minimising disturbance to other participants. The cognitive demands included recognition and memory of the words or tune, while using the simple musical instruments required an understanding of how to make a sound with the instrument. Supporters, simple musical instruments, a selection of CDs and the host disk jockey (and equipment) were required.

A stable aligned supported posture was required to maintain a sitting position and to maximise upper limb function. Some participants were able to add to the cacophony of sound by manipulating the musical instruments to make a noise, or by singing. Concentration throughout the session required a lengthy attention period. Communication could be required if the participant needed assistance, wished to discuss their experience or to sing along. The music requested did not reflect the cultural background of any single participant. The music appeared to evoke memories and conversation about past events. Participants with a strong musical past could join in or shunned their current ability in comparison with their pre-disability musical skill. The participants appeared to attend regularly and chatted with the DJ or their supporters about the music, their requests, and their preferences. The group lasted for sixty minutes, with participants staying for the duration. The observation data describes the first forty-five minutes (once the case was underway) of their attendance at the session. During the observations, the researcher sat facing the group, approximately 3 feet higher than the participants to see them all. This position was up on the stage with the D.J. and so the researcher appeared to be helping (a role that reduced the sense of observation).

5.3.7 Interactive Drama

Interactive Drama requires the audience to participate as 'Spect-Actors', with their interventions becoming part of the performance. During this case, the performers engaged participants, staff, volunteers and family members in their world, listening and responding in character. The characters valued everyone's contribution by accepting everything they were told and using it to develop their story and interactions. The Interactive drama performance occurred in a sunlit day room with no ambient smells or noises, which was kept at a comfortable temperature for non-mobile participants. The likelihood of detecting touch sensation in response to movement with in wheelchairs and clothes was reduced by the participant's limited mobility. The participants could hear speaking, music and singing. Participants (not at risk of aspiration) had "wine" to drink during the ballroom scene and so experienced its taste. Furthermore, participants had props to hold or use and these could have generated tactile stimulation if held, and when struck against another surface. The participants had the opportunity to see the performers, their supporters, each other, the costumes and the props. Using the props and costumes, moving to the rhythm of the music, nodding their heads could have led to the participants experiencing proprioceptive stimulation. The wheelchairs of those participants who were acting were moved around the floor offering vestibular stimulation. Furthermore, other participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing vestibular stimulation. Therefore, for some participants the case included elements of proprioceptive, taste, touch, hearing, seeing or vestibular, sensation.

The participants experienced this real world situation rarely. However, in a laboratory situation this case would have probably involved data collection within a theatrical context similar to the one offered here, to reduce extraneous visual, tactile and auditory stimulation. It could also have been possible to collect data about a single participant interacting with the performers alone so that there was no one else for the participant to interact with, removing even the supporters. Given that watching a live performance is usually a social activity this could have made the audience member feel embarrassed, aware of the observation and therefore not behaving naturally. Proprioceptive and vestibular stimulation would have varied depending on whether the participant was able to move or respond to the performers etc. This case brought with it the opportunity for

intergenerational leisure (Downs, 2008) since it appeared to interest not only the participants but also their visitors and supporters, which could also have influenced engagement. Because this was a novel case, removing the social element to this case could have greatly influenced engagement. The option of offering this case in a socially isolated or laboratory context was inappropriate because data collection was about occupational-engagement in a real world context and so the whole study reflects the occupations occurring in their natural context. The precautions and contraindications included the avoidance of offering liquids to participants with dysphagia. The performers avoided engaging with participants with challenging behaviour. The performers were very careful to acknowledge the participants' age, culture, experience and gender. The behavioural demands of the case included accepting and holding the props. In order not to detract from other participants' enjoyment, socially acceptable behaviour was expected. Responding to the performers appropriately involved repeating lines as prompted or responding when addressed by the characters. The cognitive demands include remembering lines, following the story, and remembering to attend performances. The resources required included supporters, props, scenery, and performers. The space used was a room, arranged so that the stage and props were in the middle and away from the entrance. Dimmed lighting demonstrated the boundaries between different scenes. Maintaining engagement, attention, and concentration throughout a performance appeared tiring for some participants. Memory and understanding of what was going on influenced the choices made, the props used, and discussion of the performance. Communication was required to request assistance, discuss the case, or direct the wheelchair attendant.

This experience involved a change in routine for participants and supporters. The participants' role when participating in the interactive drama was to stimulate the characters and influence the performance. For some, interactive drama was an opportunity to link their experience of theatre, the themes portrayed and their current situation. Participants varied in their personal, cultural, spiritual and clinical context. As with the other occupations observed, the researcher placed herself on a stool behind the stage and to one side, whilst being as unobtrusive as possible.

5.3.8 Aquability session

Aquability has been variously described as a pool based recreational activity (Stonier, 2008), and leisure sessions held in a pool (Cunningham *et al.,* 2012). Each Aquability session was participant-centred, including choosing their own music and water-based activities. Being in the water potentially leads to a greater level of interaction between supporters and participants, whilst enabling participants to gain self-confidence by determining the nature of the sessions themselves. Aquability offers participants the potential to experience olfactory, auditory, visual, proprioceptive, and vestibular and touch stimulation. A session required access to a hydrotherapy pool, a hoist, support staff, plus equipment such as floats, water pistols and balls and so could only have been provided in a pool context. Participants could then float, relax, exercise, play games, or swim as they chose. The hydrotherapy staff had initially assessed all participants who used the pool. Contraindications included mood, fear, or health-related conditions such as vomiting and diarrhoea, chlorine sensitivity, uncontrolled epilepsy, heart-related symptoms, pyrexia amongst others. Special considerations included gender and age awareness of the case and the supporters.

This is a real world situation that the participants experienced occasionally and so could have felt like a special occasion. Given the need for a pool, a laboratory situation would have probably involved a context similar to the one offered

here. In this study, sensory stimulation would have resulted from their being more than one individual in the pool at the time, which was unavoidable in a potentially life-threatening environment. Proprioceptive, touch and vestibular stimulation occurred due to the movement of the participant once in the hoist and the water. The movement of the water and those participants who were moving to the rhythm of the music, nodding their heads, feet and arms, could have added to the experience of proprioceptive stimulation. The participants could have been moving to the rhythm of the music, or moving, rocking or nodding their heads, feet and arms, and so experiencing vestibular stimulation. The participants had the opportunity to play their own music selection, and auditory stimulation would have included the echoing and amplification of the noises in the room cause by the water, when people spoke, sang, laughed or shouted. Participants who were aware of the chlorine in the pool experienced smell or even taste. The latter, was important to avoid because of the risk of aspiration. Each participant was hoisted into the pool, which would have led to the participants feeling the sling, and their swimming costume prior to habituation. They would also have felt the sensation of the tides and ripples generated. Furthermore, the participants had toys and games to hold or use and these would have generated tactile stimulation. The pool also offered quite a hard atmosphere since the floor; walls and pool sides were all tiled and were cool to the touch. The pool was a very light and airy hexagonal room. The opened curtains let in the sunshine and the room was warm enough for non-mobile and less than normally dressed participants. Visual stimulation would have resulted from the brightly coloured games, their supporters, and the stained glass in the roof, and the patterns that this made in the water and the toys available.

The physical demands of the case included the effects of hydrostatic pressure and the temperature of the water (34^{o}C), which could be tiring, but could reduce muscle tone, pain and even choreaform movements. The effects of buoyancy may enable participants to move their bodies in ways which gravity would normally restrict, sometimes allowing them to stand or walk. With the support of floats, they floated independently, rather than being limited by gravity or the weight of their own bodies. Some participants kicked with their legs or move their arms a little. They could therefore have chosen to exercise to try to maintain this improvement, through actively attempting to move or play games with floats or balls. Equally, they could have preferred to relax and simply float and enjoy the current and the sense of being unencumbered. Participants appeared more playful in the pool. Their communication level appeared to increase, despite the fact that they did not have access to their usual assistive technology. The behavioural demands of the case included responding to the staff and volunteers. The cognitive demands of Aquability were dependent on the activity chosen e.g. aiming a ball towards a goal, or just floating listening to music. Each individual's participation varied according to his or her personal, cultural, spiritual and clinical context. Aquability offered a different environment and a new experience of their body for participants. This could have been a regular but infrequent occurrence if the individual enjoyed it (taking place every two to three weeks). The participants' role in the pool was to focus on their own wishes and instruct the supporters about what they would like to do.

5.4 Analysis of the observations findings about engagement

The ICER captured categorical data about the engagement of the participants. As a result, non-parametric tests were used initially (see appendix vi). More importantly, descriptive statistics and pattern matching compared a pattern in the results (raw data presented in Appendix xvii) with the anticipated patterns of engagement based on professional knowledge about the effect on occupational-engagement of sensory stimulation. Pattern-matching involves no precise comparisons of

the significance between data but focuses on the pattern overall (Yin, 2009), therefore the statistical analysis is presented in appendix vi. As a result, chapter seven will discuss some explanations for the differences between anticipated pattern and actual data (Yin, 2009), giving an overview of changes over time in Figure 6. The data were not suitable for analysis using through time and non-linear regression statistical techniques, and therefore the difference between the anticipated and actual results could not be statistically analysed.

To address the second research question 'How does engagement in casual leisure occupations (by individuals with NPC) alter with different levels of sensory attributes'?, the researcher was looking for signs of engagement. The dependent variable being an engagement category (Field, 2009). The data produced was categorical and therefore not equidistant and continuous, with the category titles being attributed number; from active engagement (5), passive engagement (4), undifferentiated engagement (3), passive non-engagement (2), to active non-engagement (1). A case methodology with replication has been used, making this a multiple, case study.

Swets (1961), suggested that sensory thresholds followed a normal distribution of combined sensory levels. While, Luce and Edwards (1958) and Swets *et al.* (1955) implied that at the extremes of stimulation intensity, environmental interference could influence the detectability of sensory stimulation (masking or exaggerating it). Theory (e.g. Howell, 1999; Wood, 1991) would suggest that sensory processing may influence engagement by producing more or less information than the RAS could cope with. Therefore, a normal distribution in engagement with under or over-stimulation decreasing the engagement category was anticipated. The difference in engagement category between passive engagement and passive non-engagement, could arguably relate to the participants degree of sensory-overload, with those who were participating passively appearing less overloaded than those who were passively non-engaged. However, a lack of awareness of sensory processing may mean that the effects of inappropriate sensory stimulation may be perceived by onlookers as fatigue (see textbox 1) rather than sensory-overload.

Figure 4 shows the median participant engagement in each of the cases, based upon the median engagement categories of each participant from each case observed. The engagement categories for the Listening and the Control case appear substantially lower than for the other cases. It would also appear that the median engagement categories increases as the number of sensory attributes presented increased.

Table 11 and Figure 3 demonstrates the occurrence of each engagement category for each case, while Table 11 and Figure 4 demonstrate the trend of increasing median engagement with increasing levels of sensory attributes. The median engagement trend dips during the Interactive Video case, perhaps due to the novelty of the case, which meant that the initial observations could have illustrated thinking, familiarisation and understanding time on the part of the participants.

Figure 3 The occurrence of each engagement category for each case

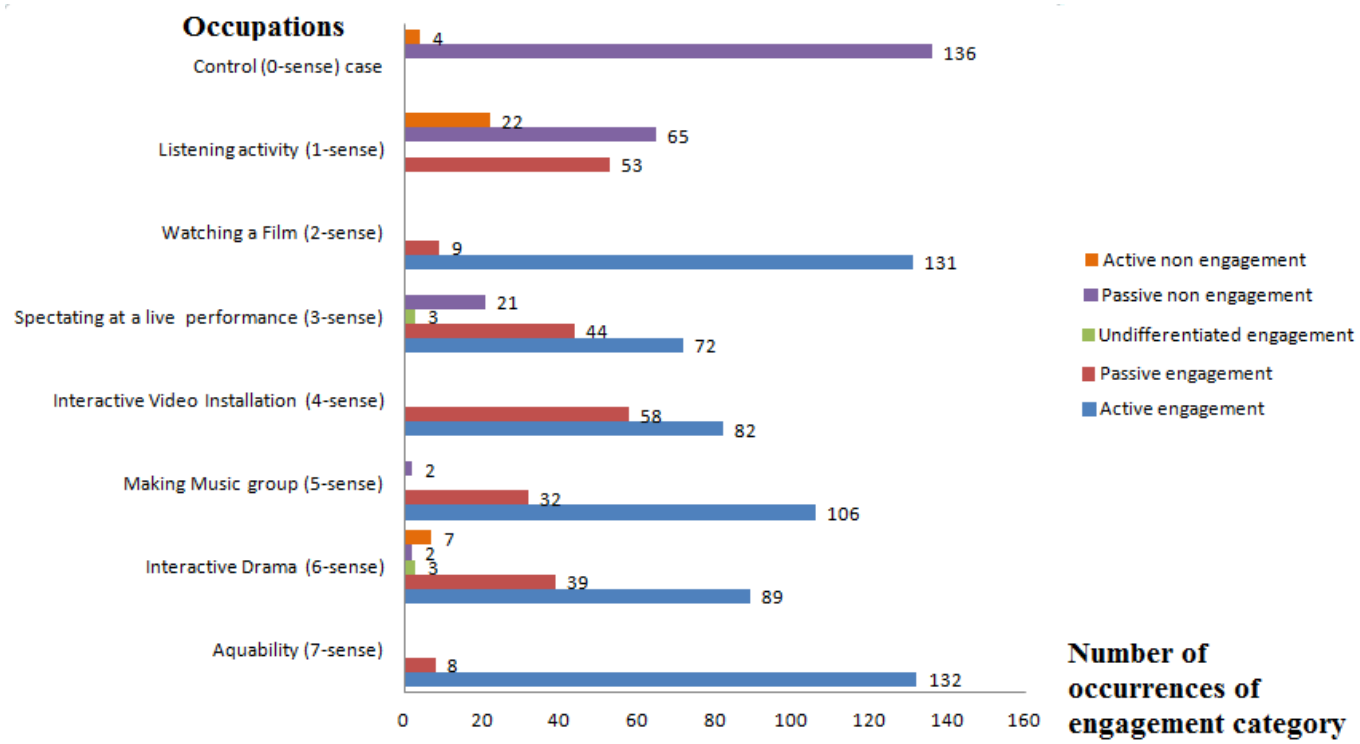


Figure 4 Median participant engagement levels

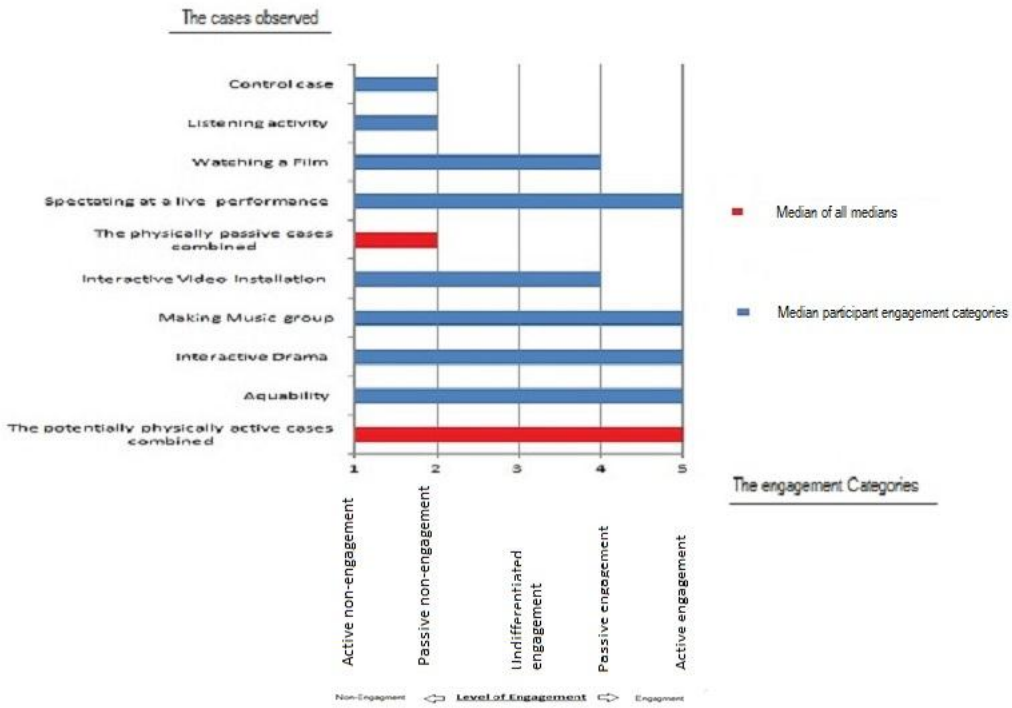
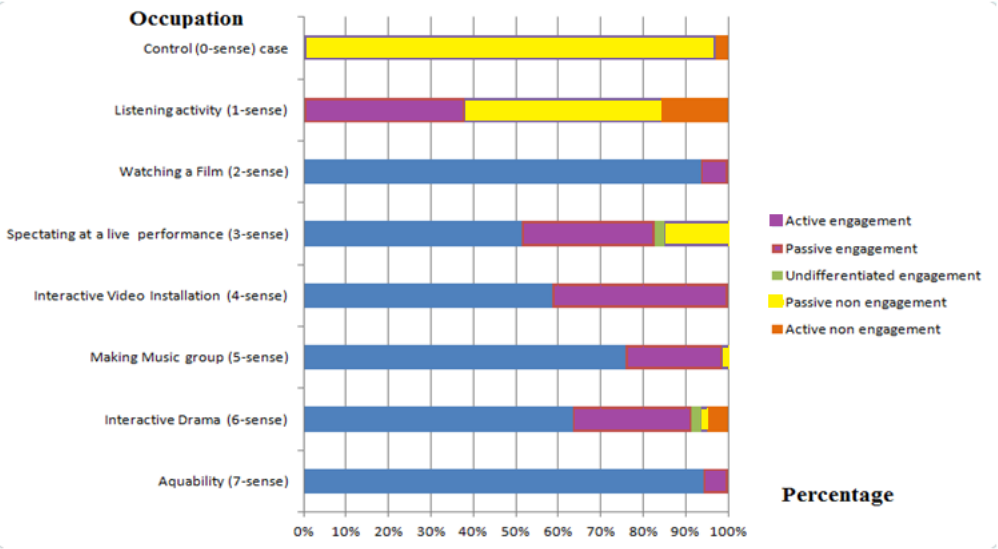


Table 11 Number of occurrences and median participant engagement

levels across cases

				Number of occurrences of each catergory				
	Lowest category of engagement observed	Highest category of engagement observed	Median	Active engagement	Passive engagement	Undifferentiated engagement	Passive non engagement	Active non engagement
Aquability (7-sense)	Passive engagement	Active engagement	Active engagement	132	8			
Interactive Drama (6-sense)	Active non-engagement	Active engagement	Active engagement	89	39	3	2	7
Making Music group (5-sense)	Passive non-engagement	Active engagement	Active engagement	106	32		2	
Interactive Video Installation (4-sense)	Passive engagement	Active engagement	Passive engagement	82	58			
Spectating at a live performance (3-sense)	Undifferentiated engagement	Passive engagement	Active engagement	72	44	3	21	
Watching a Film (2-sense)	Active non-engagement	Passive engagement	Passive engagement	131	9			
Listening activity (1-sense)	Active non-engagement	Passive non-engagement	Passive non-engagement		53		65	22
Control (0-sense) case	Active non-engagement	Passive non-engagement	Passive non-engagement				136	4

Figure 5 The percentage of engagement categories per case



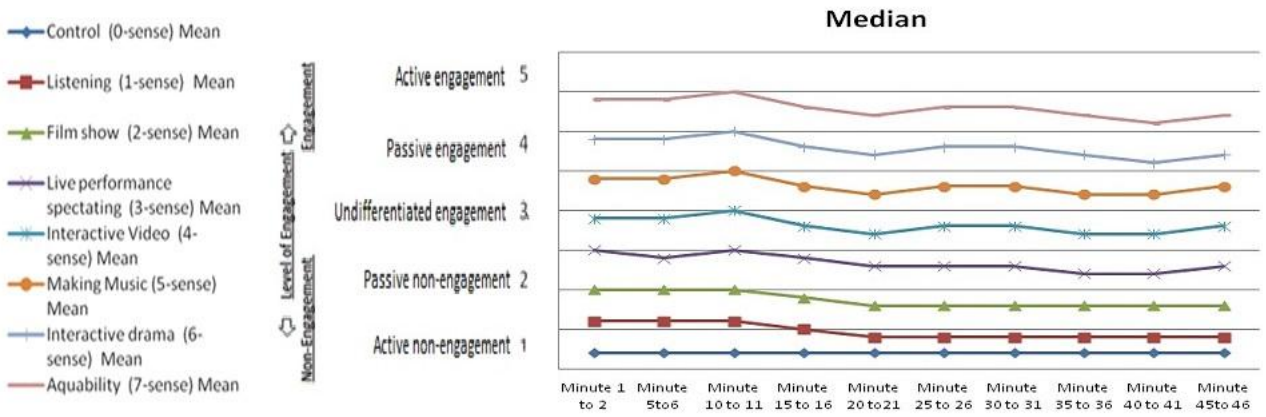
	% Engagement categories per case	% Undifferentiated Engagement categories per case	% Non-Engagement categories per case
Aquability	100	0	0
Interactive Drama	91.4	2.1	6.4
Making Music Group	98.6	0	1.4
Interactive Video	100	0	0
Live performance	82.9	2.1	15
Film Watching	93.6	6.4	0
Listening	37.9	0	62.1
Control	0	0	100

Figure 5 demonstrates the percentage of the total categories each combined engagement category the participants achieved for each case. The aquability session earned 100% of the engaged categories for the case. The interactive drama performance earned 91.4% of the engaged categories, 2.1% of the undifferentiated engagement categories, 6.4% of the non-engaged categories. The making music group earned 98.6% of the engaged categories, and 1.4% of the non-engaged categories. The interactive video installation earned 100% of the engaged categories. Spectating at a live performance earned 82.9% of the engaged categories, 2.1% of the undifferentiated engagement categories, and 15% of the non-engaged categories. The film show earned 93.6% of the engaged categories, 6.4% of the undifferentiated engagement categories. The listening activity earned 37.9% of the engaged categories, and 62.1% of the non-engaged categories. The control case earned 100% of the non-engaged categories.

By combining the levels of active and passive engagement, Figure 5 shows a stronger trend towards engagement. It demonstrates that the Aquability, Interactive Drama, Making Music Group, Interactive Video Installation, spectating at a live performance and watching a film show all achieved engagement categories for more than 80% of their time samples.

The interactive video installation was totally new to the residents being a newly invented technology and being offered at the home for the first time. Aquability was another fairly infrequent experience, which on the whole reduced the constraints of the participants'. The making music group was a popular but regular favourite, which enabled intergenerational leisure. The Interactive Drama project encouraged joining in on many levels and was novel from that point of view although many theatre groups came to the home. Watching a film show was a regular event.

Figure 6 Median engagement categories during each case for each time sample



Time Point->	Minute1to2	Minute5to6	Minute10to11	Minute15to16	Minute20to21	Minute25to26	Minute30to31	Minute35to36	Minute40to41	Minute45to46
control	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement
listening	passive engagement	passive engagement	passive engagement	undifferentiated engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement	passive non-engagement
filmshow	passive engagement	passive engagement	passive engagement	passive engagement	passive engagement	passive engagement	passive engagement	passive engagement	passive engagement	passive engagement
live	active engagement	passive engagement	active engagement	active engagement	active engagement	active engagement	active engagement	passive engagement	passive engagement	active engagement
interactivevid	passive engagement	active engagement	active engagement	passive engagement	passive engagement	active engagement	active engagement	active engagement	active engagement	active engagement
makingmusic	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement
drama	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	passive engagement	passive engagement
aquability	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement	active engagement

Occupational therapists value active above passive leisure and the engagement that results (Desha & Ziviani, 2007; Minato & Zemke, 2006; Trail *et al.,* 2003; Passmore & French, 2000; Law *et al.,* 1998; Passmore, 1998). So it is significant that figure 6 showed a drop from engagement to non-engagement in the cases which offered the participants a passive over a potentially active role. Figure 6 illustrates that, the Aquability case showed a consistent active engagement pattern throughout. The median engagement category was therefore active engagement. The Interactive Drama performance, showed active engagement for 80% of the case before declining to passive engagement at its end. The median engagement category was therefore active engagement. The Making Music case showed a consistent active engagement pattern throughout, so that the median engagement category was active engagement. The Interactive Video installation (perhaps due to its novelty) began with passive engagement, increasing to active engagement before returning to passive engagement during the first half, and showed a consistent actively engaging pattern for the second half of the case. The median engagement category was passive engagement. Spectating at a Live Performance case appears to represent a double curve pattern of engagement, starting at active engagement dropping quickly to passive engagement and then returning to active engagement for half of the case and then dropping back to passive engagement before finishing on active engagement. The median engagement category was active engagement. The Film Show earned a consistent passive engagement category, so the median engagement category was passive engagement. The Listening case appeared to start as a passively engaging case and then trails off to being a passively non-engaging case. This activity has the lowest combined number of sensory attributes, which suggests that engagement could be more at the mercy of the length of the attention span of the participants, with a median engagement category of passive non-engagement. The Control condition showed a consistent passive non-engagement pattern, with a median engagement category of passive non-engagement.

5.4.1 Comparison of engagement between the passive and the potentially physically active occupations

Arguably, passive engagement is not true engagement, while active engagement involves a greater degree of participation. Therefore, the field data included a description of whether the occupational role offered was a passive or potentially an active one. Although Csikszentmihalyi (2002) appeared to discount “Flow” in this clinical group, the concept of the potentially active role appeared similar to the idea of the “possibility of control” which is one of the six attributes of “Flow”, a concept reinforced by Reed *et al.* (2010). Csikszentmihalyi (1991, 2002), Ghani and Deshpande (1994), Sassatelli (1999), Zaman and Vanden Abeele (2007), Jackson and Eklund (2002) and Rupayana (2008) have all suggested that the possibility rather than actual control, is one of the most important factors to cause or maintain flow. Therefore, offering the possibility of a more active role could be enough to make an occupation engagement worthy (Reed *et al.,* 2010), even if not used.

As shown in Figure 4 the cases and the Control condition fell into two groups: potentially physically active occupations, and passive occupations. Figure 4 shows the median engagement category of the grouped potentially active and passive occupations. The passive occupation category and the remainder were averaged to give a median potentially physically active occupation category.

Figure 7 Median engagement categories of the grouped potentially physically active and passive occupations

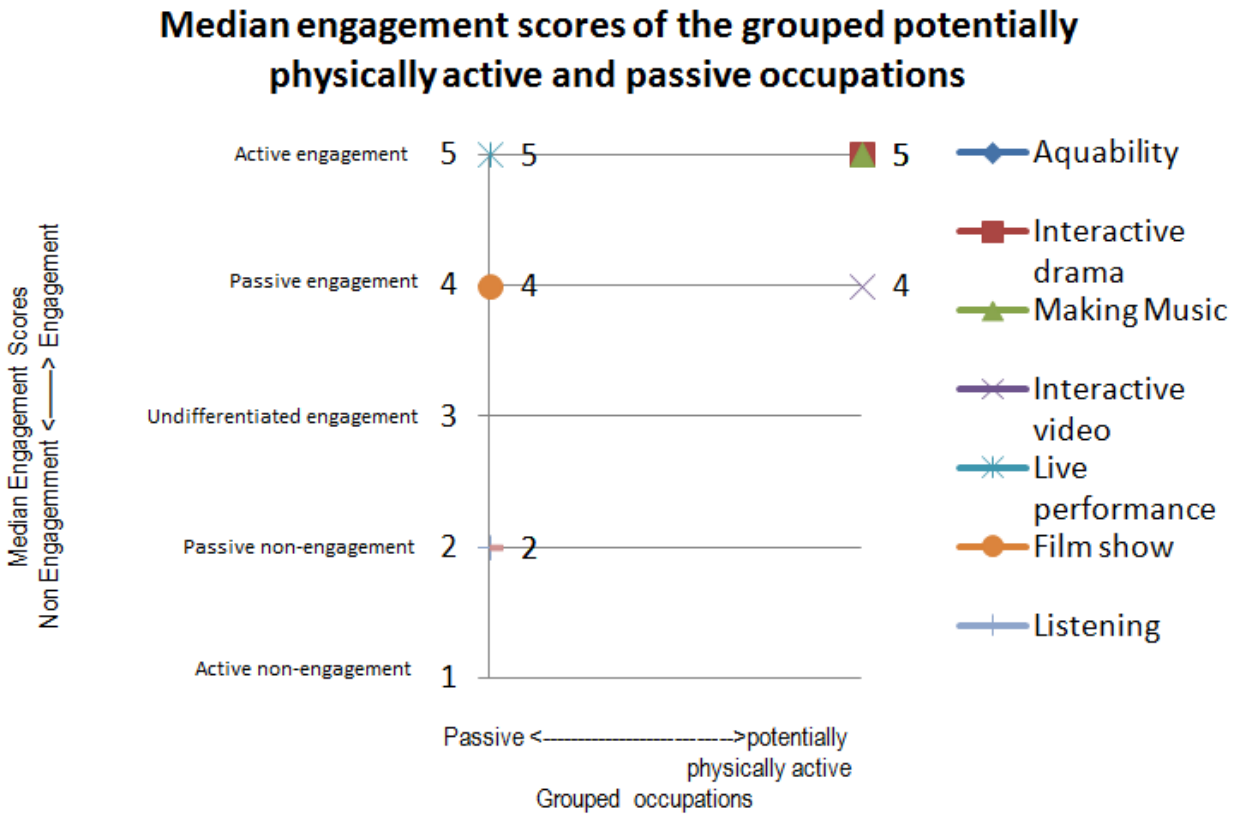


Figure 7 shows the median engagement categories of the grouped potentially physically active and passive occupations. This grouping highlighted that the potentially active occupations were also the ones with the higher supporter-to-participant ratios. For the purpose of this study, supporters did not facilitate the participants in the Control case and the Listening case, to reduce the combined number of sensory attributes that participants received. This could have contributed to the substantially lower engagement level of participants during these cases.

Table 12 presents a comparison of the minimum and maximum sensory stimulation offered by each case, and field data such as the supporter-to-participant ratios and the passive or potentially active nature of the case. This table demonstrates that a low supporter to participant ratio was observed in the Control (0:1), and in the Listening (0:1) and Film Show (0.3:1) cases. Mid-level supporter-to-participant ratios occurred during the Live Performance (0.5:1), the Interactive Video installation (0.66:1), the Making Music group (0.75:1) and the Interactive Drama performance (0.9:1). Aquability offered a much higher (3:1) supporter-to-participant ratio. The cases could also be grouped according to whether the case was novel or frequent. The Control condition, Listening, the Film Show, the Live Performance and the Making Music group occurred frequently and were therefore familiar to the participants, while the Interactive Video installation, the Interactive Drama performance and the Aquability cases were novel or infrequent occurrences. Whether a case was physically active or

passive was evenly divided, with the Control condition, Listening, the Film Show and the Live Performance being noted in the field notes as passive experiences, while the Interactive Video installation, Making Music group, Interactive Drama and Aquability had the potential to involve a physically active role.

Table 12 Comparison of minimum and maximum sensory involvement, supporter-to-participant ratios and the passive or potentially active status of each case

	Control (0-sense) case	Listening activity (1-sense)	Watching a Film (2-sense)	Spectating at a live performance (3-sense)	Interactive Video Installation (4-sense)	Making Music group (5-sense)	Interactive Drama (6-sense)	Aquability (7-sense)
Supporter-to-resident ratio	0:1	0:1	0.3:1	0.5:1	0.66:1	0.75:1	0.9:1	3:1
Supporter to resident ratio groups	low			mid				high
Novel/ frequent	frequent	frequent	frequent	frequent	novel	frequent	novel	novel
Physically active/ passive	Passive	Passive	Passive	Passive	Potentially active	Potentially active	Potentially active	Potentially active
minimum senses	0	1	2	2	3	4	3	6
maximum senses	2	1	2	3	4	5	6	7
Median engagement category	2	2	4	5	4	5	5	5

5.4.2 Comparison of supporter-to-participant ratios with engagement

Cermak and Mitchell (2006) proposed that an individual's SI was greatest within a 1:1 individual to supporter ratio, suggesting that group interventions require higher-level integration skills than those of a 1:1 nature. The field data about the ratio of supporters to participants highlighted this as another factor that could have influenced the participants' engagement (Creek, 2010). As shown in Table 12, the data fell into three subgroups:

- Cases grouped according to a **Low** or > 0.5:1 supporter-to-participant ratio showed the median engagement level to be passive non-engagement.
- Cases grouped according to a **Mid** supporter-to-participant ratio, between 0.5:1 & 1:1 showed the median engagement level to be active engagement.
- Cases grouped according to a **High <** 1:1 of supporter-to-participant ratio showed the median engagement level to be active engagement.

Figure 8 Median engagement across cases with a >0.5:1 (low), between 0.5:1 & 1:1 (mid) and < 1:1 (high) of supporter to participant ratio

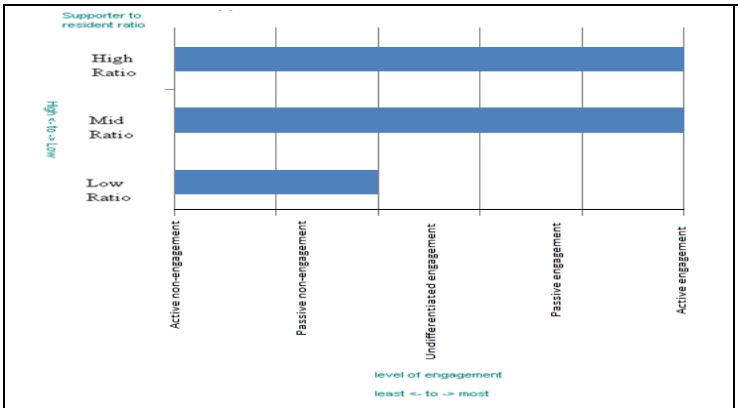
	Control case	Listening activity	Watching a Film	Spectating at a live performance	Interactive Video Installation	Making Music group	Interactive Drama	Aquability
Median engagement category	2	2	4	5	4	5	5	5
Supporter to resident ratio groups	low			mid				high

Figure 8 shows that the supporter-to-participant ratios of the low, mid and high ratio groups could have influenced the participants' engagement. The Control and Listening cases involved low stimulation, including a low supporter-to-participant ratio. The Aquability case on the other hand had a high supporter-to-participant ratio for safety reasons. However, a question that remains unanswered is why the supporter-to-participant ratio differed so markedly, across the cases such as the Film Show, Live performance, Interactive Drama, Making Music and the Interactive Video installation. For a reason that is unclear, as the sensory attributes level of each case increased, so did the supporter-to-participant ratio.

5. 5 Validity and credibility of the results

Validation of the findings included auditing participants post occupation feedback, discussion of the findings with participants and their families at “Meet the researcher's” events held by the home. These events involved presentations using PowerPoint, posters, and 1:1 discussions. Furthermore, leaflets and newsletters went to all family members, residents and volunteers.

Validation of the findings also occurred at research seminars, and staff feedback sessions. Families had additional opportunities to validate the findings at groups such as the Patients’ Advocacy Committee, the Carers’ Support Group and the Carers’ Research Review Forum, hosted by the home. The comprehensiveness of the definitions of the engagement categories defined by the ICER was a helpful factor in determining its transferability beyond the domain of profound and multiple developmental disabilities, and this helped to ensure the accurate coding of the data, along with the findings of the interview with the Residence Manager. The plausibility of the findings can be reinforced by reflecting upon the lives of profoundly disabled individuals, by visiting the organisation studied or reviewing video clips broadcast by the BBC, on the home’s website, or by watching the film “*The Diving Bell and the Butterfly*” (based on the book by Bauby (McCammon, 2008).

5.6 Reliability and Transparency of the results

Repeatability is the variation in measurements taken under the same circumstances and could be caused by intra-observer variability. Repeatability involves the same measurement procedure, location, measuring tool, used under the same conditions or as in the case of this thesis all the data was collected by a single observer over a very short period of time (within 2 months).

Internal reliability measures the extent to which all of the items of a test measure the same thing. Cronbach's alpha, a statistic calculated from the correlations between pairs of items, can measure internal consistency, which ranges between zero and one. Because there was no missing data this test produced trustworthy results, having examined the extent to which the ratings were consistent, dependable and internally valid, and measuring the same construct. Cronbach's alpha's internal validity statistics can be reframed as: $\alpha \geq .9$=Excellent,$.9 > \alpha \geq .8$=Good,$.8 > \alpha \geq .7$=Acceptable,$.7 > \alpha \geq .6$=Questionable,$.6 > \alpha \geq .5$=Poor,$.5 > \alpha$=Unacceptable. The test-retest reliability of the observation data indicated that the measures were highly reliable both across time period, and (as demonstrated during the piloting phase) between raters. Two cases were found to have a questionable coefficient (lower than 0.70). The reason for the low alpha was not due to a lack of consistency across time, but rather it was due to the similarity between them and the Control condition. For the Control condition, almost all of the engagement level ratings were passive non-engagement (136 of 140 ratings). For the Film, almost all the engagement level ratings were passive engagement (131 or 140). Therefore, the low coefficients shown in Table 13 seem to be caused by this low variation, rather than any inconsistency in ratings across time periods.

Table 13 Reliability coefficients of time-sampled observation data

	Main data
	Consistency across time
Control	0.53
Listening	0.81
Film Show	0.64
Live Performance	0.91
Interactive Video	0.88
Making Music	0.80
Interactive Drama	0.77
Aquability	0.88

Several articles presenting the findings have been published (see chapter six). However, the repeatability of this study is problematic. The occupational science focus of this study means that it could be repeated by an occupational scientist. The findings of the study could be transferable to other settings or to another clinical group, because the methodology has been made explicit in this thesis and published (including the data collection tools) in peer-reviewed articles. However, because of the specialised nature of the home and the profound level of disability that the participants experienced, this transferability would be limited. By their very nature, casual leisure occupations are situation specific and occur in the moment, and so the cases would not be repeatable. Therefore, the findings appear to be transferable but not generalisable beyond other individuals with NPC.

5.7 Summary

The ICER captured the engagement category of the participants, in a multiple, case study. Therefore, descriptive statistics were used to describe patterns in the results. Swets (1961), suggested that sensory thresholds followed a normal distribution. Additionally faulty sensory processing may influence engagement if the RAS is not gating efficiently. Therefore, a normal distribution in engagement with under or over-stimulation decreasing the engagement category was anticipated.

Conversely, Figure 4 demonstrates a trend for increasing engagement with increasing levels of sensory attributes. Additionally, supporter-to-participant ratios appear to influence engagement, as do the differing roles offered (between passive and potentially active occupations). By aggregating the engagement categories, Figure 5 shows a stronger trend towards engagement as opposed to non-engagement overall. It demonstrates that the Aquability, Interactive Drama, Making Music Group, Interactive Video Installation, spectating at a live performance and watching a film show all achieved engagement categories.

Arguably, active engagement involves a greater degree of involvement. Therefore, the field data included a description of whether the occupational role offered was a passive or potentially an active one. This data was collected because offering the participant the potential or possibility of a more active role could be enough to make an occupation meaningful (Reed, Hocking and Smythe, 2010) and engaging, even if not used. The passive occupations produced a median of passive non-engagement, and the potentially physically active occupations produced a median of active engagement.

Aggregating the data into two groups in Figure 7, highlighted that the potentially active occupations were also the ones with the higher supporter-to-participant ratios. This could also have contributed to the substantially lower engagement level of participants during the Control case and the Listening case.

Figure 8 and Table 12 demonstrate that cases with a Low or > 0.5:1 supporter-to-participant ratio achieved a median engagement category of passive non-engagement. Cases with a Mid supporter-to-participant ratio, produced a median engagement level of active engagement, as did the cases with a High < 1:1 of supporter-to-participant ratio.

Chapter SIX

6.0 Review of the researcher's publications about leisure

This chapter overviews the researcher's publications about leisure, between 2005 and 2012, providing a brief commentary on each paper. Appendix xv lists all the author's publications to date. Appendix xvi discusses some publications by other authors, which acknowledge the influence of the researcher's publications.

2005

Fenech's (2005) critical discussion of the literature on leisure occupations, proposed that such occupations combat boredom, enabling the maintainance of a social identity been lost when work roles ceased. Literature on the general population, the effects of unemployment, chronic illness, and stroke were discussed (since profoundly disabling strokes can become NPC). The author also considered the role of meaningful occupation in the lives of individuals with NPCs but reviews little research about individuals with NPC directly and without giving a search strategy. The article appeared biased towards journals from Australia and the UK, potentially missing important information. No critique of the literature was offered, because it was intended as a discussion article, and so might also be biased towards literature that supported the author's arguments (Oxman & Guyatt, 1988). Concerns can also be raised about the definition used for leisure within this article. According to Godbey (1985), there should be freedom from obligations, work, and cultural demands and the freedom to try out preferred occupations. However Prost (1992), noted that individuals with disabilities experienced limited freedom of choice because of limited access to leisure occupations. Currently, problems of accessibility, lack of employment and social stigma restrict the freedom of community participation for individual with disabilities; however the London 2012 Paralympics may change attitudes. The article describes the importance of leisure time in the lives of the general population and of the costs of losing meaningful occupations. The article therefore highlights the need for meaningful leisure occupations for individuals with NPC and for more research to be conducted in this area. It has suggested that leisure occupations are important to the self-image of participants; some recent writers say that individuals with disabilities engage in social leisure occupations to a different degree, but the level of depression following neurological disability would suggest that it is still not enough. Above all society is prompteds to acknowledge the right of all human beings to engage in meaningful occupations to maintain their identity and avoid boredom. As a result of this insight the article suggested that facilitating leisure engagement should begin as soon as possible after the individual is medically stable to allow them to gain a renewed sense of self.

2006 & 2007

During 2006 & 2007 two service evaluations were conducted by the researcher. These were the Mapping Discussion Document (RHN 2006) which reported a service evaluation conducted just before the interactive drama project (which happened in 2006 and was published as Fenech 2009), and the Leisure Satisfaction Audit Report (RHN 2007) which reported a service evaluation conducted after the interactive drama project (in 2007). Both produced recommendations for

implementation as part of the homes Recreation and Leisure Service action plan for 2007- 8. These had an impact on the home's staff, on informal carers and on the residents themselves. A summary of the recommendations and findings of these service evaluations overlapped and reinforced each other and so are presented together to avoid repetition. The resource packs (which were recommended and later produced) contained practical ideas to inspire the provision of leisure opportunities both instantaneously or to plan for future events. Having collated best practice information from around the world, this information was shared with the Recreation and Leisure Service to inspire service development and resident focussed leisure opportunities. A supporter to resident ratio of 1:2 was proposed to have a significant effect on resident engagement during group occupations. Recommendations included the computer room opening at weekends, as well as the provision of activities which were age appropriate, challenging, as well as those that would enable residents to express their gender identity. For example those activities organised by residences might include a trip to a pub, while the social & recreational team develop a relaxation room e.g. for manicures. Therapists were encouraged to observe their residents carrying out leisure activities as part of their informal assessments, followed by sharing recommendations about adaptations, so that all staff could implement them. As a result, an information sharing process was designed to enhance relationships between the occupational therapy and physiotherapy departments and the Recreation and Leisure Service staff. Fact sheets on outing venues across the southeast were prepared, to support staff and visitors to arrange days out. The home induction programme now includes a section on leisure, alongside human rights, self-identity, and the risks posed by occupational deprivation. Training about how to enabling leisure engagement began on Huntington's Disease unit, and was rolled out across the home, by the end of the fellowship. More opportunities for movement such as extend groups, water shiatsu, Aquability, Music and Movement groups were suggested. Additionally, Boccia was added to the programme of leisure opportunities.

For informal carers, links to leisure associations for residents to access were made available on the home's website/ Intranet. Additionally, relatives were invited to enter the water with their family member during Aquability sessions or to participate with residents in creative projects. To accommodate the preferred activity periods of residents, matinee show trips as well as early evening activities were organised. Activities that allowed for personal challenge and choice also began, e.g. taster sessions. The Volunteer Coordinator changed to focussing on recruiting 1:1 volunteers, with specific skills to suit the individual resident. A permanent library space for CD, DVD, and Audio books was created, in addition to the mobile library service, and links were made with local public libraries to broaden the range of items on offer. Improving the accessibility of the activities list available to residents in hard copy and online, including formatting, raising its profile, stressing the importance of leisure activities to staff. More outdoor leisure opportunities were suggested. Therefore, the horticulture group, the breath of fresh air campaign, and animal visiting were started. Exploring the possibility of a Drop in Leisure Facility, involved submitting an unsuccessful bid for funding for capital projects and revenue for staffing. However, the computer room and Art room were opened at weekends. Further research was suggested to highlight passive but satisfying activities e.g. through sensory or virtual reality. Across the home, leisure was given a higher profile and a wider range of creative and physical activities was suggested which Cunningham et al (2012) as being in existence. A wider range of themed events was suggested, covering all faiths and nationalities represented among the residents e.g. Chinese New Year. An active programme of events was organised on each residence by designated link staff.

2008

In 2008, a special edition of the journal, NeuroRehabilitation was published which focused on leisure. The editor was the researcher who invited contributions from Israel, the USA, Canada and the UK.

Fenech & Baker's (2008) article in the special edition explored sensory diet based leisure lifestyles as a means of improving the quality of life of individuals with NPC. Two case studies were presented featuring a woman with Huntington's disease and another with Locked-in syndrome. Each sensory diet was based upon a sensory profile assessment, which highlighted the individual's sensory preferences. Both individuals were satisfied with their casual leisure choices. The case study design incorporated detail about the occupations and methods of enabling occupational engagement. Each case was an individual participant, who experienced a casual leisure lifestyle which encompassed a balance of the full range of sensory stimulation. Both individuals were known by those people around them for having a clear sense of 'self-identity'. Fenech & Baker (2008) suggested that the risk for individuals with NPC was that their casual leisure occupations might focus on one or two senses and due to the perceived lack of options available, risking the overuse of these senses, leading to boredom. Further research to explore the experience of individuals whose leisure lifestyle involves a sensory diet, as compared to uni-sensory or limited sensory leisure experiences, was suggested. By its very nature, a case report proves a point, this article was therefore not bias free and cannot be generalised, being specific to two individuals. The article advocated greater use of sensory diet's in the domain of NPC and in relation to leisure provision. It also, proposed a direction for future research to provide casual leisure opportunities for individuals with severe cognitive dysfunction.

Another article was Fenech's (2008) editorial introducing the special edition, this linked all the articles together stressing the need for adapting activities to the needs of the individual, whilst highlighting some existing barriers to leisure participation. The central assumption of this opinion piece and the entire special edition was that leisure was a key variable in the quality of life of individuals whose opportunities for employment and self-care were rare, to the point that leisure provided their main resource for avoiding occupational deprivation. The editorial emphasised how leisure enhanced cognitive activity, delaying or preventing the occurrence of mental health problems. The editorial also emphasised how leisure enhanced goal orientation and purposefulness, creativity, feelings of altruism, and expression of individuality. The editorial also stressed the importance of a of surroundings throughout the day. The attitude of others and the choices of the leisure supporters were also suggested to influence the leisure occupations chosen. The editorial provided examples to confirm the information provided by authors such as Bhogal *et al.* (2003) in describing the reduction in leisure occupations after a stroke. The arguments made throughout the editorial listed many of the meanings derived from occupational-engagement published at that point. At the time of publication it was suggested that this bringing together of all these benefits into one editorial was quite novel.

Another article published by the researcher in 2008, drew together occupational science, positive psychology, and therapeutic recreation literature to highlight how vital a sense of identity and meaningfulness is to well-being and quality of Life. Fenech's (2008) opinion piece discussed why leisure occupations could be described as meaningful, and beneficial for health, well-being and quality of life.

In 2008, the Maltese Journal of Occupational Therapy published an article to link the residents experience of leisure to the literature of occupational science. This opinion piece offered no search strategy, or critical appraisal of the literature, therefore it may have been biased towards literature that supported the author's arguments (Oxman & Guyatt, 1988).

2009

Fenech's (2009) article compared a two week long interactive drama project, with a control condition, to examine the effect of interactive drama on engagement (n=74). Three data collection methods were used: semi-structured interviews with residents and staff, time sampled observations of engagement, and observers' free text notes to allow triangulation of data, to give more robust results (Denzin, 1988; Robson, 2002). This study involved discussions with staff to identify what leisure occupations the individual was carrying out, their diagnosis, and cognitive dysfunction and to establish their usual behaviour. Observations of engagement occurred, noting the engagement of 14 residents every five minutes during each performance (only one performance is presented in Chapter Five). Comparison of these data with the resident's normal resting behaviour indicated their engagement category. Free text field notes and a structured observation format were used because there was no suitable observation schedule available for use with individuals with NPC. A semi-structured interview was conducted in the week following the project with 31 (41%) of the participants. The topics covered were based on the facets of meaningful occupation documented in the occupational science literature, their level of enjoyment and anticipation of each performance, and whether their social interaction had changed as a result of the project. The interviews also explored their satisfaction with their contribution to the performances, and whether they had learned anything. Residents answers were documented verbatim, coded, and analysed using a thematic analysis, to supplement and verify the observational data collected during the performances. During the interview, residents were asked to mark their enjoyment on a 10 cm long scale, from which their percentage enjoyment was calculated. Additionally, 27 staff completed a questionnaire (distributed via email to nursing and allied health professional staff and returned in hard copy anonymously). This was to ensure that there was no influence or interpretation of staff opinions prior to the thematic analysis. The topics covered in the staff questionnaire included their perceptions of the residents responses to the project (including social interaction levels, mood and confidence) and the impacts that it had on their practice. They also described the project's impacts on staff: resident relationships and the importance and meaning of such activities. Residents' engagement was coded by the researcher at each of 12 time samples but the categories were aggregated so that the entire period was divided into quarters into 12/12 9/12, 6/12, 3/12, 0/12.

'Fully engaged' indicated that an individual was demonstrating active or passive engagement for the whole performance, i.e., all 12/12 of the observations (conducted every 5 min) over the 60-min period of the performance.

'Mostly engaged' indicated that an individual was engaged for 9/12 of the observations over the 60-min period of the performance.

'Partially engaged' indicated that an individual was engaged for 6/12 of the observations over the 60-min period of the performance.

'Low engagement' indicated that an individual was engaged for 3/12 of the observations over the 60-min period of the performance.

'No sign of engagement at all' indicated that an individual gave no sign of engagement at any stage in the performance, i.e., they were engaged for 0/12 of the observations over the 60-min period of the performance.

The coded data was reviewed for patterns, such consistent engagement, or becoming more or less engaged over time. Eighty residents were invited to participate and 74 (92.4%), aged between 22 and 88, eventually did so. Fifty-five (74.3%) of the residents had moderate to severe cognitive dysfunction. A further 16 (21.6%) had no or only mild cognitive dysfunction, whilst three (4%) demonstrated no obvious awareness of the environment around them. Fenech (2009) suggested that as the level of cognitive function decreased, engagement in an interactive drama project also decreased. The majority of residents engaged with interactive drama for some of the time. The results might have been more convincing if the validated and clinically specific data collection tools were used. Another approach might have been to use a self-reported leisure satisfaction scale, and a measure of flow or optimal engagement. Equally, the CMOP might have highlighted the individuals' satisfaction with their own leisure participation, performance and engagement. However, these assessments were inappropriate given the participants profound level of disability and especially their cognitive and communication limitations. Despite the fact that the structured observation format originated at the home, this study coincided most with the original plan for this thesis, because like Fenech and Shaw-Fisher (2012) it included data about the meaning of the occupations engaged in. It also gauged the opinions of staff as to the effects on their residents. As a result there is a danger that the researcher might be accused of merely "proving" what she already believed, however this study was formative in designing future studies. Meaningful leisure for individuals with NPC appears vital but sidelined by staff. The participants, staff, and actors were blind to the hypothesis but the observer was well aware of the professional knowledge of occupational therapy, around the meaning of occupations and sensory integration/ processing. The researcher met the participants for the first time during the service evaluation, which might have increased objectivity; but also influenced the interpretations of behaviour made during the observations. The researcher was not a frequent or recognisable visitor. However, most staff appeared to assume that the researcher worked for the theatre group, potentially resulting in socially desirable responses. The staff questionnaire responses may have reflected their feelings of threat and disruption about such an all encompassing project, or alternatively reflected personal interests in drama and the arts. The residents' vulnerability might have led to socially desirable responses, despite assurances that feedback was anonymous and that their care would not be affected by their responses. Despite the unobtrusive style of observations, the presence of a constant stranger might have drawn attention away from the performances since the researcher attempted neither to hide nor join in with the performances actively, preferring to take the role of an observer-as-participant. The project involved a subjective interpretation by the researcher of whether the resident was engaged. This was countered by using a structured observation tool. The videoing of participants might have given an opportunity for more detailed observation but would have been obtrusive and possibly intrusive. The use of video would have been helpful in determining whether the engagement was with the performance rather than other activities not related to the performance. However, the use of video for research was not sanctioned. This was a single-site study; however, the national lottery funded interactive drama project was being repeated across six

hospitals, all in very different clinical areas, which could have been an opportunity to investigate the benefits of interactive drama in many contexts and to trial the use of the structured observation format in other clinical settings. This service evaluation aimed to establish whether an interactive drama project for long-term care residents with NPC had any effect on participants. A weakness of the methodology was the lack of a pilot survey; however, arguably this study was indeed a pilot as it identified information which informed the later observation study. Ideally, there would have been a pilot performance taking place to examine the suitability of observation format, the "observer-as-participant" design, the suitability of the questionnaire design and interview structure for residents and staff. A pilot study would have highlighted the ability of the investigator, the reliability of the results and methodological issues to be addressed (Lancaster *et al.,* 2004). For example, the researcher might have produced more detailed, accurate observations if she had been noting the engagement of only 7-8 participants instead of every participant, as there would have been less distraction, and more focus on fewer individuals. The "observer-as-participant" methodology has limitations. The same single observer noted the engagement of participants in every performance which is problematic but was the option chosen given the reflexivity which may occur if the observer influences the engagement of participants. The researcher acknowledged that this practice was open to criticism no matter how experienced and well trained this observer was, since using more than one observer or video recording the participants might increase the reliability of the results, evaluating both the observer's work and the engagement of participants. However, it was explained that this was avoided as the "use of video is regarded as an intrusion into residents' privacy by some staff and has not been welcomed" (Fenech, 2009, p. 125). The study gave a description of the diagnostic categories and the scale of dysfunction of the participants. Levels of language comprehension were of vital importance in terms of the validity of their responses. A central issue was how well the participants really understood the concepts used in the questionnaire. The inclusion or exclusion of residents who are unaware of their environment might be problematic, Fenech (2009, p. 120) states that "the philosophy held by the units, whether correct or not, was that inclusion was better than exclusion – this view may well have been supported by the fact that at least one non-responsive individual demonstrated responses to the project". It would be useful to examine different levels of dysfunction separately, as this might have aided interpretation of the results. In this study written consent was sought, but there was no clear statement, that every resident or relative gave an informed consent and there are no details regarding the way in which it was obtained. It is not clear how the investigators ensured that everything was understood by the resident or by his/ her relatives, which is a drawback of the article. A key limitation for generalising the findings of this study is that the results are from one home. This article gave sufficient detail to enable replication of the study, and presented a well-structured discussion. Raw data were presented in the text and in tables in the appendices, providing a useful insight into the positive effects of interactive drama on individuals with NPC. The need for further research in this area is emphasised and weaknesses of the study were highlighted. As a result, the findings require cautious interpretation.

2010

Fenech's (2010) article compared a live dramatic performance, an interactive performance, and a control condition to describe the effects of a potentially active, rather than a passive, participant role on engagement. The dependency level of the participants and the small sample size meant the results could not be generalised to other populations. There was a

significant difference between the engagement categories between the control condition and the two drama cases; but not between the live performance and the interactive drama performance. The article suggested that the factors to take into consideration when offering a leisure occupation included the individuals' sensory processing capacity, the level and type of support offered, and whether the individual feels that they have a choice of occupational role. Alternative methodologies could have included the use of a self-reported satisfaction questionnaires, or the use of measures designed specifically for use with adults living with NPC. Ideally such a measure would include an element of sensory integration/overload measurement. Additionally, more detailed and recorded observation might have determined whether the engagement was with the case rather than other factors, allowing for inter-rater agreement and objectivity. However, this might have heightened the likelihood of altering the participants' behaviour in response to being observed. The limitations of the article relate to the characteristics of the sample, data collection and data analysis techniques and to the reliability of the results. Many of these limitations result from compromises, made to protect vulnerable adults. The large amount of data collected using a time sampling methodology, partly countered the small number of participants. The lack of preliminary evaluation dedicated to establishing how participants defined leisure could be a flaw in this research, given the concern about whether an activity is considered as a leisure occupation or not depending on the perspective of the person engaging in it. It is unlikely that all the participants were taking the same perspective about the case as that taken by the observer (Creek 2010); because, it was not established first hand that all fourteen participants considered drama as leisure, although they did choose to attend these performances over other opportunities available. Additionally, the article failed to give much detail about the drama used, or the anticipated occupational-performance of the participants. Insufficient rationale for the methodology used in creating the control condition was provided, or for the selection of drama, other than to make the most of an ad hoc and externally funded leisure project. While the findings are interesting and informative, a lack of experimental rigour reduces the reliability and validity of the findings.

2011

Fenech's (2011) article described a case design study conducted to compare levels of leisure satisfaction and engagement in adults (n=14) with NPC who took part in a 45-minute session of Aquability versus those who did nothing. Engagement behaviours were coded for 1-minute every 5-minutes, using the ICER during a 45-minute control condition and an Aquability session (as presented in chapter five). The participant's leisure satisfaction levels were assessed via the self-reported Leisure Satisfaction Scale – short form (LSS-Short form) (adapted). The participants were the same 14 participants of the study presented in chapter five. Data was collected using an adapted version of the Leisure Satisfaction Scale following consultation with a Speech and Language Therapist to accommodate the cognitive limitations of the participants. This might have influenced the validity of the research; since it was important to ask questions that the participants could understand and respond to. A pilot study used both the LSS–short form and the adapted LSS–short form 14 days apart following concurrent Aquability sessions with three participants. The Pearson product–moment correlations demonstrated acceptable test–retest reliability coefficients for each subscale (psychological, 0.70; educational, 0.58; social, 0.67; relaxational, 0.70; physiological, 0.69). The Cronbach's alpha for each dimension demonstrated an acceptable level of internal consistency (psychological, 0.79; educational, 0.63; social, 0.75; relaxational, 0.554; physiological, 0.76). Therefore, results of the pilot encouraged the use of the adapted LSS –short form with this population and added rigour to the findings. Additionally, a 10-

cm scale (see article appendix) allowed the residents to quantify their percentage satisfaction. The results of the pilot supported the use of the adapted LSS–short form with this population. Because this article was part of a series of articles comparing each of the casual leisure occupations with the control condition, there was a danger that the articles might become formulaic and sound as though they are merely "proving" what the author already believed. To avoid this, a different methodology to previous articles was used in this instance, by using not only observations of engagement but also the LSS–short form (adapted). A strength of this study is the adaptation of an appropriate measure to make it applicable to individuals with NPC. However, a further study to validate the LSS–short form (adapted) is required. The recommendations suggested a higher the staff to resident ratio, opportunities for active involvement and consideration of sensory attributes involved. The participants and staff were unaware of the study hypothesis. Ideally the study would have used outcome measures designed specifically for use with adults living with NPC. Repetition by a different observer, with the same participants, a blinded data collector, cross analysis of data by other researcher's, and training someone who was normally present to collect data at the same time were all considered and rejected by the DCS. Leaving only the option of practicing by watching several participants prior to coding and data collection. The small sample size (n=14) and the use of a single observer without video-recording backup might have compromised the reliability of the data, whilst complying with the home's POVA policy. Because the observations were of casual leisure satisfaction, data were gathered during each single (non-replicable) short-term leisure experience. The uniquely profound nature of the participants' disabilities and the small population size meant that the findings were not generalisable beyond the participants or neuropalliative services. The case methodology allowed for comparison of an intervention case and control condition. Although written consent was obtained from participants, there is no mention of informed consent, which is of particular importance when working with vulnerable populations. The Residence Manager identified those who would be suitable for inclusion. The criterion used to establish whether residents understood what they were consenting to should have been included, as should a description of the cognitive levels of the participants, and their level of language comprehension to ensure the validity of the responses to the adapted LSS. A central issue was how well the clients really understood the subjective concepts used in the questionnaire. A single observer coded the participant's behaviour in each condition. Using another observer, or a brief video of part of one session would have helped evaluate the observers' skills and to suggest inter-rater reliability. However, permission for video recording and the use of multiple observers was declined due to the home's philosophy of non-intrusion (although it is debatable whether ethnographic research is intrusive). Thus, a balance was struck to carry out research while not violating organisational imperatives. Methodological challenges included working within policies designed to protect resident well being and privacy. The article offers insight into the benefits of Aquability sessions for individuals with NPCs, emphasising the need for further research in this area. The findings should be interpreted with caution; Aquability may be accountable for some rather than all of the positive outcomes reported.

2012

Fenech & Shaw-Fisher's (2012) book chapter introduced recreation and leisure occupations; recreation during rehabilitation; lifelong leisure; and organisational funding issues. However, the part of the chapter which adds to this thesis is the section about lifelong leisure. This section presented the voice of 50 individuals through secondary conceptual analysis. It portrayed the value and meaning of leisure to individuals with brain injuries once rehabilitation had ceased. It did this by

clustering the words of participants gathered from service evaluations conducted at the home, using as its deductive framework the facets that contribute meaning to occupations in table 5. It appears that the leisure occupations being discussed by Fenech & Shaw-Fisher's participants offered many opportunities to experience meaning, each of which were discussed within this chapter, with examples from the participants own words being given, to reinforce the message (appendix xv). Since lifelong leisure can offer the individual a sense of importance, purpose and meaning, among other benefits, the chapter recommended that “a rounded therapeutic recreation program should include community integration, leisure education, exercise, adapted sports, and/or expressive arts” (Fenech and Shaw-Fisher, 2012, p. 1369).

When compared to the earlier works of Fenech, it is clear that this chapter has benefited from several years of experience of publication within the domain of neuropalliative rehabilitation and leisure occupations. Previous works comprised many limitations, albeit less so as the dates get closer to the present day, culminating in this book chapter.

Clinical messages

This section will discuss what the researcher has learned from other authors who cited her work and from her own critique of her publications. This section will also reprise the clinical implications of the fellowships outputs and its influence on practice.

Society

The researcher hopes that by publishing about profound disability she will influence the view that "no one is that disabled" and that all occupational deprivation is already surmountable with sufficient adaptation. Alongside Baker (2012) she has suggested that individuals with NPC experience environmental barriers, issues of lack of choice, high levels of dependence, and issues of communication and decision-making capacity.

Achievements to date

On reflection, much was achieved by the Fellowship. All the suggestions and recommendations required funding, and so fundraising through organising events, sponsors, submitting bids to grant giving organisations, became part of the Fellow's role. Puzzlingly as the sensory attributes level of each case increased so did the staff to resident ratio. This might have been because the higher sensory attribute occupations attracted staff who were therefore available to facilitate engagement, and to enable residents to continue to engage beyond their own sensory threshold. As a result, a supporter to resident ratio of 1:2 was suggested, as was the offering of leisure opportunities 7 days a week and through to bed time. Additionally, a residence based Leisure Coordinator Role, in addition to and separate from the care staffing establishment. Both were suggested with a view to enhancing and normalising engagement. To support leisure facilitation, staff were encouraged to assess during leisure occupations, and share the results of assessments to enable occupational participation. Additionally, support was offered to supporters such as fact sheets on outing venues, and a range of training opportunities from induction to Activity Specialist Training. Additionally a benefit of more joined up communication might be that leisure requests were shared between departments rather than forcing the resident use a scattergun approach until the found the "right" person to target their request to. A clear link between resident leisure satisfaction and funding was established e.g. refurbishing the pool as a

multisensory area, a relaxation room for use by beauticians, manicurists, etc., and a permanent library space; which might have led to ambitions to enhance satisfaction through improved facilities and vice versa. The suggestion was also made to improve the accessibility of activities programme through formatting, accessibility via the internet, notice boards etc was beginning to raise its profile, and therefore the importance of leisure activities to carers and supporters. The suggestion to explore the possibility of subsidised outings despite the evidence by so many authors that specialised transport was an important barrier to leisure failed to make an impression on the finance orientated members of the board of management. Therefore, the Recreation and Leisure Service staff started collecting evidence about which residents this affected most.

The effects of, and causes of sensory-overload and it's similarity to Kishida & Kemp's (2006) definition of passive non-engagement, (which staff might have often witnessed but not reflected upon, having taken it as read) were brought to prominence, hopefully leading to increased vigilance and avoidance. However, given the lack of sensory profile assessments being conducted this might have been less beneficial than it could have been. Aquability being suggested as a very satisfying leisure occupation, partly due to the freedom offered by the buoyancy of the water, might have instigated of thoughts of investigating gravity free leisure.

Care staff

The family members who attended the leisure opportunities with their resident were reported (by staff) as more relaxed. This encouraged the change of philosophy to including family in leisure and providing information about leisure opportunities, in the leisure provision standards which had been drafted, but not rectified by the end of the fellowship. On reflection, the researcher valued the concept of doing as you would be done by, as a tool for persuading staff to practice differently, but this required a shift in thinking towards residents being occupational beings, who were therefore not being offered the opportunity to be fully human. This shift in valuing residents, as human and occupational beings would seem to be fundamental and an organisational culture, as well as a professional culture issue. Taken at face value, perhaps there might be merit in offering leisure opportunities that would attract supporters in order that they should facilitate (in sufficient numbers and with sufficient enthusiasm) the engagement of residents. This feels extremely unsafe, taking the emphasis off the resident and placing it back where it started at the beginning of the fellowship i.e. arranged for the pleasure of the staff. Therefore, the supporter to resident ratio of 1:2 was made part of the standards of leisure provision drafted for the home. To emphasise the value of leisure support was offered to staff including new posts, making leisure engagement part of the goal planning process for the rehabilitation arm of the organisation as well as the home. Making the organisation of outings and events less arduous, offering ready-made information, and a range of training opportunities was all part of encouraging staff to enhance and normalise leisure engagement.

Being fully human

Part of treating the residents as occupational and human beings involved offering the choice of what, when, where, with whom and how to "do" their leisure occupations. This might include opportunities for active participation, choice, an opportunity to explore their age, gender, faith and national identity, and experience movement. Additionally, evening and

weekend, indoor and outdoor opportunities, and intergenerational leisure opportunities were offered. Part of offering control and choice included improving the accessibility of activities programme to residents themselves as well as to staff.

The effects of sensory processing

This leaves the knotty problem at the heart of this thesis, i.e. the effects of sensory-overload being similar to Kishida & Kemp's (2006) definition of passive non-engagement. However, given the lack of sensory profile assessments being conducted this might have been less beneficial than it could have been. Here the work of Cook *et al.,* (2012) might be usefully employed, since their guidelines will reinforce the researcher's message at a European level. As a result, the researcher is reflecting on whether there are some battles which are better left to the weight of evidence (or as Tolstoy (2008) would have it les gros bataillons or the wisdom of targeted hindsight (Dieu n'est pas pour les gros bataillons, mais pour ceux qui tirent le mieux (Voltaire in Douzinas, 2008)). Therefore, it is interesting to note the influence of the researcher on practice, some of it positive and some of it perplexing. For example Cook *et al.* (2012) recommended the use of the sensory profile to draw up leisure based sensory diets as a way to engage residents with severe cognitive dysfunction amongst their symptoms, in occupations. It is hoped that Cook *et al's.* (2012) recommendation about the use of the sensory profile to draw up leisure based sensory diets might be taken on board at some point too. Spring et al (2011) suggested the need to increase sensory stimulation for individuals with NPC. This should be treated with caution, (in the light of the preliminary study) given the lack of sensory profile assessment undertaken at the home. Therefore, it appears that the message about sensory-overload needs further work, despite the wealth of medical research that is emerging about sensory gating deficits in individuals with NPC.

Social leisure

Additionally, the article by Cunningham et al (2012), discusses Aquability, the use of the ICER and the sport of Boccia at the home four years after the end of the fellowship. While Baker (2011) suggested that for relatives of people living with NPC, spending time with the individual might help in strengthening their sense of partnership, positive use of leisure time, and social contacts. Stonier (2008) argued that although individualised leisure was important; there was also a need for social leisure events. So some of the researcher's work is still in use; for example Aquability, the use of the ICER, relatives engaging in leisure with their resident and the sport of Boccia at the home.

The personalisation agenda

Wensley & Slade (2012), Mackenzie & O'Toole (2011) and Broadhurst *et al.* (2008) all suggested that the role of the leisure supporter is to ensure that an activity is adapted (based on an occupational analysis) to fit the person and not the other way around and that without suitable adaptation (to the occupation and the occupational environment), an individual might not be able to access a leisure occupation. The most exciting thing though is that Martelli *et al.* (2013) recommended an assessment of the occupational environment since the authors are not Occupational Therapists. Additionally, they suggested that leisure is an important attribute of identity, self and life satisfaction, meaning and occupational balance, which was very gratifying, since occupational science, is a fairly new academic discipline and only by breaking into new domains like leisure science and medical texts books will it get widely known. Staff were encouraged to facilitate active participation, and

to offer a variety of opportunities, including trying new and challenging things, choice from a range of age, gender, faith and nationality appropriate movement orientated activities. Additionally, indoor and outdoor opportunities were offered throughout each week. In other words, the emphasis was on offering residents what the supporters would probably resent not receiving in relation to their own leisure, the choice of what, when, where, with whom and how to "do" their leisure occupations and evaluating them.

Summary

Running throughout these publications is the theme of enhancing engagement through individual meaning, role or sensory content. Fenech & Shaw-Fisher's (2012) book chapter highlighted opportunities to experience meaning during a leisure occupation. Fenech's (2011) article suggested a higher staff to resident ratio, more opportunities for active involvement and consideration of sensory attributes involved in a leisure occupation. Fenech's (2010) article described the effects of a potentially active, rather than a passive, participant role on engagement. Fenech's (2009) article reported increased social interaction, mood, confidence, and better staff: resident relationships and the meaning of leisure for participants were highlighted. Fenech & Baker's (2008) article suggested greater use of the existing sensory diet framework in the domain of NPC and in relation to leisure provision. Fenech's (2008) editorial suggested that understanding the individual's leisure context, sense of dependence or lack of control, interest and motivation, spirituality and beliefs, were key to understanding occupational-engagement. The Mapping Discussion Document (RHN 2006) and the Leisure Satisfaction Audit Report (RHN 2007) led to the creation of a resource pack for staff and later one for visitors and then one for residents themselves. These reports suggested raising the supporter to resident ratio and a wider range of leisure opportunities being available round the clock, as well as opportunities for movement, relatives joining leisure occupations with their NPC relatives.

Chapter SEVEN

7.0 Discussion, limitations, and future directions

This thesis has explored the normal and sensory-overloaded behaviours exhibited by individuals with NPC, to determine whether sensory-overload effects them, and whether engagement alters with different levels of sensory attributes. The study sought to establish whether it is possible to mark the thresholds, to create a sensory environment that participants can handle competently and enjoyably. This chapter discusses the results of chapters FOUR and FIVE, and the contribution of the researcher's publications; followed by recommendations for future research directions.

The results lead the researcher to discuss whether there is more to participant engagement than the number of sensory attributes offered, since co-existing contextual factors may influence occupational-engagement (Taylor, 2008), turning an occupation into an engaging one (Jonsson, Josephsson & Kielhofner, 2001), thereby encouraging engagement beyond the individual's upper sensory threshold. The influences on engagement will be sub-divided into individual, occupation, and environment to influence the preparation of casual leisure occupations for individuals with NPC. This is necessary because as Nilsson (2006) pointed out, leisure has the potential to be unsatisfying if it is unengaging, while active engagement in leisure enhances wellbeing and perceived satisfaction with life.

7.1 Study Limitations

In all research there are limitations to the conclusions that can be drawn. This study was greatly influenced by real-world imperatives, making it applicable to practice because the findings have been demonstrated rather than hypothesised (Sinclair, 2007). This first section will consider the limitations of this thesis, which relate to the characteristics of the participant group, the study design, the data collection, and data analysis techniques and the reliability of the findings within the context of a real occupational environment.

The limitations associated with the characteristics of the participant group included the difference in the dependency levels between the residents discussed by the Residence Manager and the ones observed. A further observational study of participants with higher dependency levels would be useful to determine whether the results were replicable. The sample size was small, but was representative of individuals with NPC in the UK, and could be enlarged by conducting a multi-centre trial.

The limitations to the study design in relation to the normal and sensory-overloaded behaviours exhibited include the greater authenticity of first-hand data. However, the participants limitations reduced the participant's ability to explore such a subjective and unfamiliar topic, and therefore to express their opinions reliably and consistently. Ideally, third-party data would have been collected from a practitioner who was experienced in sensory processing and its influence, because such a person was not available, a structured interview format was used to enhance the comparability of the data (Wimmer & Dominick, 1997). The potential for bias in a structured interview format, gathering data on a range of individuals from one

staff member's opinion, could result from the use of small and potentially unrepresentative samples. A structured interview format relies on respondents being able to answer the questions (Breakwell, Hammond & Fife-Schaw, 1995), without the need to disguise feelings of inadequacy or confusion (Wimmer & Dominick, 1997), which could have affected the validity and reliability of the data (Breakwell, Hammond & Fife-Schaw, 1995).

In relation to the research question about whether engagement alters with different levels of sensory attributes, the study has not answered the research question, because it became apparent that more was involved in occupational-engagement that simply sensory stimulation. This might have been due to the choice to honour the spirit of both leisure and meaningful occupations by not allocating cases randomly, or using a matrix to design the cases. Ideally, the participants' first-hand views on their engagement would have been sought. A multiple, case quasi experimental design involved repeated measurement of engagement, while changing the variable for each case (Drummond, 1996). This methodology was used previously to highlight causal relationships (Noyes, 1999).

Arguably, limitations in data collection for the interview included the Residence Manager's limited understanding of sensory processing, whilst producing data unbiased by anticipation of the expected results. Observation data about the residents' momentary engagement, was appropriate given the leisure focus of the study. Other methodologies could have included a qualitative study about engagement choices, or an auto-ethnographic study design. However, the participants ability to explore such an unfamiliar and subjective issues is questionable. Arguably, several observers should have collected and recorded (inter-rater reliability tested) data, whilst potentially altering the participants behaviour in response to being observed and being intrusive of the participants' leisure. Additionally, a larger participant group would have increased the reliability of the results, bringing with it the complexities of a multi-centred trial. It would have been useful to interview the Residence Manager about all the residents to give a larger sample, or to interview all ten Residence Manager's about all the 14 residents observed.

Limiting the participants to those who could express their own consent to participate altered the study, so that the data collected from the Residence Manager and the later observations became irreconcilable. Ideally, a measurement tool designed specifically for use with participants living with NPC, including an element of sensory processing and overload measurement, would have been (created, validated and) used. The researcher tried to be unobtrusive, however the presence of an observer could have drawn attention away from the cases, since the researcher attempted neither to hide, nor to join in, preferring to take a marginal and passive observer role. Videoing could have offered more detailed observation, determining whether the engagement was with the occupation itself or with other contextual factors. The use of a single marginal observer offered no possibility of inter-rater reliability comparison, but reduced intrusion on residents' engagement. The data collected from the Residence Manager, and using the engagement categories defined by Kishida and Kemp (2006), aimed to counteract this flaw.

Limitations to the data analysis techniques included pattern matching involving the researcher's clinical reasoning. As a result a researcher with different theoretical and professional experience could have interpreted the data differently. Ideally, the use of several blinded observers could have overcome this flaw, as would calculating the significance of the

differences between the data. Additionally, data collection from an Residence Manager, knowledgeable about sensory processing would have been more valid (but arguably could have risked issues of clinical equipoise).

The reliability and consistency of the observations relies on the findings of the preliminary study, and Kishida and Kemp's (2006) definitions of the engagement categories. The small sample size of the study reduced its statistical power, but exceeded that necessary for a viable study. Using several blinded observers or cross coding the findings with the data from another observer, or another data set would have enhanced both reliability and consistency, as would videoing the participants engagement. However, Kishida and Kemp (2006), the only similar study at the time, had not been followed up by other publications at the time of data collection.

Despite these limitations, this thesis has made a theoretical, methodological, empirical, and practical contribution to neuropalliative rehabilitation and leisure service provision.

7.2 Discussion of the Residence Manager study

The signs of sensory-overload suggested in chapter four appear very similar to Kishida and Kemp's (2006) definitions of passive non-engagement and passive engagement, since both could render an individual fairly passive. The limitations experienced included sensitivity to light and sound, altered vocalisation, eye contact and eye gaze, anxiety level, mood, muscle tone, information processing and concentration, as well as meaning deafness. Whereas, Kishida and Kemp (2006) define passive engagement as interacting with the environment without handling or discussing the material, and passive non-engagement as being passive, not interacting with the environment or reacting as expected. The degree of engagement therefore alters between passive engagement and passive non-engagement, which might be related to their degree of sensory-overload; with those who were participating passively appearing less overloaded than those who were passively non-engaged. Conversely, the greater the sensory-overload, the greater the impact on engagement, both at an individual behavioural level (see the rows of table 7), and at a more global level (see the columns in table 7). The residents presented by the Residence Manager were described as experiencing sensory-overload which not only exacerbates their level of disability (making them unable to participate), but could lead to fatigue and depression, sleep difficulties, headaches, tense muscles, decreased memory and concentration (Heller, 2002).

As described by the Residence Manager, the participants' behaviour (in response to a busy environment) appeared similar to sensory defensiveness (Heller, 2002). Sensory-overload could have led to challenging behaviour or dissociation (a partial or complete disruption of normal functioning (Dell & O'Neil, 2009)), to avoid excessive stimulation. Furthermore, boredom, was suggested by Martin *et al.* (2012) and Edmund and Morris (2000) to result from information overload, and the sensory-overload described by the Residence Manager, and which appeared to lead to a state of passive non-engagement similar to dissociation. This is relevant because boredom is a term used frequently by participants when describing their free time, perhaps as a result of inappropriate stimulation. The next section will therefore consider the findings from the interview with the Residence Manager in terms of the concepts of sensory-overload and passive non-engagement.

Based on the data from the interview, Kishida and Kemp's (2006) definition of passive non-engagement appears similar to the behaviour resulting from an overloading sensory environment. Kishida and Kemp's (2006) definition of passive non-engagement was that an individual does not interact with the environment. The Residence Manager described the passive state of individuals experiencing sensory-overload as being uncomfortable with light or sound, with a reduced ability to vocalise, maintain eye contact, direct their gaze, and understand speech or text. Dissociated individuals also use a monotone tone of voice, show a less accurate perceptual ability and sense of time passing. Furthermore, they could demonstrate reduced concentration and coordination, weaker orientation to time, place and person, and poorer memory and self-regulation. Additionally, they could exhibit altered muscle tone, increased anxiety, perseveration and word-finding difficulties and were generally lower in mood, with slower information processing. All of these factors could reduce occupational-engagement capacity, arguably making the individual appear passive. Arciniegas *et al.* (1999) described how attention, perception, memory and acquiring new information in the presence of competing stimuli were basic cognitive functions that were necessary for engagement, but which could be disrupted by sensory gating deficits, thus reducing ability. Sensory-overload such as that experienced by the participants also appeared to lead to a passive state of engagement or non-engagement, which in turn could lead on to occupational deprivation.

Kishida and Kemp (2006) described active non-engagement as an individual interacting with the environment in an inappropriate manner, similar to the challenging behaviour exhibited by some participants. Whilst their definition of passive non-engagement and passive engagement relates strongly to the passivity induced by sensory-overload (Wirrell & Livingston, 2011), both of these states would exacerbate the individuals' limitations to participation. Therefore, it could be reasonable to anticipate that engagement falls as sensory stimulation rises.

Conversely, the data from the observations appears to demonstrate that as the sensory attributes level of the cases rose, so did engagement. This could be due to the differences in dependency levels between the participants observed and those discussed by the Residence Manager (who were more susceptible to sensory-overload). The reader will recall that originally, a more profoundly disabled group of participants was to have been observed, which would have meant that the group discussed by the Residence Manager was the same as the group of participants observed. Additionally, it could be conjectured that the sensory gating deficits of the participants and the sensory attributes level of the case are only some of the factors that could influence engagement, because as Brown and Dunn (2010) suggested, behaviour could be influenced by the context within which it occurs, including the built, social and sensory environment.

Striking similarities exist between Martin *et al's.* (2012) and Edmund and Morris's (2000) concept of overload-induced disengagement and boredom, and the participants' susceptibility to and response to sensory-overload as described by the Residence Manager. The participants' inability to cope with high levels of sensory attributes, leading to patterns of sensory defensiveness, was expected to reduce their capacity to cope with the higher combined sensory level of casual leisure occupations. However, the observations of engagement showed the opposite effect. In fact, participants appeared more engaged overall in the higher-level sensory occupations. This raises a question about whether, rather than a simple cut-off point for all engagement, there is a threshold (on a scale of increasing dependency), beyond which

increasing sensory stimulation is engaging for some and overloading for others. This supports the various findings of Olson (2011), Bundy & Murray, (2002), Dunn (2001). For example, Olson (2011) noted that individuals in different quadrants of the MoSP respond differently to sensory stimulation. She suggested (like Bundy & Murray, (2002)) that low registration and sensation seeking individuals require more stimulation than most, seeking activities with more sensory attributes (Dunn, 2001). This might contribute to an explanation of why higher levels of sensory attributes led to higher engagement categories (by individuals whose occupational deprivation led them to crave sensory stimulation masked by environmental interference or gated by an inefficient RAS), since Schaaf & Miller (2005) suggested that occupational-engagement with a high level of sensory attributes may facilitate SI and thus further enable engagement. What is not known is how many of the participants sensory profiles, were in which quadrant of the MoSP, and therefore whether this might have been a factor in their engagement.

Sensory gating deficits have been researched in NPC (UC *et al.,* 2003; Kumar *et al.,* 2005; Arciniegas *et al.,* 1999), and suggested to leave the individual open to over-stimulation. This can occur because of damage to the RAS and the resultant sensory gating deficits that characterise NPC, leaving the individual unable to filter out irrelevant and excessive information. Therefore, individuals with NPC who experience sensory gating deficits could also be at risk of sensory-overload.

The implications of sensory-overload on the observations of engagement include removing the residents' engagement even if they wanted to, and removing their control over their own behaviour. This lack of engagement could not have been solely caused by the combined sensory level of the occupation, since alterations to sensory processing may have resulted from the NPC itself or the effects of medication (Harvey, 2010). Whatever its cause, sensory-overload could present to the observer in a manner similar to fatigue (which is how it appears to have been perceived at the home; see Text box 2).

Text box 2 – Home Research Forum 28 Nov 2006 Minutes

Fatigue: KA had noted that some individuals could not tolerate a full activity due to fatigue. It was agreed that this was a problem with Locked-In and MS individuals. Fatigue was seen in SLT (including feeding), OT and leisure occupations, computer room and Music Therapy. Could this be a topic for future research?

Sensory-overload could cause one or more areas of functioning to shut down, leading to a partial or total inability to understand and react appropriately to sensory information (Bunney *et al.,* 1999). Total sensory-overload could leave an individual unresponsive, apparently sleepy, experiencing hyper or hypo tonus (Miller & Loos, 2005), and vulnerable to further bouts of sensory-overload with repeated stimulation. Equally, challenging behaviour could provide a means to escape from a situation that is too confusing and too overwhelming. Arguably, both of these situations were mirrored in the ICER, with dissociation appearing similar to the

behaviour described as passive non-engagement, and challenging behaviour appearing similar to the descriptions of active non-engagement.

Sensory-overload could therefore influence an individual's ability to participate, but it appears to be a little-known concept beyond the Allied Health Professions and Developmental Disability. Therefore, this thesis sought to determine whether there could be an approximate level of stimulation, which maximises occupational-engagement while minimising the potential for sensory-overload. This insight could contribute to preventing the occupational deprivation resulting from repeated sensory-overload-induced non-engagement.

7.3 Discussion of the observations of engagement study

This study explored whether engagement in casual leisure occupations (by individuals with NPC) altered with different levels of sensory attributes. Olson's (2011) PhD thesis used behavioural observations similar to those presented in chapter five to suggest that the occupational-engagement of individuals with sensory gating deficits were indeed altered as a result of sensory stimulation. Therefore, a normal distribution in engagement with under or over-stimulation decreasing engagement was anticipated. However, the results demonstrated a trend for increasing engagement with increasing levels of sensory attributes. Additionally, supporter-to-participant ratios appeared to influence engagement, as did the differing roles offered (between passive and potentially active occupations).

Arguably, active engagement involves a greater degree of involvement (Lancioni *et al.,* 2013). Therefore, the field data included a description of whether the occupational role offered was a passive or potentially an active one, so it is significant that figure 6 and figure 4 showed a marked drop from engagement to non-engagement in the occupations which offered the participants a passive role. The passive occupations produced a median category of passive non-engagement, and the potentially physically active occupations produced a median category of active engagement (which concurs with Lancioni et al's. (2013) findings). Lancioni et al. (2013) studied the role of the participant when listening to music. An active role allowing the participants to regulate the music through simple responses was suggested to involve more engagement, thus enhancing their attention and presence.

Aggregating the data, highlighted that the potentially active occupations were also the ones with the higher supporter-to-participant ratios. Cases with a Low supporter-to-participant ratio achieved a median engagement category of passive non-engagement. Cases with a Mid to High supporter-to-participant ratio, produced a median engagement level of active engagement. These results coincided with Scerri & Cassar's (2013) suggestion that not only a higher supporter-to-participant was more enabling but that the skills of the supporter to facilitate were crucial. Additionally, Cermak and Mitchell (2006) proposed that an individual's SI was greatest within a 1:1 individual to supporter ratio, suggesting that group interventions require higher-level integration skills than those of a 1:1 nature. Therefore the supporter-to-participant ratios could have influenced the participants' engagement. So it is intriguing that as the sensory attributes level of each case increased, so did the supporter-to-participant ratio. This may reflect more than attachment theory because some of the volunteer leisure supporters did not have long term relationships with the residents.

The results in CHAPTER FIVE therefore raised the question whether rather than a simple cut-off point for all engagement, there is a combined sensory threshold (on a scale of increasing dependency), beyond which increasing sensory stimulation is engaging for some and overloading for others.

Descriptive statistics and pattern matching were used to compare the results in CHAPTER FIVE, about the effect on occupational-engagement of sensory stimulation, with the normal distribution of engagement indicated by the professional knowledge of occupational therapy. Tracing changes in engagement category over time produced data which were not suitable for analysis using through-time and non-linear regression statistical techniques and therefore the difference between the anticipated and actual results were not statistically analysed.

Swets (1961), suggested that sensory thresholds followed a normal distribution of combined sensory levels. While, Luce and Edwards (1958) and Swets *et al's.* (1955) implied that environmental interference could mask or exaggerate the detectability of sensory stimulation. Additionally sensory processing may result in more or less information than the RAS can cope with if it is not functioning efficiently. Therefore, a normal distribution in engagement with under or over-stimulation decreasing the engagement category was anticipated. The difference in engagement category between passive engagement and passive non-engagement, could arguably relate to the participants degree of sensory-overload, with those who were participating passively appearing less overloaded than those who were passively non-engaged.

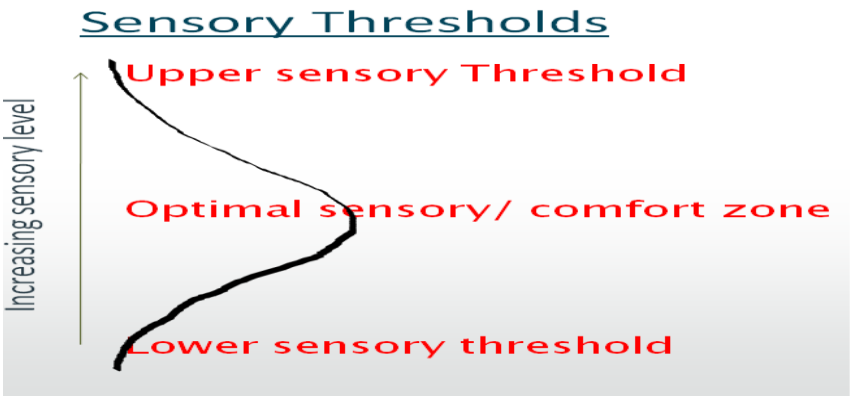
For the purpose of this thesis, the combined sensory threshold is defined as the level at which the total sensory stimulation of a case triggers behaviour (Evans, 2008). Above the upper and below the lower combined sensory thresholds, the individual's response could be active non-engagement (including challenging behaviour) or passive (non-) engagement/dissociation. Between the lower and the upper combined sensory thresholds, it was therefore anticipated that there could be a zone where engagement is most likely to occur. However, the anticipated reduction in engagement at the extremes of sensory attributes was not observed, instead engagement appeared to increase with the sensory attributes. This reflects Olson's (2011) suggestion that individuals with different sensory preferences behave differently in response to sensory stimulation, some requiring more stimulation and therefore demonstrating engagement behaviours similar to individuals who are under-responsive, including greater engagement in activities with more sensory attributes (Dunn, 2001). Furthermore, there could be differences in sensory detection, profile and preference because of the threshold, gender, muscle strength and so forth (Torgen & Swerup, 2002). Therefore higher levels of sensory attributes might have led to higher engagement categories (by individuals whose occupational deprivation led them to crave sensory stimulation masked by environmental interference or gated by an inefficient RAS), or higher levels of sensory attributes may facilitate SI, thus further enabling occupational-engagement (Schaaf & Miller, 2005). Therefore enhanced capacity for occupational-engagement (as a result of sensory integration) may have resulted in higher engagement categories being recorded.

Additionally, Csikszentmihalyi (2002), Zaman and Vanden Abeele (2007), Jackson and Eklund (2002) and Rupayana (2008) have all studied optimal engagement, and suggested that the possibility rather than actual control is an important factor in initiating and maintaining engagement, through enhancing the meaningfulness of an occupation (Reed *et al.*, 2010). Therefore, it is noteworthy that there was a difference between the engagement categories in potentially active and only passive occupations. This would appear to support Csikszentmihalyi's (1990) belief that full engagement to the point of

"Flow" is more likely if the individual has a sense of the possibility, rather than actual control over the role undertaken. The potentially active occupations were, incidentally, also the ones with unplanned and higher supporter-to-participant ratios.

At the extremes of a combined sensory level continuum, above the upper threshold and below the lower one, occupational-engagement was expected to fall into the categories of active non-engagement (including challenging behaviour) or passive (non-) engagement. Arguably active non-engagement/ challenging behaviour could be on a continuum with active engagement in the centre and passive (non-) engagement/ sensory overload at the opposite end. So that, between the lower and the upper combined sensory thresholds a comfortable zone (see Figure 9), within which participants could engage in casual leisure occupations, if they were enjoyable, meaningful and freely chosen, was anticipated.

Figure 9 The anticipated normal distribution of engagement, showing the comfort zone where engagement should be most likely to occur.

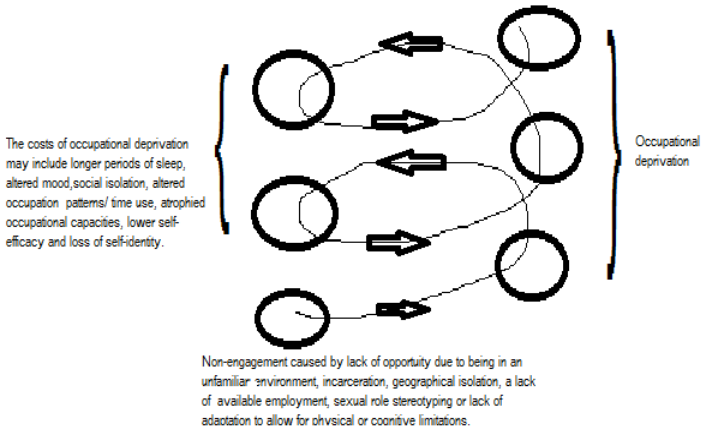


Beyond the upper combined sensory threshold, a point where increasing stimulation became unpleasant was anticipated. Therefore, it could be helpful to review combined sensory thresholds and whether sensory-overload is a relevant concept in the domain of NPC. The motivation to study this topic was the tension between the belief that all human beings have a unique sensory profile (Dunn 2009) and the lack of value placed upon the influence of sensory stimulation. This could have been significant because the knowledge that sensory-overload could negatively influence health and further disable people, and of which participants it could affect appeared lacking at the home. The philosophy of the home was about minimising intrusion on the participants, resulting in a total lack of assessment of sensory profiles, potentially compounding this problem. On the other hand, non-Huntington's residents (individuals or groups) who were observed slumped down in their chairs, not moving, communicating or making eye contact when spoken to, and who appeared disorientated and slow to respond, regularly occupied the MSE suites at the home. These individuals were experiencing what the researcher had inferred to be sensory-overload, and yet when the same participants were observed in other settings, they behaved very differently.

Another area of tension for this clinical group is the disparity between society's apparent attitudes to individuals with such profound levels of disability, and those of the government in terms of equality and rights to care based on best interest,

as described in the Mental Capacity Act (UK Parliament, 2005) and the Equality Act (2010) (Fredman, 2010). The use of the MSE suites described above would seem at odds with the aspiration about finding ability in disability. Sensory-overload has been described as leading to non-engagement, shutting down/dissociation, challenging behaviour, or boredom. The researcher also hypothesised that the exhibited signs of sensory-overload appeared similar to those of the costs of (and causes of) occupational deprivation – i.e. active or passive non-engagement (see Figure 10). This could imply that profound disability or sensory-overload can reduce the individual's opportunities for occupational-engagement, and that occupational deprivation could lead on to a spiral of further dis-enabling/non-engaging behaviour. This hypothesis is supported by the work of O'Sullivan and Hocking (2006) and Hearle *et al.* (2005), who described the insidious effects of occupational deprivation, suggesting that as individuals do less, they lose capacity. When doing gets harder, occupations become less rewarding and individuals are less motivated to try, so they do less.

Figure 10 The spiralling links between the causes and costs of occupational deprivation, and their influence on non-engagement.



One such home has a philosophy of "finding ability in disability" (RHN, 2011). This links to Darzi's (DoH, 2008) definition of quality as including continual service development and personalised care, therefore an incongruity appears between the lack of staff knowledge about the effects of sensory stimulation and its potential to do harm, and the expectations of a care home. This mismatch continues between the lack of value of the benefits of leisure in comparison with the value placed on physical maintenance and tissue viability, highlighted by the researcher in an as yet unpublished study of staff prioritisation of the meanings of leisure occupation for participants.

Another incongruity appeared, in an audit of leisure satisfaction (RHN 2007) between the expectations of participants and their supporters about what is suitable for them to do, and the individuals' role preferences. In addition to what is deemed suitable, earned, available or preferable to engage in, there could be a link between the threshold of responsiveness and occupational-engagement (Thomas *et al.,* 1963). However, Evans (2008) also suggested that studies of combined sensory thresholds involve factors in the occupational context, such as emotions or discomfort. Furthermore,

combined sensory thresholds depend on both the peripheral and the central nervous system, which could be affected by NPC, influencing sensory processing, preferences and therefore occupational capacity. Furthermore, this thesis has considered the influence of differing levels of sensory attributes on engagement, assuming that each additional sensory attribute will contribute to a combined sensory experience (Schroeder & Foxe, 2005; Dunn & Brown, 1997) and therefore intersensory processing (Lickliter & Bahrick, 2000), with an associated overlap in behavioural and neurological thresholds (Dunn, 1997; Evans, 2008). Therefore, the following section will consider the relevance of sensory-overload in NPC and the findings of the interview with the Residence Manager, by discussing the findings of the observations of engagement study.

Occupational-engagement is an innate human need (Wilcock, 1993), which usually falls into categories such as productivity, self-care and leisure (Reed & Sanderson, 1999). However, for individuals with profound levels of disability, it appears common to withdraw from all but the most passive of occupations (Farrow & Reid, 2004; Pollock & Stewart, 1990), either because sensory-overload renders them unable to take part any further, or because they prefer a passive spectator role. Occupations that are more active could be carried out for the individual (Nyman & Larsson-Lund, 2007), so that their only opportunity to be a truly occupational being is through leisure engagement.

In the home studied, the leisure occupations undertaken were mainly casual leisure occupations, and therefore had a high sensory attributes level (Stebbins, 1997). Engagement in leisure occupations matters for individuals with NPC because without it general satisfaction with life has been found to fall markedly (Backman, 1991), potentially reducing wellbeing, self-esteem and health. Equally, occupational deprivation matters because it could result in active or passive non-engagement in the short term, with associated altered patterns of time use. In the longer term, it could lead to dependence, lower mood, lack of social status, reduced abilities, loss of self-identity and self-efficacy, and social isolation (see section 2.2.7.). Therefore, it is of relevance that the key findings of the observations of engagement study include the following:

Engagement categories across each time sample showed increasing engagement at higher levels of sensory attributes

By simplifying the data into two categories, i.e. non and undifferentiated engagement, and engagement, it becomes apparent that:

- The Control condition remained non-engaging throughout.
- The Listening case appeared to start as an engaging occupation and then becomes non-engaging.
- The Film Show, Live Performance, Interactive Video, Making Music, Interactive Drama, Aquability occupations were all engaging occupations.

The occupational role offered influences engagement

Comparison of the engagement categories of the passive occupations and the potentially physically active occupations showed a difference, indicating that the potentially physically active group exhibited significantly higher engagement categories when compared to the passive occupations.

Supporter-to-participant ratios influence engagement

The supporter-to-participant ratios of the low, mid and high ratio groups could each influence engagement differently. However, it was noteworthy that as the sensory attributes level of each case increased, so did the supporter-to-participant ratio.

Therefore, a higher supporter-to-participant ratio, and the occupational roles available, may all influence engagement. Furthermore, beyond an expected upper combined sensory threshold, the increase in engagement categories documented could have resulted from other factors in the occupational environment. These factors could include supporters attitudes to the participants' leisure, and the role offered compared to the participants' role preferences. Other factors could include the concept that what is leisure for one individual may not be leisure for another (Taylor, 2008). However, in the context of this study, tensions still existed between the lack of a normal distribution in the engagement data with the increasing sensory attribute level of the cases, and the increasing engagement category with increasing sensory stimulation (median distributions shown in Figure 4 (see section 5.3)). Therefore, having discussed the impact on the lower combined sensory threshold of factors that contribute to the occupational context, it could be helpful to consider each case and some of the factors that affect the occupational context surrounding it.

The listening case occurred in a dimly lit environment, which could have triggered the release of serotonin in the brain, preparing the body for sleep. In this context, it is possible that the low level of participation could be due to a combination of dimmed lighting, and insufficient sensory stimulation to combat the soporific environment, unchallenged by supporter facilitation or positive collaboration, which is similar to the results of Cermak and Mitchell (2006). Participants who withdrew from participation in the session would be able to withdraw from these soporific effects. The listening case offered participants a passive role, which is experienced frequently. The choice of the listening material could have increased its meaning.

Viewers of the Film Show may also have experienced soporific effects, but to a lesser extent due to the slightly higher combined number of sensory attributes and the slightly higher level of support available. Other factors to consider included the peer and social pressure of a group context, such as avoiding falling asleep in public, trying not to disturb the others, and displaying control and dignity through showing interest and understanding. The Film offered participants a passive role, within a familiar context. The group chose each film at an earlier session, so if the film was requested by the participant or was of a genre of interest, this could increase its meaning for the individual. The complexity of this case could have been derived from coping with multisensory stimulation, or from understanding and following the story, which could have been part of a series and therefore required association with previous knowledge and habits. This case could have offered a sense

of time passing if the story was set within the lifetime of the individual, or if they had an appointment after the film to focus upon. This case would be relatively easy for participants to access, since it occurred weekly.

In addition to the social norms previously mentioned, the Live Performance also included an altruistic concern for the performers' efforts, e.g. showing interest or enjoyment. A difference in the interactivity and quality of the stimulation given by live performance performers (who could respond to the audience) and the Film Show performers (who could not respond) might have been influential. This case also had a higher supporter-to-participant ratio, in addition the supporters appeared to enjoy the performances, all of which could have prompted a higher engagement category in the participants.

The Interactive Video projection added novelty to the combination of factors. Although each show was unique, the participants regularly experienced concerts. In contrast, the Interactive Video was a new technology. Its novelty and technology provided an opportunity for intergenerational leisure (Downs, 2008), as whole families experimented with the projection. Although this case involved a darkened room, the projection gave off enough light for the participants to see clearly. Because the projection depended on movement to provoke a response, this case also involved a sense of vestibular and proprioceptive stimulation, which contributes to satisfying leisure (King, 1974). The Interactive Video case had a mid-range supporter-to-participant ratio, and also offered a potentially physically active role to participants. This was an experimental opportunity, and so it would not be possible for participants to access this occupation later. It could have become meaningful to the participants through their intergenerational interaction, or because the theme of the projection linked to past memories or interests. The occupational capacity demanded, and the complexity of the case included, an understanding that the projection responded to their movements. The participants who stayed beyond the forty-five minute session could have done so because they lost track of time (Tzanidaki & Reynolds, 2011), which Csikszentmihalyi and Csikszentmihalyi (1988) suggested was a sign of optimal engagement.

The Making Music group was a large noisy group which offered vestibular stimulation depending on the role undertaken. It had a mid-range supporter to participant ratio, mainly including very enthusiastic volunteers. The residence staff appeared to prefer to escort participants to this group and then leave them with the volunteers who ran the group. The continuity of this group could also have added complexity, given that each group had links with those before and after it, in terms of the music requested, and the topics discussed. The skill demands of the case included remembering the words and tunes, playing the instruments offered, and moving about. The participants could have reflected on changing tastes in music, or on other occasions when a piece of music had been heard. Furthermore, the experience could have reinforced family and cultural aspects of the participants' life. This case was relatively easy for participants to access since it happened weekly, and could be heard throughout the home.

The Interactive Drama session appeared attractive to staff, who therefore remained present during the performances. As with the Live Performance, the performers could see and respond to the participants' reactions. The performance offered a potentially active role, with some participants taking a performing role and others holding props. It also offered a visual sense of movement and of vestibular stimulation as the participants who became performers moved around the stage. The Interactive Drama session offered participants a mid-range supporter-to-participant ratio. The

complexity of this case derived from the higher-level of sensory attributes available, from remembering previous performances, and performing themselves. The participants could have derived a sense of meaning through reflecting on similar experiences, or through ownership of the story to which they had contributed. This was an experimental and so novel experience.

The Aquability sessions were participant driven, so the supporters constantly sought their participation. The buoyancy of the water offered a freedom of movement that was not possible out of the water. These factors could have enhanced their engagement in the case, as could the vestibular stimulation experienced. Participants could have derived a sense of meaning through reflecting on similar experiences, or through ownership of what they decided to do with their session. Aquability offered participants a high supporter-to-participant ratio, as well as a potentially physically active role. This experience occurred infrequently being available only when the hydrotherapy pool was not being used for therapy sessions. The pool was in a large sunlit octagonal room dominated by a ceiling hoist, and was full of brightly coloured floating toys. The skill demands of the case included playing with the games and toys. Its complexity could, have been influenced by the freedom of movement afforded by the buoyancy of the water. This case was not easy to access because it required the pool and hoist, and a high supporter-to-participant ratio.

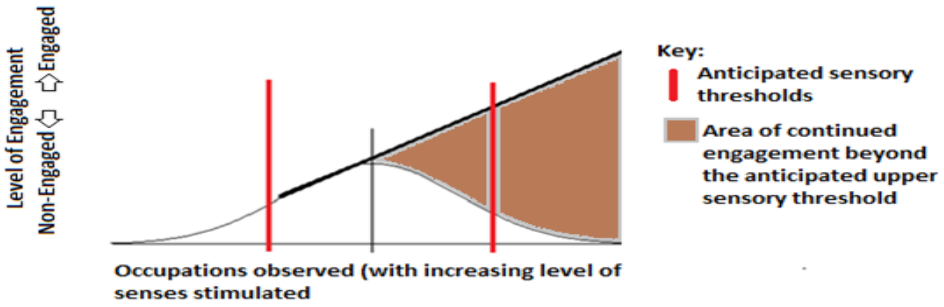
Vestibular stimulation could have been a feature of the potentially active participant roles of the Interactive Video projection, the Interactive Drama session, the Making Music group and Aquability, so that this type of stimulation could have contributed to the higher engagement categories during these occupations. Furthermore, consideration of the other factors that were involved in the participants' casual leisure could be instructive – e.g. whether there was a correlation between the level of facilitation and the individuals' engagement. It could have been coincidental that the higher combined number of sensory attributes was also associated with a case being potentially active, rather than physically passive, or the relationship could have resulted from the potential for active physical participation. Although Csikszentmihalyi (2002) appeared to discount "Flow" in this clinical group, this concept of the potentially active role could draw parallels with the idea of the "possibility of control" which is one of the six attributes of "Flow", and was suggested by Reed *et al.* (2010) to contribute to the meaning of occupation. The suggestion that possibility rather than actual control is one of the most important factors that could encourage and maintain engagement is intriguing. Therefore, offering the participants the possibility of a more active role could be enough to engage their participation, even if it was not taken up.

The original data were collected using the ICER, with additional field notes including data about the passive or potentially active nature of the role offered, and the level of support available. Because these additional contextual data were not part of the planned data collection, these factors were not built into the observed occupations prior to their occurrence. Instead, the supporter-to-participant ratios fell naturally into low, mid and high groups. It is interesting to note that the cases grouped naturally into 50% physically passive and 50% potentially physically active, and that the passive occupations occurred at the lower levels of sensory attributes as shown in Table 12 (see section 5.3.1). Whether the case was novel or a frequent experience fell into a less definite pattern, since the Control group, Listening occupation, Film watching and watching a Live Performance were all experienced frequently, as was the higher sensory attribute case of Making Music. This left the

Interactive Video, Interactive Drama and Aquability as less frequently experienced occupations, which offered potentially active roles and at the higher sensory attribute end of the continuum of occupations observed.

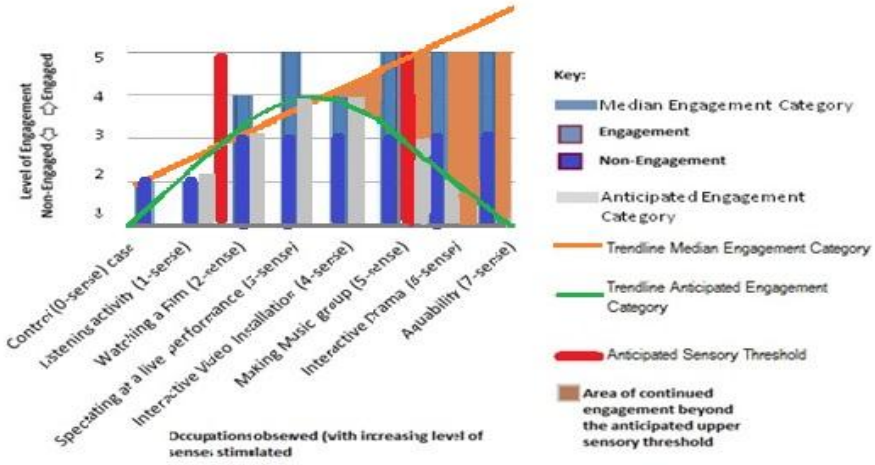
Reverting back to Luce and Edward (1958) and Swets et al. (1955) continuing to engage beyond the upper combined sensory threshold at the extremes of sensory stimulation intensity, could result from the stimulation being masked or exaggerated by environmental factors. Brown and Dunn (2010) also proposed that behaviour (including engagement) could be influenced by contextual factors. However, the natural occurrence of the co-variants collected as field data did not lend itself to regression analysis to determine whether there was a significant relationship between engagement and occupational role, between engagement and the level of support offered, or between engagement and the familiarity or novelty of the case. Regression analysis could have demonstrated what encouraged the participants to engage beyond their combined sensory threshold.

Figure 11 Increasing engagement at and beyond the participants' anticipated upper combined sensory threshold



The brown area in Figure 11 represents the unanticipated continuance of increasing engagement at higher combined sensory levels. The red lines indicate where the researcher had expected that the approximate combined sensory thresholds of the group might have occurred, but these expectations were not supported by the data. This is clearly illustrated in Figure 12, which is comprised of Figure 4 (see section 5.3) and Figure 11 (above) superimposed. Figure 12 shows that the engagement categories do not conform to a normal distribution.

Figure 12 The median engagement categories overlaying the increasing engagement at and beyond the participants' anticipated upper and lower combined sensory threshold



Given the unexpected engagement levels, it is unfortunate that regression analysis was not an appropriate statistical tool for use with the data. The data appears to be confounded by the swap from passive to active engagement and from low to mid-levels of support available, both of which occurred concurrently, between the Live Performance and the Interactive Video (i.e. the upper combined sensory level, occurred above the 50th quartile of the occupations). If these changes in category had not occurred concurrently, the effect of these co-variants could have been explored statistically. Another confounding factor was the lack of opportunities for triangulation (Edexcel, 2011) with the contextual data gathered in the field notes. Furthermore, had the overarching philosophy of this study not been one of leisure, then the participants could have been allocated to a crossover study design, using a matrix to design the co-variants of each case. This would have enabled an analysis of variance approach to explore the differences within and between engagement, combined sensory level, passive vs. active role, and supporter-to-participant ratio, as well as novel or frequently experienced occupations.

This thesis has shown that engagement increases with increasing sensory attributes. This raises a question about whether there is a threshold (on a scale of increasing dependency), beyond which increasing sensory stimulation is engaging for some and overloading for others. This idea supports the various findings of Olson (2011), Bundy & Murray, (2002), Dunn (2001). For example, Olson (2011) noted that individuals in different quadrants of the MoSP respond differently to sensory stimulation. She suggested (like Bundy & Murray, (2002)) that low registration and sensation seeking individuals require more stimulation than most, seeking activities with more sensory attributes (Dunn, 2001). This might contribute to an explanation of why higher levels of sensory attributes led to higher engagement categories (by individuals whose occupational deprivation led them to crave sensory stimulation masked by environmental interference or gated by an inefficient RAS), since Schaaf & Miller (2005) suggested that occupational-engagement with a high level of sensory attributes may facilitate SI and thus

further enable engagement. What is not known is how many of the participants sensory profiles, where in which quadrant of the MoSP, and therefore whether this might have been a factor in their engagement.

Using inductive clinical reasoning the linkage between passive engagement/ passive non-engagement and an individual's behaviour when experiencing sensory-overload has been suggested, based on the proportion of behaviours reported as the signs of sensory-overload when compared with the engagement categories defined by Kishida & Kemp (2006), (supporting Rose's (2011) assertion), which could have clinical applications. For instance, passive non-engagement is suggested to include reduced ability to vocalise, maintain eye contact and direct gaze, perceptual ability, self-regulation, limb eye coordination, muscle tone (e.g. weaker grip), understanding of speech, concentration and orientation to time place, person and poorer memory, slower information processing speed, meaning blindness and increased sensitivity or defensiveness to light or sound, perseveration, word-finding difficulties, muscle tone (e.g. difficulty releasing grip or moving). Whereas, passive engagement is suggested to include a reduced ability to vocalise, understanding of speech, self-regulation, maintain eye contact and direct gaze; increased muscle tone, perseveration, word-finding difficulties, alongside meaning blindness, less accurate perceptual ability and a more monotone tone of voice.

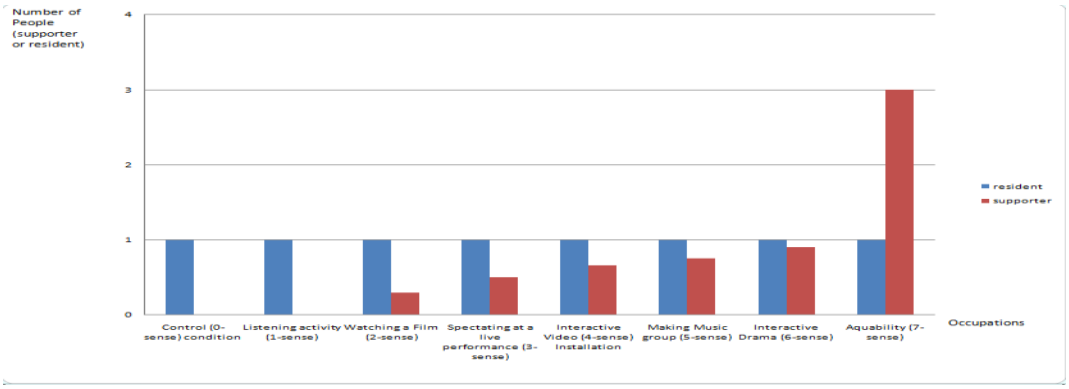
Additionally, the occupational role offered influences engagement, since a comparison of the engagement categories of the passive occupations and the potentially physically active occupations showed a difference, indicating that the potentially physically active group exhibited significantly higher engagement categories when compared to the passive occupations. Furthermore, the supporter-to-participant ratios of the low, mid and high ratio groups could each influence engagement differently. However, it was noteworthy that as the sensory attributes level of each case increased, so did the supporter-to-participant ratio.

However, the researcher believes that the results do not show the whole picture because the findings are incongruent with the current understanding of sensory processing in practice. The occupational context could have contributed to turning a case into an engaging occupation (Jonsson, Josephsson & Kielhofner, 2001), thereby encouraging engagement beyond the anticipated sensory threshold. As highlighted in Chapter TWO, this could have included the ease of accessibility of the occupation, and the level of support received. The timing or sense of time passing could also have been a factor, as could the participant's sense of altruism. Furthermore, the meaning of the occupation for the individual participant and the sense of experiencing occupational balance might have contributed. Other factors could have included the novelty of the case, the occupational capacity of the participant, and the complexity of the case; as well as the occupational role offered. Personal interest could motivate occupational-engagement (Yerxa, 2002), especially if (as Gallimore & Lopez (2002) suggest) occupations are a compromise between what is sought after and what is convenient. Jonsson *et al.* (2000) showed that occupational-engagement was influenced by internal motivations and external demands, for example the participants' ability to attend or be absorbed, and the depletion or enrichment of their physical and psychological resources through their occupational-engagement.

If it is supporter facilitation (defined by Creek (2008) as assistance through advocacy or support) and positive collaboration that increases the engagement potential of a case, then the observations should have found that the Listening

case was the least engaging, followed by Film watching, because these two occupations had the lowest supporter-to-participant ratio. Thereafter, the Live performance, the Interactive Video installation, the Making Music group, Interactive Drama, and Aquability, in that order. The supporter-to-participant ratio during the occupations was similar to this pattern, and could have influenced the participants' engagement in the cases. Also, as the sensory attributes level of the occupations increased, so did the supporter-to-participant ratio. In fact, as shown in Table 12 (see section 5.3.1) and Figure 13, the lowest supporter-to-participant ratio was experienced during the Control group and the Listening case. This increased to Film watching, followed by the Live Performance, the Interactive Video installation, the Making Music group, Interactive Drama, and finally Aquability. This order also mirrors the split between passive and potentially active occupations and those that include vestibular stimulation.

Figure 13 The number of participants (in blue) compared to the number of supporters (in red) for each case



Therefore, one reason for the contrast between the actual and anticipated engagement beyond any upper sensory threshold, could be the (sensory-overload-induced) boredom described by participants which could have left the participants in a position where they were grateful to, and took up the opportunity to engage, whenever an opportunity arose. Furthermore, Long (2004) noted that some environments are more boring than others, through being unchanging and non-stimulating. Therefore the higher sensory attribute level and supporter facilitation ratio could have partially contributed to maintaining the participants' engagement beyond their anticipated upper sensory threshold. Whiteford (2000) suggested that individuals who are more likely to be bored would be attracted to high stimulus or high challenge occupations as part of their search for meaning. She suggested that for some individuals, seeking stimulation or fleeing boredom could be a pervasive feature of their existence. She also proposed that there could be a relationship between the compulsion to escape boredom and a difficulty settling into lower levels of occupational-engagement. Additionally, Olson (2011) suggested that low registration and sensation seeking individuals require more stimulation than most, demonstrating engagement behaviours similar to individuals who demonstrate under-responsivity which may include greater engagement in activities with more sensory attributes (Dunn, 2001). Likewise, individuals whose occupational deprivation led them to crave stimulation masked by environmental interference or inefficient RAS gating, might have valued engaging in the higher sensory attribute cases. Also, Schaaf & Miller (2005) suggested that occupational-engagement with a high level of sensory attributes may facilitate SI

and thus further enable occupational-engagement. This may mean that with greater SI comes greater occupational capacity and therefore opportunity reversing the insidious effects of occupational deprivation (Turner, 2002; O'Sullivan and Hocking, 2006; Hearle et al., 2005). As it becomes easier to do things, they require less effort, becoming more rewarding and motivating. Furthermore, Jonsson and Persson (2006) suggested that boredom contributes to reaching higher engagement categories, since it could have both calming as well as negative qualities. However, this would seem unlikely in the context of participants who were experiencing sensory-overload, which does not normally leave the sufferer with any control over the outcome. Then again, the observations in this study were conducted with a less disabled group than the participants who were described as experiencing sensory-overload, so they could have been at less risk of sensory-overload than those for whom the study was designed. Therefore, it could be simply that at the higher level of sensory attributes, there was a greater likelihood of participants' preferred sensory stimulation being presented, attracting their attention and then building engagement.

Aegler and Satink's (2009) concept of engaging at an auspicious moment could have reflected how the participants were feeling in themselves at the time of the occupation. However, this argument could not hold true here, since the increasing engagement at higher sensory attribute level was a group phenomenon (and how the individuals felt in themselves was not known). Equally, according to Aegler and Satink (2009), given the participants' limited ability to complete an occupation (given their sitting tolerance, for example); the challenge to finish performing could have been a factor. Aegler and Satink's (2009) participants were motivated to start an occupation at the right time, and for them the challenge was to finish it. A similar motivation could have carried the participants beyond their combined sensory threshold towards the goal of uninterrupted completion, even if they were tired after the event. This could potentially contribute to the higher sensory attribute level occupations, maintaining the participant's engagement – especially as the observations were conducted with a more able group than those discussed by the Residence Manager. These individuals could have been at less risk of sensory-overload. Another factor that could have enhanced engagement could have been the feeling of contributing to their community in some way.

Arguably, the control condition and isolated listening offered little opportunity for altruism (unless the listening material was discussed later with someone else, e.g. a grandchild). However, Film watching with others has already been shown to include an element of social expectations about behaviour, as has spectating at a live performance, the Making Music group, the Interactive Drama performance and Aquability. Arguably, if the Interactive Video was known to be an experimental art form, this could also have fostered a sense of tolerance of its faults, along with interest. Hence, a sense of altruism could also have influenced engagement. If so, it is noteworthy that the occupations engendering a sense of social expectation were the ones with two or more sensory attributes. Again, this could have partially contributed to maintaining the participants' engagement at the higher sensory stimulation levels, especially because the observations were conducted with a more able group than those discussed by the Residence Manager, who could have been at less risk of sensory-overload, and who could also have been more aware of social expectations. Another factor to enhance engagement could have been the meaning of the occupation for the individual.

In particular, occupational science has explored how occupational balance influences health and wellbeing and vice versa (Håkansson *et al.,* 2006; Matuska & Erickson, 2008; Stamm *et al.,* 2009), whereas occupational imbalance could feel similar to overload (Håkansson *et al.,* 2006). Attempting to gain a sense of occupational balance could have partially contributed to maintaining the participant's engagement at the higher combined sensory levels. This could be particularly true since the observations were conducted with a more able group than those initially discussed by the Residence Manager. The participant group could therefore have been at a lower risk of sensory-overload, and could therefore have been more aware of their overall occupational balance. Novelty could also have played a part in enhancing engagement.

Additionally, Larson and Von Eye (2010) suggested that novelty required a higher level of perceptive processing, thereby generating a perception of time being shorter and passing more quickly. Conversely, occupations that are too challenging could overwhelm the individual, making time seem to pass slowly. Therefore, another factor encouraging engagement could have been the relative merits of familiarity with the occupation i.e. a comparison between non-routine and routine occupations. Therefore, it is noteworthy that Kishida and Kemp (2006) reported that their sample was more engaged in routine occupations than in unusual ones. McLean (2005) reinforced this with the finding that participants demonstrated a lack of interest in joining in with non-routine occupations. This contrasts with Berlyne's (1966) proposal that novel situations would be more engaging. Berlyne's conclusion would lead the reader to anticipate that unique leisure opportunities, such as the Interactive Video installation and the Interactive drama project, and infrequent occupations like the Aquability sessions, would be more engaging than more regular occupations such as the Making Music group, Film Watching and Live Performances. This would make the least engaging occupation the daily experience of listening, although psychological ownership of the listening material could have prevented disengagement.

On the other hand, Kishida and Kemp's (2006) and McLean's (2005) studies would appear to reverse the order of preference, suggesting that the most frequently experienced occupations (such as the Control condition, the Listening occupation, Film watching, Live Performances, and the Making Music group) should be the most engaging. Kishida and Kemp would then predict that the novel Interactive Video installation and the experimental Interactive Drama performance, or the infrequent Aquability session, would be least engaging. The novel occupations observed were towards the higher number of sensory attributes offered. This sense of novelty could have contributed to maintaining the participant's engagement, at the higher level of sensory attributes. This supports Berlyne's (1966) argument, especially since the observations were conducted on a more able group than those discussed with the Residence Manager.

Another factor that could have affected the participants' engagement with the potentially more dis-enabling higher number of sensory attributes could have been the quality of the facilitation and prompting offered by supporters, to enhance or maintain the participants' skill/occupational capacity and therefore their engagement. The level of prompting offered would have depended on the supporter's experience of enabling engagement, as well as the time taken by the participant to process and respond to the prompt. Using this hierarchy escalates the level of prompting if the desired response is not elicited at a lower level (Wilder & Atwell, 2006). Since the occupations that attracted a higher supporter-to-participant ratio were towards the higher levels of sensory attributes, this element of positive supporter collaboration could have partially

contributed to the higher sensory attribute level occupations apparently maintaining the participants' engagement. Another factor that could influence engagement could be the occupational role offered to the individual.

Furthermore, the residents' leisure pursuits were mainly passive and solitary leisure which offers an opportunity for independence, rather than requiring support to engage in active leisure occupations (Pollock & Stewart, 1990). The participants' profound level of disability limits their experience of physically active leisure (Goodman, 1996); in part, this could have been because the options for occupational participation decreased as the complexity of disability increased, leaving only the occupations with a passive/spectator role as do-able (Stanley & Dolby, 1999). Unconstrained leisure choices should therefore offer a choice between either watching or doing, across the whole range of occupational experience. The profound level of disability experienced by the participants limits what they can get involved in, especially when combined with a lack of timely adaptation to make them accessible. The relative merits of role preference versus the role offered by the leisure occupations could be another factor. A disparity appears between the role preferences as perceived by staff, residents and family members (RHN, 2007). Staff and family members appeared to expect their participant to prefer spectating, or to have a choice of role as dictated by the occupation, with little expectation that the individual would prefer an active participant role (RHN, 2007). However, participants themselves had the highest preference for spectating, followed by participation and finally having the choice of either role; their preferences were therefore spread across the range of roles. Consequently they should be offered the choice, on every occasion.

7.4 Contribution of the researchers publications

Fenech & Shaw Fisher (2012) suggested a range of meanings which could be derived from leisure by individuals with NPC, with a view to influencing a readership of doctors about the value of engaging in leisure occupations. The chapter stressed the costs of not engaging in leisure, such as longer periods of sleep, altered quality of life, lack of social acceptance and social status, diminished sense of self-efficacy, atrophied occupational capacities, loss of self-identity (individual or social), social exclusion, altered patterns of occupational-engagement and time use, enforced dependence, and/or lack of opportunity to access the tools required to engage in occupations.

In addition to the results included in chapter five, Fenech (2011) presented the results of a Staff Questionnaire about the benefits of Aquability. The staff reported that residents' were more relaxed, controlled and positive with greater curiosity and reduced irritability and stress. Residents' strength was described as increasing while pain and uncontrolled movements were described as decreased. Also, improvements in sleep were noted. Residents were able to do things and make movements in the pool which they were not able to do on dry land. Residents' coordination was reported to improve with muscle tone normalising as they become more relaxed. They were reported as enjoying using the pool for fun and as experiencing increased confidence and sense of self-identity. Resident's experienced opportunities for challenge and therefore achievement which increased their sense of self worth.

The residents' responses to the Leisure Satisfaction Scale also presented in Fenech (2011), showed that most residents experienced a sense of self determination, achievement, learning, and feeling healthier as a result of using the pool which was a variation from their usual activities. Aquability was reported as interesting, enjoyable and a shared experience

with friends who also enjoyed using the pool. The freedom of movement offered by the water, appeared to increase their self worth, self expression and creativity (Passmore, 2003).

Fenech (2010) suggested that drama offered residents an engaging way to use their free time. Participant engagement appeared to be influenced by a three-part combination of supporter facilitation, the number of sensory attributes, and the potential for active as opposed to passive participation. This was at odds with the findings of Lockwood & Lockwood (1991) and Nelson & Gordon-Larsen (2006), whose participants had preferred to undertake an independent but passive role. The strongest themes fed back from residents were that they enjoyed the interactive drama project, felt valued by having been part of it, developed an atmosphere of community spirit, and had learned something, and wanted it to continue.

Fenech (2009) highlighted the challenges for care staff supporting leisure, especially when seen as competing with care needs. Fenech & Baker (2008) reported on lifestyles delivered through individualised sensory diets. Using their sensory profile appeared to enable the participants (who were resident in a different facility to the one studied in this thesis) to maintain a sense of 'self-identity', which contributed to their coping with transcending negative life events. This article warned against the indiscriminate use of easily accessible stimulation such as being "parked" in front of the television or only being offered recorded music to listen to, in preference to a range of experiences involving all seven stimuli of the sensory diet.

The Mapping Discussion Document (RHN 2006) reported on the wide range of leisure opportunities available to the residents, and the Leisure Satisfaction Audit Report (RHN 2007) added staff and carer opinions about the leisure engagement and opportunities of residents which were at times at odds with the opinions of residents themselves. Fenech's (2005) critical discussion overviewed the literature on leisure occupations, proposing that such occupations combat boredom and may "enable the individual to maintain a social identity that may have been lost when work roles were no longer an option" (Fenech, 2005, p. 13). She drew together the work of other authors to suggest that NPC's restrict access to leisure (leading to a loss of valued roles), and that any occupational-engagement could be influenced by environmental, family and personal factors. This was her first article to suggest that facilitating leisure should begin as soon as the person is medically stable, in order to redefine their sense of self and transcend negative life events.

7.5 Future Directions

The thesis has reported studies of a population with extreme and special needs. It has explored whether sensory-overload is a relevant concept to NPCs. The research suggests that occupational-engagement could be affected by the sensory-overload experienced by individuals with NPC, leading to a passive state of engagement or non-engagement. One factor, unique to Aquability, is the freedom offered by weightlessness. This is worthy of future study, since weightlessness would appear to offer an enabling environment.

Further studies at the higher sensory attribute level, are needed, using participants who are not able to express their own consent because this group could be more at risk of sensory-overload. It would be particularly relevant to study this group when using an MSE, because the most disabled residents are perceived by staff members to benefit from high levels of

sensory attributes (see for example Spring et al, 2011), which appears contrary to emerging evidence about sensory-overload and sensory gating deficits in individuals with NPC. Individuals with NPC could be just as much at risk of sensory-overload as those with developmental disabilities, and further exploration of this idea would also influence the quality of residents' leisure experience.

Additionally, studies about how to identify and support the residents' role preferences through environmental adaptation could enhance future service provision. Other topics for further study could include the effects of goal orientation/anticipation, and the impact of maintaining the residents' rhythm of life through offering a cycle of seasonal leisure opportunities similar to the current programme. The opportunities provided by leisure occupations to keep in touch with the rhythm of life were appreciated by staff, but could also be explored with families and residents in further studies.

To explore the tensions between the research findings and the researcher's clinical experience in more depth, further studies may avoid the philosophy of leisure occupations and focus purely on self-care or productivity occupations with different levels of sensory attributes. Another suggestion for a future study would be to use a matrix to determine the way that sensory stimuli are combined, at the same time as increasing the number of sensory attributes. This design feature could rule out the possibility of sensory preference encouraging engagement, if the participants' preferred stimulation is offered. This change of philosophy could enable an experimental crossover design. However, such a study could not be described as a study of leisure occupations. A factor that could confound this proposal, however, derives from a belief in occupational science that meaningfulness is idiosyncratic, individual and context-specific.

A further study could explore the contextual factors in the environment that constrain or enable occupational-engagement. Furthermore, an exploration of the factors that pertain to the individual, such as meaning could be combined with observations of engagement by conducting an interview with the residents after each case. This would limit the observations to residents who can express their own consent to participate and answer questions.

7.6 Summary

Several similar concepts, such as the sensory diet and sensory regulation, aim to increase physical and cognitive functioning by establishing an optimal sensory attribute level. The thesis sought to determine whether sensory-overload affects individuals with NPC, and whether there might be an approximate optimal level of stimulation that maximises occupational-engagement while minimising the potential for sensory-overload. The aim therefore was to create a sensory environment that participants can handle competently and enjoyably. This sensory threshold can only be approximate, since each individual has a unique sensory profile of preferences, interests and experience. In no way, did the study set out to establish whether one leisure occupation might be more suitable for a diagnostic group than another.

The unique contribution of this study is that it has studied the influence of sensory stimulation on engagement in casual leisure occupations for a group of individuals who experienced a leisure lifestyle as a result of NPC. The study occurred with a group of participants rather than individual's; because the researcher had noted that many of the casual leisure

opportunities offered to the participants, were offered from a menu. As such, although they were tailored towards NPC in general, they did not take into account the sensory profile of individual participants.

This study has explored whether sensory-overload is a concept that is relevant to the domain of NPC. Consequently, occupational-engagement has been proposed to be influenced by the sensory stimulation experienced by individuals with NPC. This sensory response to over-stimulation (which Dunn (2001) and Arciniegas *et al.* (1999) suggested could be caused by sensory gating deficits resulting from NPC) could have led to a less able state which manifested itself as passivity, which is perceived at the home as similar to fatigue (see Text box 2). This preliminary study concluded that sensory-overload could be just as relevant to NPC as to other conditions such as the autism spectrum. The participants' sensory-overloaded behaviour presented as a passive state of engagement or non-engagement, which may lead on to occupational deprivation if left unchecked. Consequently, it became clear that the individuals' sensory profile could influence their engagement behaviour. Therefore, this research has suggested that consideration of the individuals' sensory profile should be undertaken when creating any casual leisure occupation, to reduce the possibility of occupational deprivation resulting from sensory-overload, and to enhance each individual's prospects for engagement.

The second study suggested that the sensory attributes influenced engagement in casual leisure occupations in combination with other factors. On the surface it appeared that the greater the sensory attributes the participants experienced, the more likely they were to engage in occupations. This conclusion ran counter to the researcher's clinical experience of sensory-overload, and therefore has been tempered by the understanding that the occupation alone could not be the only influence on engagement. Consequently, similar to the CMOP-E (Polatajko, *et al.,* 2007) consideration of the occupation, the individuals' sensory profile and also whether the occupational environment is conducive to engagement is suggested.

Tensions remain between the lack of a normal distribution of occupational-engagement, and the increasing engagement category with increasing sensory attributes. Therefore it could be considered that some participants could have met their combined sensory threshold, but continued to engage beyond it.

It would appear, therefore, that there could be more to engagement than simply the number of sensory attributes offered by a casual leisure occupation. Some of the co-existing factors that could over-rule the upper combined sensory threshold and thus enable engagement to continue beyond the upper combined sensory threshold have been considered. As stated in 7.7, these included the accessibility of the occupation, the support available, and preventing boredom. Furthermore, timing or the sense of time passing could have been a factor, as could the participants' sense of altruistic engagement. Furthermore, the sense of experiencing an occupational balance could have been important, and also the meaning of the occupation for the participant. Consequently, Fenech (2009) and Fenech & Shaw-Fisher (2012) suggested some of the facets that could make an occupation meaningful for the individual. These included a sense of importance, purpose or meaning, goal orientation, accomplishment, self-identity, individual growth, rhythm of life, belonging, self-expression and creativity, health, wellbeing and capability, self-determination, and self-efficacy. In terms of the occupational context, other factors to note include the novelty and/or complexity of an occupation, and the occupational capacity of the participant. Furthermore, the

individual's capacity for attention, absorption, the occupational role that the participants were offered, the level of collaborative support available, and the emotional and mood state of the participants could also have influenced engagement. This supports Larson and Von Eye's (2010) suggestion that the experience of occupational-engagement is influenced by contextual factors in the occupational environment. These environmental and contextual factors can constrain or enable occupational-engagement (Taylor, 2008). Combined with the tendency to withdraw from all but the most passive occupations, which could have a long-term negative influence on health and wellbeing; individuals with NPC could be at risk of sensory-overload, leading to an increased risk of occupational deprivation and its associated costs.

As previously stated, many researchers have explored the meaning of occupation. Even so, a theoretical contribution to occupational science has emerged from this study, building on existing knowledge about the meaning of occupation and considering the influence of contextual factors on the occupational experience. As illustrated in Figure 14, both Reed *et al.* (2010) and Taylor (2008) have described interconnectedness in the meaning of occupation. Therefore, this discussion chapter has reviewed the environmental and contextual factors that could also contribute to the occupational experience, and which could have contributed to turning an occupation into an engaging one (Jonsson, Josephsson & Kielhofner, 2001), thereby encouraging engagement beyond the anticipated upper sensory threshold. Engaging occupations have therefore been suggested to take place amongst, and influence or be influenced by, factors in the social, cultural and physical environment around the occupation.

To demonstrate the inter-relatedness of these factors, Figure 14 presents them in terms of three overlapping circles, which could constrain or enable engagement (Taylor, 2008). The influences on engagement have been sub-divided to make them easier to understand. They include those that pertain to the individual, to the occupation, and to the environment, thus mirroring the CMOP-E (Polatajko, *et al.,* 2007) as factors that contribute to occupational performance. Some of the environmental and contextual factors in the occupational environment that have been suggested to enable engagement beyond the anticipated upper combined sensory threshold could include:

- Accessibility
- Supporter facilitation
- Timing
- Effects of an occupational environment that was conducive to engagement

Related to these, there could be factors that pertain to the occupation and that could influence its engagingness, such as:

- Sensory attribute level
- Novelty
- Complexity
- Opportunities for self-expression and creativity
- Occupational role

Furthermore, factors that pertaining to the individual could also influence their engagement, such as:

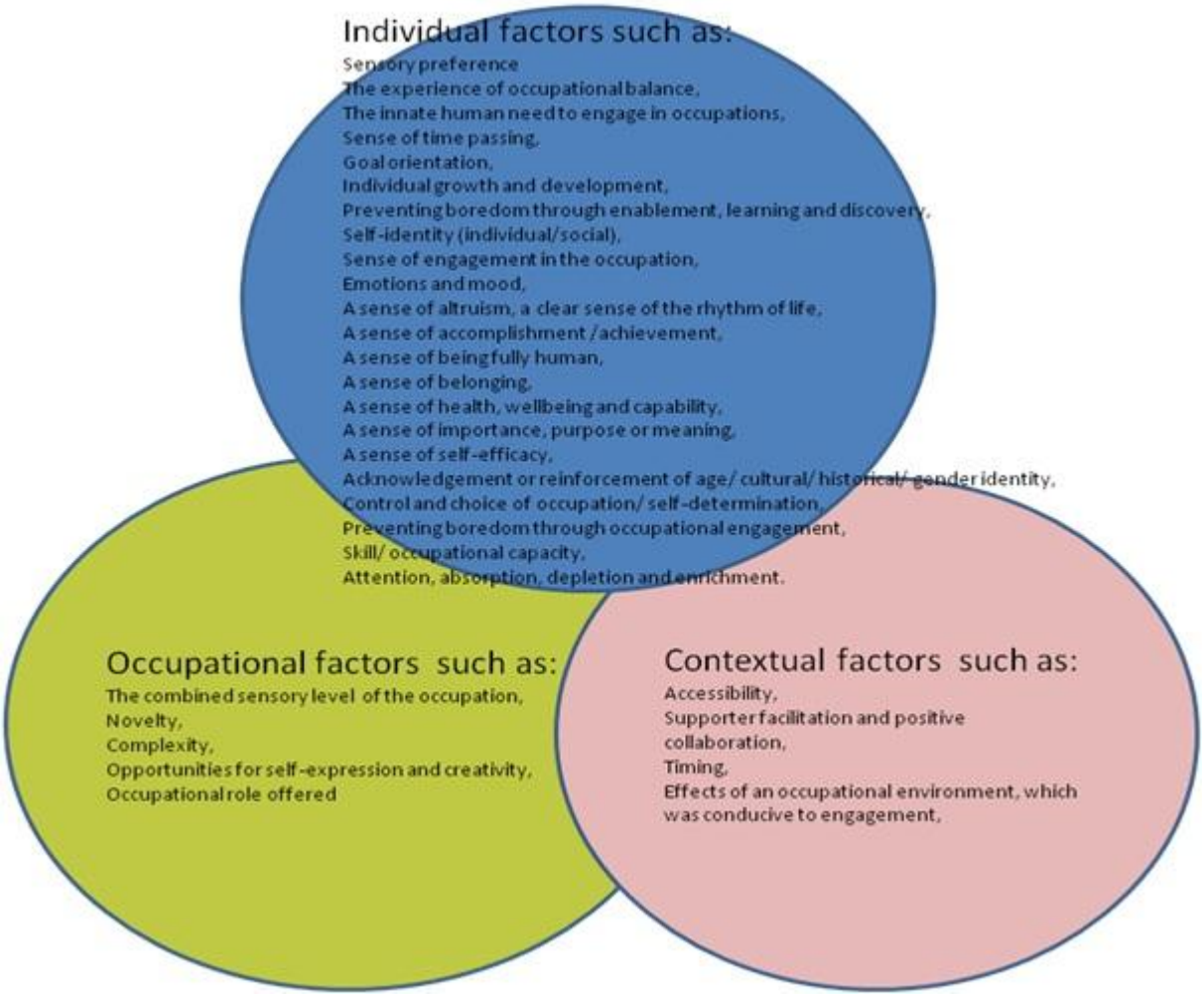
- Sensory preference
- The experience of occupational balance
- The innate human need to engage in occupations
- Goal orientation
- Emotions and mood
- Individual growth and development
- A Sense of :
    - time passing
    - Self-identity
    - engagement in the occupation
    - altruism
    - the rhythm of life
    - achievement
    - being fully human
    - belonging
    - health, wellbeing and capability
    - meaning
    - self-efficacy
- Acknowledgement or reinforcement of age/cultural/historical/gender identity
- Self-determination
- Preventing boredom through occupational-engagement
- Skill/occupational capacity
- Attention, absorption, depletion and enrichment.

The findings from this research could influence the preparation of casual leisure occupations for individuals with NPC. The point of presenting them in a figure format is to bridge the gap between theory and practice for supporters, so that the relevance of the findings to their service users becomes apparent.

As Nilsson (2006) pointed out, leisure has the potential to be unsatisfying if it is unengaging, while active engagement in leisure enhances wellbeing and life satisfaction. This coincides with Wilcock's (1993), Gauvin & Spence's (1996) and Molineux & Whiteford's (1999) assertion that engaging in truly (rather than partially) meaningful occupations could influence physical or psychological health. Therefore, occupational-engagement can be seen as promoting overall health and wellbeing, and preventing occupational deprivation. It is hoped that the findings of this research will encourage leisure supporters to involve the individual in the leisure occupation as much as possible, i.e. by offering them the opportunity to participate rather than simply putting music or the radio on in the background, or positioning the individual where they can

see the television without establishing their preference. Both of these situations are not only passive roles, but they could be considered abuse if the individual was not consulted, the media is inappropriate for the individual, is not of their choosing or is meaningless to them. Therefore, the individual should have the autonomy to choose his or her preferred occupational role, which could involve appropriately timed and planned collaboration from someone offering to support his or her leisure engagement.

Figure 14 The factors that could contribute to changing an occupation into an engaging occupation



Appendices

Appendix i Discussion of the non-sensory influences on occupational-engagement including the facets which contribute meaning to an occupation

Some people have suggested that occupational science is too individualistic in its conceptualisation of occupation (for example by both Dickie *et al's.* (2006) case studies and Hocking's (2000) reflective article). In its defence however, Pierce *et al's.* (2010) grounded theory based examination of conference abstracts suggested that it is appropriately individualistic for a science and a profession instigated to support occupational therapy practice. Individualism is a belief in the importance and worth of each person. It encompasses an ethos of equal rights. Also of economic liberalism which infers a freedom from external control, individual ownership of assets, and an expectation that every human being can rise above his or her circumstances. Additionally, it espouses the individual's right to express their personality and their individual uniqueness.

This individualism highlights the pursuit of individual interests and achievements rather than shared goals, and collectivism, and so instantly puts it at odds with the clan system, collective communities such as kibbutzim**,** spiritual or religious communities, ecovillages, communes, survivalist retreats, ashrams, and housing cooperatives where the needs of the many outweigh the needs of the few.

If the focus of occupational science is on individuals, their uniqueness, experience and development; occupational scientists have set themselves up to fail to interrogate the complex causes that underpin occupational phenomena; such as, interactions between socio-cultural and religious mores, economics, history and politics and the impacts these have on either supporting, precluding or depriving people of opportunities for occupational participation. It also rejects ideological issues, and power relations, so that occupational deprivation can only be explored in relation to what happens to people who experience it, rather than the forces beyond the individual that bring it about. Arguably, the causes of occupational deprivation could be immaterial.

For the researcher this concept of being self-determined is problematic because she perceives evidence of animals and people who are subject to the influence of their bio-psychosocial and sensory environment, and their health on their behaviour and occupational-performance on a daily basis. Therefore, she cannot believe wholeheartedly that participation in healthful occupations is a matter of individual choice and personal responsibility. Instead, she believes that the physical and social context around an occupation could influence engagement with it (according to Jonsson *et al's.* (2001) longitudinal qualitative study), in addition to an individuals sensory preferences and threshold. Accessibility for example may influence engagement (by experimental studies by Verghese,2006; Verghese *et al.,* 2003; Verghese *et al.,* 2006), especially if being easy to access reduces its value turning a leisure occupation into an imposed, arbitrary or easy option for supporters to provide. The level of support received and a desire to prevent boredom may influence engagingness. The timing or sense of time passing could also be a factor, since occupations are a way of using time. Another influencing factor could be the participant's sense of altruism (i.e. engaging for someone else's benefit), as could the individual's interest (Yerxa, 2002). Additionally, the meaning of the occupation for the individual participant and the sense of experiencing occupational balance could both be important. Other factors could include the novelty of an occupation, the participant's occupational capacity, and the complexity of the occupation as well as the occupational role offered. Jonsson *et al.* (2000) suggested that occupational-

engagement may be influenced by internal motivations and external demands, for example the participants' ability to attend or be absorbed, and the depletion or enrichment of their physical and psychological resources through their occupational-engagement. Other influences of engagement could include:

1 Supporter facilitation and positive collaboration

The quality of the facilitation and prompting offered by supporters, to enhance or maintain the participants' skill/occupational capacity could influence participants' engagement. This facilitation could include preparing the occupation and the environment, using a prompting hierarchy, and ensuring that participation is worthwhile and meaningful (according to Toogood's (2008) questionnaire data). McKay's (2011) thesis described several ways of escalating assistive prompting from least-to-most intrusive, with the aim of encouraging an individual's participation and decreasing the amount of assistance offered by the prompts as the individual becomes more able. The hierarchy of prompts could also range from least to most intrusive, i.e. the supporters could give verbal indirect cues, moving on to verbal direct cues, then visual cues, and finally using physical gesturing (according to Greber *et al's.* (2007) clinical guidance article). In this thesis, the level of prompting offered could depend on the supporter's experience of enabling engagement with the individual, as well as the time taken by the participant to process and respond to the prompt. Using this hierarchy escalates the level of prompting if the desired response does not occur at a lower level (according to Wilder & Atwell's (2006) evaluation of procedure article).

Creek's (2008) literature review defined supporter facilitation as assistance through advocacy or support and positive collaboration. Nyman and Larsson-Lund's (2007) interview data suggested that the social environment influences occupational-engagement through either constructive or inadequate collaboration (actions undertaken to influence engagement). They suggested that this constructive collaboration involved actions such as anticipating and instigating adaptation, prior to, or during (if it was proving too demanding) the occupation. Nyman and Larsson-Lund (2007) also suggested that supporters could carry out parts of the occupation that were too demanding. This collaboration could result in a sense of interdependence (creek, 2010), with the supporter doing the occupation on behalf of the individual with a disability, encouraging occupational-engagement of mutual interest, or facilitating new occupations to replace ones that are too demanding. On the other hand, inadequate collaboration could involve adapting or doing the occupation on behalf of the individual, only after requests from the participant. The supporters' understanding of the participants' occupational capacity is therefore important, as is their understanding of the meaning of and preference for the occupation for that individual, and an ability to adapt the occupation to enable engagement. Nyman and Larsson-Lund (2007) suggested that a lack of collaboration influenced the support offered, in that the supporters did not anticipate the individuals' need for assistance adequately, or the right type and amount of assistance required. Some took little or no responsibility, while others took too much responsibility. To substantiate this, Larsson-Lund and Nygard (2004), and Neugebauer and Katz (2004) (who both collected interview data and Tham and Kielhofner (2003) (who conducted an experimental study) all suggested that the actions of supporters could influence an individual's opportunities for engagement. However, helping an individual to engage could be a waste of time if the supporter does not value leisure, like the occupation or see the point in it. Positive collaboration on the other hand, between the individuals and their social environment, and an understanding among the

supporters of the preferences and previous experiences of the individuals, could facilitate their engagement (Tham & Kielhofner, 2003; Vikstrom *et al.,* 2005). This insight could be particularly useful if combined with an awareness of the consequences of the timeliness and appropriateness of collaboration (Nyman & Larsson-Lund, 2007). Another factor that could influence engagement could be the aim of preventing boredom.

2 Preventing boredom through occupational-engagement

Martin *et al's.* (2012) literature review argued that boredom arises from occupational deprivation as well as from personality type, attention deficit, attitude, and lack of stimulation. Prior to this Berlyne (1966) had reported that curiosity results from insufficient information or stimulation. He also proposed that learning, attitude change and social interaction results from achieving the optimal assortment of ability to surprise, originality, intricacy and change. Another literature review by Cervone (2004) proposed that experience resulted from change and consistency. While Wegner & Flisher's (2009) literature review supported Farnworth's (1998, 2004) suggestion that boredom was experienced significantly more when an individual engages in passive leisure, or when an individual perceives the challenge of an occupation to be less than the skills they bring to it. While Wright *et al.* (2007) reviewed literature to describe optimal engagement as a complex mixture of challenge, skills, enjoyment, diversion and mindfulness. Alternatively, Goldberg's (2012) textbook explored how the constant information inundation of the twentieth century could become a demotivator, diluting meaning and influencing wellbeing. This led to the suggestion that under-stimulated individuals could choose stimulation of any kind to achieve a balance, while the overload of and inability to control or process stimulation results in boredom, and the inability to deal with distractions and distress.

Additionally, Long's (2004) book chapter suggested that all client-centred interventions could unintentionally address boredom by offering a meaning and a purpose. Whiteford (2000) suggested that individuals who are more likely to be bored could be attracted to high stimulus or high challenge occupations as part of their search for meaning. This is what Dunn (1997) describes as sensory seeking. Whiteford (2000) suggested that for some individuals, seeking stimulation or fleeing boredom could be a pervasive feature of their existence. She also proposed that there was a relationship between the compulsion to escape boredom and a difficulty settling into lower levels of occupational-engagement. However, doing nothing avoids risks such as falling, choking or dropping something, and that therefore boredom could at least keep the individual safe.

Additionally, Jonsson and Persson (2006) suggested that boredom contributes to reaching higher engagement categories, since it could have both calming and negative qualities. However, this would seem unlikely if the individual was experiencing sensory-overload, since this does not normally leave the sufferer with any control over the outcome. Although, at the higher level of sensory attributes, there could be a greater likelihood of participants' preferred sensory stimulation occurring, attracting their attention and then building engagement.

Additionally, as Larson and Von Eye's Dynamic Occupation in Time Model (DOiT) suggests (2006 & 2010), there could be an interaction of factors contributing to engagement, such as its meaning, context, complexity, novelty, the individual's

abilities, and sense of time passing. Moreover, Cernigoj's (2008) case study argued that despite the long-held relationship between the workplace and boredom, from an individual perspective, boredom could lead to a higher likelihood of anxiety, depression, drug addiction and alcoholism, work dissatisfaction and poor work productivity.

3 Timing and sense of time passing

Absorbed involvement may modify the perceived duration of an occupation by altering the subjective perception of time, giving the sense of time passing quickly (see for example Glicksohn's (2001) extensive literature review), based on emotional experience during participation. Sackett *et al's.* (2010) meta analysis of experimental studies suggested that when time appears to pass quickly, occupations appear pleasant. However, time pressure could increase stress with associated negative impacts on wellbeing and perceived health (Sackett *et al.,* 2010). However, Larson & von Eye (2010) suggested that "Flow", although associated with a sense of timelessness, could not necessarily be a pleasant experience. Additionally, they suggested that an altered sense of time only results from active participation in an activity. They suggest that being present passively rather than actively engaged, could lead to a perception of time passing slowly, in a similar manner to perceptions of time during unfilled periods (Larson & von Eye, 2010).

Additionally, Aegler and Satink's (2009) interview data described how individuals could challenge themselves to remain occupationally engaged by beginning their engagement at an auspicious moment, i.e. when experiencing reduced symptoms. These researcher's reported participants who were motivated to start an occupation at the right time, and for them the challenge was to finish it, even though they were less well after the event (e.g. because of tiredness). However, Arguably, individuals with NPC have too much free time and therefore should be grateful for whatever occupies them, however inappropriate, quick or long winded. Another factor that could influence engagement could be the participant's wish to be altruistic.

4 Altruism

Stamm *et al's.* (2009) narrative study suggested that occupational balance included a mix of challenging and relaxing occupations that were meaningful within a socio-cultural context, including caring occupations. Additionally, Borell *et al's.* (2006) interview data also led the authors to conclude that ''doing something for others'' was part of the complexity of an occupation. Altruistic beliefs could also influence the feeling of being part of a group (Stebbins, 2004; Miller Polgar & Landry, 2004; Crombie *et al.,* 2004), so that rather than performers, staff or family members supporting the participants, instead the participants were engaging to please their supporters (or the performers). However, the freely chosen and enjoyable nature of leisure could preclude doing something to please others. However, Arguably, individuals with such profound levels of disability cannot do anything for anyone else and therefore altruism is not a relevant concept for individuals with NPC. Another factor that could influence engagement could be the meaning of the occupation for the participant.

Conversely, the motivation behind and motive-based perceptions of engagement such as altruism, could be difficult to measure, however altruism whilst being a motivation to enagege may also be a meaning derived from that engagement.

McClelland *et al.* (1982) described projective techniques to measure motives but this concept does not appear to have gained much support. Alternatively, using survey tools to describe motives may create issues of social desirability. It would also be questionable to describe people's own personality traits via self-report measures. Additionally, despite the extended use of self-report measures in research, there may be little correlation between self's and other's report of an individual's personality. Despite these issues, by 1976, Steers and Braunstein had developed several behavioural models that measure an individual's achievement, power motives and affiliation.

5 Meaning

Section 5 will discuss the meaning of occupational-engagement and the importance of matching meaningfulness to the individual, in contrast to the concepts of Functioning, Disability and Health described by the World Health Organisation (2001), which could also influence participation. A repeated theme throughout Christiansen & Townsend's (2004) book and Wilcock (2006) is that humans attribute meaning to their lives and their unfolding autobiography through their occupational-engagement, its development, and the sense of belonging that results. Additionally, opportunities for choice, e.g. about the role to undertake, could influence the meaning of an occupation (according to the Canadian Association of Occupational Therapists' (CAOT) (2001) book). Literature reviews have suggested that choice could be linked to intrinsic motivation (Deci & Ryan (2008); and Ryan & Deci (2000, 2006, 2008)), inquisitiveness (Berlyne, 1966) and a sense of self-identity (LaLiberte-Rudman, 2002). Bartalos' (1993) recreational guidelines suggested links between motivation, inquisitiveness and self-identity and adapting to, or coping with life and the environment. LaLiberte-Rudman (2002) inferred a relationship between occupation and identity when presenting the results of a secondary analysis of qualitative data. Furthermore, she suggested that the social environment could influence which occupations are suitable for different types of social identity, which in turn could influence the way in which individuals select the occupations they engage in.

Careful assessment of the individual's capacity, preferences and the attributes of a necessary occupation are imperative (Mackenzie & O'Toole, 2011), to ensure that an occupation has the potential to be meaningful to the individual. If this assessment is not undertaken, a discrepancy could occur between the individual's capabilities and those required by the occupation. This could result in others completing the inappropriate activity on the individual's behalf. For individuals with NPC, choice may be limited because others carry out a role on their behalf, e.g. self-care, or imposed based on assumptions about suitability. In this situation, an occupation could well lack appropriateness and meaning. Despite, or perhaps because of, having residents' self-care needs met, Bontje *et al's.* (2004) qualitative interviews therefore suggested that it is difficult for these individuals to retain a sense of self. Despite the challenges involved in adapting an occupation to the needs of the individual, occupational-engagement contributes to self-identity (Christiansen & Townsend, 2004; Wilcock, 2006). As has been shown in case study based articles, many leisure occupations can be adapted to enable individuals with NPC to participate (Bache & Derwent, 2008; Malley *et al.,* 2008; Blacker *et al.,* 2008; Magee & Bowen, 2008), but the question remains about whether this adaptation is suitable and will enable independence.

As occupational science is replete with definitions of occupation (Dunn & Hocking, 2001), different perspectives on the meaning of occupation have emerged. The importance of meaning arises in a variety of models of occupation

Consequently. Meaning is a key element in designing therapeutic occupations. Furthermore, Hasselkus (2002) suggested that the experience of meaning is the premier aspect of an occupation. Despite this history of apparent consensus regarding the central place of meaning to occupation, the meaning of meaning remains ambiguous. Nelson's (1996) seminal text defined meaning as, “The person’s entire interpretive process when encountering an occupational form, including perceptual, symbolic, and affective experience” (pg. 776). Accordingly, (Nelson 1996) meaning occurs as part of the relationship between occupational form (objective physical and sociocultural circumstances external to an individual) and occupational performance. As an individual encounters an occupational emerges in part as a response to “The present nature of the person as a holistic being with sensorimotor, cognitive, and psychosocial characteristics”. The meaning ascribed to an occupation in turn instils the occupational-performance with purpose (Nelson 1996).

The meaning of an occupation is important (Hammell, 2004) and unique (Primeau, 1996; Taylor, 2008; Yerxa et al., 1989) because meaningfulness and a balance of occupations (Christiansen, 1996; Meyer, 1977) are important attributes of occupation. Only an individual, those who perceive the demands and their abilities, the meaningfulness or lack of it, can explain their engagement in and the meaningfulness of a occupation (Yerxa et al., 1989; Jonsson *et al.,* 2000). This makes meaning a difficult concept to define since each individual attributes meanings that are unique to them.

Csikszentmihalyi (2002) however, defined the meaning of life as meaning: whatever it is, wherever its source. He defined it as a unifying purpose, which gives meaning to life, through being goal directed, intended and involving commitment to complete and meet their challenges.

Many researcher's (see section 2.3.1) have described how occupations could offer meaning to participants through opportunities to experience the benefits of occupational-engagement. For example, achievement leisure could include competition, personal challenge (according to Passmore & French's (2003) focus group data) to contribute towards personal development (according to Passmore's (1998) meta analysis involving 1145 adolescents). In addition to the satisfaction derived from goal achievement (either directly or through others; Hocking, 2000), belonging to a community (Passmore, 1998) or engaging in truly meaningful occupations (according to Wilcock's (1993) theory of the human need for occupation).

The meaning of occupations is the defining characteristic of the concept of occupation and of occupational science (according to Dickie *et al's.* (2006) challenging literature review). Engaging in truly (rather than partially) meaningful occupations could influence physical or psychological health (according to Gauvin & Spence's (1996) knowledge base review; and also publications by Molineux & Whiteford, 1999 and Wilcock, 1993). Meaning could therefore be an important motivator (or demotivator) (Kielhofner, 2002). Jonsson *et al's.,* (2000) research with recently retired participants highlighted a transition process, which included altered time use, adjustment, altered meanings, control, and future planning. However, whilst arguably that meaningless occupations are not good for health and wellbeing, this could not matter since individuals with NPC could be argued to be non productive or disabled anyway. A factor that could influence engagement could be the goal orientation of the participant.

5.1 Goal Orientation

A sense of individual purpose (O'Sullivan & Hocking, 2006; Kielhofner, 2002) or goal orientation could influence occupational performance, resulting from reflection about how to achieve the goal (Townsend & Wilcock, 2004). The sense of goal orientation could be unique to the individual whilst also contributing to a group's shared values. An occupation could also contribute to several goals depending on its context and the motivations of the individual. Moss & Ritossa's (2007) data, based on self-reported questionnaires about goal orientation and commitment, revealed that learning orientation was able to maximise the advantages from contingent reward, where leaders give adequate and clear-cut incentives to the followers. Additionally, when employees worked to obtain favourable assessment, such intellectual stimulation engendered commitment. Additionally, the researcher's suggested that an individual's goal orientation, if prioritised may encourage transformation and participation.

Self-selected occupations, whether intrinsically motivated by enjoyment or extrinsically motivated by the product, can lead to pride in achievement (according to Baxter *et al's.* (1995) informative book and Miller Polgar & Landry's (2004) book chapter) and a sense of wellbeing (according to Wilhite *et al's.* (2004) literature review). For individuals with NPC, achieving goals could facilitate a positive reflection on accomplishment. Arguably, achieving goals is something to reflect upon as an experience, when the individual has such profound levels of disability. Alternatively, a lack of current achievement could lead to frustration or lack of confidence (Miller Polgar & Landry, 2004). To cope with this sense of lack of success, individuals require optimism, resilience, and self-efficacy beliefs to confront failure or persist towards their goals (according to Bandura's (2000) book chapter and Seligman *et al's.* (1998) book). Crocker and Wolfe's (2001) model of global self-esteem suggested that unsuccessful goal achievement could lead to redoubled effort, or to psychological or physical withdrawal, depending on whether the effort required was realistic, and would lead to a sense of achievement.

5.2 Accomplishment/achievement

Occupations that lead to a sense of achievement could do so through competition, personal challenge (Wensely & Slade's (2012) semi structured interview data) or widening experience (according to Drummond & Walker's (1996) groundbreaking experimental study). Passmore (1998), Aldrich & Cutchin's book chapter (2012) and Bazyk's literature review (2005) all described "achievement leisure" as a potential contributor towards personal growth. Satisfaction could result from achievement and completion of tasks (according to Miller Polgar & Landry, 2004; Iwasaki's (2007) re-conceptualising literature review; Kinney & Coyle's (1992) seminal interview data; and Drummond & Walker, 1996). Furthermore, satisfaction could result from feeling part of a community, producing a product, or achieving a goal either directly or through others (LaLiberte-Rudman's literature review (2002); Passmore, 1998; Christiansen, 1999; Phelan & Kinsella's literature review (2009); Hocking, 2000). Personal reflection on occupational-performance and the individual's own role could not always be positive, especially if the roles were limited (according to LaLiberte-Rudman *et al's.* (1997) semi structured interview data and Miller Polgar & Landry's (2004) book chapter).

LaLiberte-Rudman (2002) provided a conceptual framework for the relationship between occupation and identity. She described how the social environment could influence perceptions of occupations that are suitable, and the effect of

environment on occupational choice. The majority of leisure occupations that are engaged in by individuals with disabilities tend to involve watching others participate, rather than being active leisure occupations that demand support from others (Oates *et al.* (2011) and O'sullivan & Chard's (2010); and Lockwood & Lockwood's (2007) literature review). This could be because individuals appear to choose leisure occupations where they have already achieved a goal or where they could yet develop competence (according to Caldwell's (2005) argument), leading to positive reflection on accomplishments (Miller Polgar & Landry, 2004; LaLiberte-Rudman, 2002). However, Arguably, achievement does not matter or is a luxury when an individual is receiving palliative care. The need to feel fully human could have been another factor to influence engagement.

5.3 Being fully human

The concepts of occupation and occupational potential are central to being fully human (Yerxa *et al's.* (1989); Wicks (2005); Kantartzis et al's. (2008) literature review based arguments. Occupational potential could develop over time to enable humans to fulfil their occupational roles and achieve a sense of self-efficacy (Wicks, 2005). It could build on culture, heritage, and performance to engender a sense of individuality and being fully human (Wicks, 2005). As such, Christiansen (1999), Phelan & Kinsella (2009) and Vrkljan & Miller - Polgar's (2007) exploratory study) all suggested that occupational participation could be significant to making a contribution, discovering socio-cultural and spiritual meaning and becoming a unique individual with a unique self-identity, (another factor to influence engagement). Describing people living with NPC as vegetables may lead to the argument that feeling human is not relevant. Then again, Stresemann's (2012) literature review, argued that although a successful career leads to a stronger drive for self-realisation, reduced stimulation in instances when performing continuous and dull activities will result in the fading of one's passion for self-realisation. This can instigate indifference to the accomplishment of tasks, as well as diminish the individual's productivity.

5.4 Self-identity (individual/social)

Lobo (1999) and more recently Guo *et al's.* (2011) cross sectional study suggested that leisure offers opportunities for experimentation, risk-taking, and challenge. He described how un- or underemployed individuals could feel socially excluded and demoralised, and could use leisure as a coping/escaping strategy. Christiansen (1999), Phelan & Kinsella (2009) and Miller Polgar and Landry, (2004) all reported that occupational-performance influenced self-identity and wellbeing through reflection, goal orientation and social approval. LaLiberte-Rudman (2002) therefore suggested that restrictions to occupational participation could correspondingly limit an individual's self and social identity. The goal of maintaining a participant's social and self-identity could determine how to carry out an occupation (LaLiberte-Rudman, 2002). Occupational-engagement influences our selves, and our communities, leading to unique occupational identities, the accumulation of who one is and their aspirations (Crepeau *et al.,* 2009). Additionally, the cultural, religious or spiritual attributes of an occupation, and the feedback received, could also influence self-esteem, social roles, approval and values (according to Franke & Engleke's (2001) literature review; Kleiber & Kirshnit's (1999) book chapter and others such as Creek, 2010; Molineux & Whiteford, 1999; Passmore, 1998; Crepeau *et al.,* 2009; Wilcock, 1998; Christiansen, 1999; Phelan & Kinsella, 2009; Lobo, 1999).

Furthermore, Andersen and Chen's literature review (2002) proposed a social-cognitive theory of self, whereby the internalisation of the perceptions of others influences self-identity. Hutchinson *et al.* (2003) described individuals using leisure as a defence against stress, a distraction that offered a sense of escape and a way of linking the individual to positive experiences, whilst enabling the adjustment needed to accept a new self-image. Solitary leisure could offer opportunities for self-reflection, problem solving and relaxation, which could influence identity development and transcendence over negative life events (according to Kleiber *et al.,* 2008; Hocking, 2000; Hutchinson *et al.,* 2003; and Folkman & Moskowitz's 2000 literature review). Individual growth could have been another factor to influence engagement.

5.5 Individual growth

Dickie's interviews with quilt makers (2003) suggested that learning (embedded in leisure relationships) was central to occupational-engagement, but it was not highly valued by research participants. This finding is of particular relevance to this study, since there was a common misconception amongst the staff of the home that participants could not learn and therefore that individual growth was a futile goal. The self-organisation and self-determination required to participate in occupations could enable individuals to aim for self-actualisation (according to literature reviews by Lazzarini, 2004; Maslow, 1970; Rogers, 1959), which Rogers (2005) referred to as a principle motivator. Additionally, a clear sense of where the individual is within the rhythm of life could have also influenced engagement.

5.6 A clear sense of the rhythm of life

Everyday life has been described as being made up of cycles of short- and long-term reality check occupations (conducted every day, week, month, season, or year) (according to Persson & Erlandsson's literature review (2002); Rowles' (2000) article; Matuska & Christiansen's (2008) paper proposing their model of a balanced lifestyle; and Lobo's (1999) article. These contribute to what Meyer's (1922) article described as a “kind of rhythm”. Families and groups could share values and beliefs about time use (Larson & Zemke, 2003). Larson & Zemke's (2003) literature review suggested that occupational participation could also influence the perception and use of time. The balance of internal (the heartbeat or sleep-wake cycles) or social (meal times and work) rhythms of occupational-engagement contributes to a sense of wellbeing (see Matuska & Christiansen's (2008) literature reviews); while Rowles (2000) uses complexity theory to explore the implications for of habitual use of the environment). This sense of rhythm could result from engagement in regular routines and in occupations that follow themes and trends across the lifespan (Miller Polgar & Landry, 2004) – e.g. a play focus in childhood and a productivity focus in adulthood (Miller Polgar & Landry, 2004). Larson and Zemke (2003) demonstrated how the coordination of social occupations involved an interweaving of the lives of participants (in terms of their actions, schedules and goal orientation). Their article highlighted the social coordination required by group occupations to engender a sense of belonging – i.e. engaging with and around others, to avoid a negative influence on other participants. Arguably, in residential care, the residents live in the moment, without any control which is a goal aspired to by other groups, so that a sense of the rhythm of life has little value other than to mark the passing of a wasted life?. A desire to belong could have been another factor to influence engagement.

5.7 Belonging

Larson and Zemke (2003) described how social occupations could involve coordinating our lives around the deadlines, schedules and routines of others. Tinsley's (1995) taxonomy of leisure and Miller Polgar and Landry's (2004) book chapter also described occupational participation as meeting philanthropic and belongingness needs. Dickie (2003) described the myths, rituals, shared language and sense of humour that could be part of the culture of a group, contributing to shared values, attitudes, and companionship that could be more significant than the occupation itself. These attitudes could reflect the social status, beliefs and raison d'etre of a group (according to Crombie *et al's.* (2004) survey data); indicating that occupational-engagement in a social context could bring with it an implicit belonging to the group (however short-term this could be). Altruism, social status beliefs and belongingness all have an influence on the feeling of being part of an occupational group (Tinsley, 1995; Stebbins, 2004; Miller Polgar & Landry, 2004; Crombie *et al.,* 2004). Arguably, the residents are in residential care despite their wishes and therefore that a sense of belonging is unhelpful and irrelevant, especially if they are occupationally deprived, and mainly passive spectators. Additionally, a desire to express creativity could have motivated engagement.

5.8 Self-expression and creativity

Creativity could be refreshing, invigorating, and a means of self-expression and connection with others (according to Schmid's (2005) book; Reynolds & Prior's (2006) semi-structured interview data; Tinsley, 1995). Molineux and Whiteford's (1999) literature review of occupational deprivation as a feature of prison life, suggested the importance of being able to express creativeness, while Reynolds & Prior's (2003) interpretative phenomenological analysis of interviews and written narratives, discussed strengthening self-awareness and self-esteem through self-expression. Accompanying creativity, opportunities for concentration and exhilaration could occur (Reynolds & Prior, 2006). A sense of freedom and enjoyment (Crombie *et al.,* 2004), acting as a catalyst for growth while simultaneously creating a legacy for the future (according to Cohen's (2000) book), could also result. However, Arguably, disabled people have nothing to give, and are of no value to society, and therefore self-expression would only be negative. Creativity could allow others to see who we really are (Markus & Kitayama's (1991) literature review; Sadlo's (2004) book chapter; Reynolds & Prior (2003); Molineux & Whiteford (1999); and Schmid, (2005). Cohen (2000) also wrote that creativity is a natural energy present throughout life, which could lead to growth and excitement. Tinsley (1995), Stebbins (2004) and Crombie *et al.* (2004) all described the potential rewards of occupational-engagement as self-expression, satisfaction and wellbeing. Tims *et al.* (2012) article about the development and experimental validation of the job crafting scale, also suggested that job designing is a specific form of "proactive" employee behaviour where employees trigger changes in the levels of demands and resources. The process of job designing allows employees to fit their personal knowledge and skills to the requirements of their job.

5.9 A sense of health, wellbeing and capability

Wilcock (2006), Creek (2010), Engelhardt (1977), CAOT (2008), Townsend & Polatajko (2007), Meyer (1922), Whiteford, Townsend & Hocking (2000), and Yerxa (1967) and many others have reported that occupational-engagement influences perceptions of health and wellbeing. These perceptions could be either self- or socially-orientated (Wilhite *et al.,* 2004). Additionally, Vrkljan and Miller Polgar (2001), Hammell (2004) and Vokins' (2004) survey data noted that individuals could adapt their performance to cope with altered health, viewing the resumption of meaningful occupations as proof that they are capable and healthy individuals. This concept equates doing with living. Kawaga-Singer's (1993) study also suggested that meaningful occupations enabled individuals with a life-threatening illness to perceive themselves as well, which agreed with suggestions from Vrkljan and Miller Polgar (2001), Hammell (2004) and Vokins (2004). Nelson and Gordon-Larsen's (2006) self-reported data noted the positive effects of physical leisure occupations on self-esteem and wellbeing. Iwasaki's (2001) standardised assessment data, alongside Kleiber *et al.* (2002), and Hutchinson *et al.* (2003) all reported that communal support and self-determination gained through leisure offered a significant defence against stress. This buffer could in turn have influenced wellbeing and prevented boredom (according to Barnett's (2005) assessment data; Zuzanek & Smale's (1997) national survey data; Long's (2004) book chapter; and Martin *et al.,* 2012). Moreover, Bakker and Xanthopoulou's (2009) questionnaire and diary data suggested that engaged employees have better health, which means that they are able to dedicate more attention to their skills and energy resources for their respective roles.

Experimental data collected by Crowe *et al.* (2003), Verghese *et al.* (2003), Fratiglioni *et al.* (2004), in addition to Singh-Manoux *et al's.* (2003) cohort study data, all described how leisure could help to maintain self-efficacy, self-worth, creativity and self-expression (Passmore, 2003), which in turn could lead to a sense of wellbeing (according to Lammel's (2003) dissertation). Similarly, Passmore and French (2000) concluded that social- and achievement-oriented leisure could support mental health, while un-involving leisure could lead to negative mental health outcomes because it does not require much engagement (Hutchinson *et al.,* 2003). Additionally, Creek, 2010; Yerxa *et al.* (1989) and Feather and O'Brien's (1986) test and questionnaire data suggested that an occupation could be frustrating, anxiety provoking, and/or boring if it is not meaningful. This could not matter however, since arguably, a sense of health, capability and wellbeing is irrelevant to individuals with such profound levels of disability. Self-determination could have been another factor to influence engagement.

5.10 Control and choice of occupation/self-determination

Control and choice of occupations could contribute to a perception of quality of life (Yerxa *et al.,* 1989) and act as an intrinsic motivator (Deci & Ryan (2008); Ryan & Deci (2000, 2006, 2008)), which could in turn enhance the meaning of an occupation (LaLiberte-Rudman, 2002; Townsend & Wilcock, 2004; Molineux & Whiteford, 1999). Leisure, being self-determined and autonomous (Datillo & Rusch, 2012), could allow the individual to maintain a sense of control (LaLiberte-Rudman, 2002). Downs (2008) suggested that engaging in leisure occupations facilitated happiness and a sense of control and normality. However, choice could put the individual with cognitive deficits at risk of harm, and therefore arguably, for their own protection choice should b withheld. In contrast, choice influences adapting and coping with life (Bartalos, 1993; Kleiber et al, 2002, 2008), and could result from a synthesis of the meaning and the context of an occupation (according to Datillo &

Rusch (2012) and Kuhl & Fuhrmann's (1998) Volitional Attributes Inventory). Choice could in turn influence interest, excitement, and confidence, leading to enhanced performance, persistence, self-esteem, wellbeing (Deci & Ryan (2008); Ryan & Deci (2000, 2006, 2008)) and engagement. The issues reported by Molineux and Whiteford (1999) to arise from the lack of autonomy experienced by prisoners appear to be similar to the limitations experienced by profoundly disabled individuals. These limitations included lack of support, privacy, structure, emotional feedback, social stimulation, activity, and autonomy, which appear similar to the issues experienced by the residents in this thesis. The physical and social context of an occupation could also influence engagement.

5.11 Occupational environment which is conducive to engagement

The occupational environment includes the context and situation outside the individual that influence performance. The CMOP (CAOT, 2002) proposed that the impact of the physical, institutional, social and cultural environment on occupational-performance is inseparable from performance itself. Additionally, the individual, the occupation and the environment interact internally (via sensorimotor, cognitive, and psychosocial mechanisms) to influence occupational-performance (according to Johnson's (2006) insightful but non-replicable (due to the scarcity of information about the interventions used) case study based article). Optimal occupational-performance in a changing context requires a balance of (sometimes conflicting) influences, such as occupation, and perceptions of self and environment, to cope with the fast pace of modern life (CAOT, 2002). For example, Rebeiro is a practicing OT who has spent the past fifteen years researching from a practice rather than an academic base. Her cross-disability research has conducted both quantitative and qualitative studies to explore how individuals with disabilities participate and find meaning and about how environments influence that participation. Consequently, she has suggested on many occasions that an occupational environment that is conducive enhances engagement and fosters improved self-perceptions (Rebeiro, 1998, 1999, 2001, 2004; Rebeiro & Polgar, 1998; Rebeiro & Cook, 1999; Strong & Rebeiro, 2003). The characteristics of an occupational environment that is conducive to engagement include offering control, the use of skills, goal orientation, variety, balance, suitability of resources, safety and security, interpersonal contact, and a sense of ownership (according to Warr's (1987) frequently cited book; Rebeiro & Cook (1999), and Strong & Rebeiro (2003)). Additionally, Rebeiro and Cook (1999) suggested that choice and the role offered could influence confidence and persistence.

Feather and O'Brien (1986), Clark *et al.* (1991), Hocking (2000), Wright-St Clair *et al.* (2011), Reed *et al.* (2010) and others have suggested that occupations that appear mundane, routine and tiring have costs on wellbeing, especially when they are carried out in an environment which provides low rewards for low-skilled, unvarying and externally imposed tasks. Lobo (1999) and Ross's (2008) book about vocational rehabilitation discussed the way in which leisure could substitute for the things that give meaning to paid employment, e.g. a change of location. However, Arguably, the environment is irrelevant to people who are not demonstrating an awareness of their environment. Another viewpoint is that personal growth could be a significant factor when investing meaning in an occupation and its environment (Miller Polgar & Landry, 2004; Townsend &

Wilcock, 2004). The appropriateness of the occupation for an individual's culture, age gender and so forth could also influence engagement.

5.12 Age/cultural/historical/gender identity

Occupational-engagement influences self image (Crepeau *et al.,* 2009) and the perceptions of others depending on how occupations appear within their culture (according to Magnus's (2001) interview data). Some occupations gain meaning from their rules, rituals, customs, and traditions, and so enable the participant to define him- or herself (Goldberg, 2012; Dickie, 2003; Farnworth, 1998). Occupational potential and roles can also be influenced by rules and habits (Wicks, 2005), as could cultural value judgements, abilities and the choices available (Larsson *et al.,* 1995; Crepeau *et al.,* 2009). They could also have an impact on the meaning of an occupation for an individual or a group, depending on their cultural, religious, familial and historical beliefs (Crepeau *et al.,* 2009; Molineux & Whiteford, 1999; Franke & Engleke, 2001; Wilcock, 1998; Crocker & Wolfe, 2001). Knowing who we are in terms of our cultural, historical, and religious roots, understanding the meaning of these concepts for each individual, and having these acknowledged by others, could all contribute to self-identity. Spirituality and beliefs could shape an individual's perspective on the world and the occupations that they engage in to express themselves (according to Johnston & Mayers' (2005) literature review). Gender, age, educational level, ethnicity and socio-economic status could also influence occupational patterns (Dickie, 2003), but arguably to become irrelevant when an individual becomes disabled. Additionally, Wilcock (1998, 2006) proposed that the human ability to adapt to social environments has led to norms about how to behave. The influence of an occupation on the individual's sense of self-efficacy could in turn influence engagement with it.

5.13 A sense of self-efficacy

Occupational-engagement influences our sense of self-efficacy (Crepeau *et al.,* 2009), which Bandura's (1994) informative book chapter described as an individual's belief in their ability to succeed, which influences how they think, behave and feel. The competencies needed to carry out leisure occupations could contribute to a sense of self-efficacy, self-worth, creativity and self-expression (Passmore, 2003). Successful achievement, whether experienced or witnessed in others, can strengthen the individual's sense of self-efficacy. Bandura (1994), however, argued that the best way to create a strong sense of self-efficacy is by mastery of one's experiences, and that successes could contribute a strong belief on one's personal efficacies. Conversely, failing to deal with a task or a challenge adequately can undermine and weaken self-efficacy (Bandura, 1994). Arguably, this does not matter in non-productive individuals. Vrkljan and Miller Polgar (2001), Hammell's (2004) literature review, Vokins (2004), Kagawa-Singer's (1993) interview data, and Ashing-Giwa & Kagawa-Singer's (2006) literature review proposed that individuals could adapt their occupational participation to cope with altered health, and could perceive the resumption of meaningful occupations as proof that they are competent, capable and valuable and healthy individuals. This concept equates doing with living, and could aid in adjustment to disability.

5.14 Adjustment to disability

The researcher suggests that adults living with NPC have experienced a transition from healthy adult to occupational deprivation. Hocking (2000), Kleiber (2004) and Kleiber *et al.* (2002) all discussed the individual's capacity to transcend their

current situation, or achieve a transition and adjustment as the result of self-reflection resulting from leisure occupations that generated optimism, thereby reconstructing the life story. Hocking (2000) analysed articles using a conceptual framework made up of elements of occupation, occupational processes and the relationships of occupations to other phenomena. The analysis highlighted the ways in which occupations influence health and how transcendence over limitations can result from occupational-engagement – a factor that is particularly pertinent in the context of this thesis.

Datillo *et al.* (1998), Wendelborg & Kvello (2010), Kvello (2006), Asbjørnslett *et al.* (2011) and Kleiber *et al's.* (1995 and 2002 interview data, 2008 Literature review) all suggested that leisure-based social relationships with role models could influence adjustment to a disability. Similarly, Kleiber *et al.* (1995, 2002, 2008) described the way in which the reconstruction of a leisure lifestyle could serve as a link with a past life, and help the process of learning to live with the "new self" (Jensen & Allen, 1994; Stebbins' (2008) literature review). Having a satisfying leisure lifestyle (which includes appreciation, being relaxed, relationship-building, altruism, legacy building, enjoyment and anticipation) could contribute to achieving and maintaining a sense of health and wellbeing (Wilhite *et al.,* 2004). Furthermore, carrying out occupations in ways that enhance social identity (LaLiberte-Rudman, 2002; Crepeau *et al.,* 2009) could contribute to adjustment to disability (Iwasaki, 2007; Kinney & Coyle, 1992; Kleiber *et al.,* 2008), through reconstructing an individual's life story after disability (Kleiber *et al.,* 1995, 2008).

Suto's (1998) literature review and (2004) book chapter and Scanlan *et al's.,* experimental study (2010) discussed attitudes such as leisure needing to be earned and deserved, which arguably non-productive members of society do not. However, a lack of leisure engagement could have a dramatic effect on the individual's experience of illness, since the individual could have no diversion or alternative way to occupy their time. This was a significant finding for this thesis, since leisure appeared to be the participants' main source of occupational-engagement. Therefore, a lack of engagement in diversionary or leisure occupations could remove an alternative focus or a defence against stress, negatively influencing acceptance of or adjustment to disability.

5.15 Diversion

Wright *et al.* (2007) described optimal engagement as offering diversion alongside enjoyment, and mindfulness. Likewise, diversion or distraction may help individuals cope with negative life events (Kleiber, 2002, 2004, 2008; Reynolds & Prior, 2003). Occupational-engagement could offer diversion towards escape from living with a long-term condition to prevent the condition taking over the lives, and allow reflection about how to solve problems and analyse a situation from a different standpoint. This was demonstrated (for example) in Murphy's (2010) interview with a man with inoperable cancer, who had refocused his life towards meaningful occupations to improve his quality of life, and manage his pain. Occupations may help with forgetting problems and driving away the present from negative experiences, to overcome the past, tolerate the present and to begin to rebuild the future (according to Steindl *et al's.* (2008) eye opening interviews about experiences of a Refugee Camp). The stress-releasing and stress buffering opportunities offered by leisure could also help the individual to focus on and communicate an 'able' self-identity, both to themselves and to others (as acknowledged recently by Kleiber,

2002, 2004, 2008; and further back in time by Haun's (1965) book about the medical viewpoint on recreation). Therefore, engagement in leisure occupations could have positive effects on individuals. However, individuals with NPC could experience limited opportunities to engage in occupations due to the limitations imposed by their conditions and therefore could bypass these positive effects. The contribution of an occupation to an individual's sense of occupational balance could also influence engagement. Leisure companionship could be diversional (according to Lewis's (2009) unpublished thesis) and in the context of disability could allow the individual to focus on their potential, correct the faulty thinking habits, re-establishing life rhythms (Rebeiro, 1998).

6 Occupational balance

A balance of occupations may influence health and well-being positively (according to Brajša-Žganec et al's. (2011) opinion survey). Balance has been defined in terms of the time spent in self-care, work/productivity, play/leisure occupations which focuses attention on what is done rather than on why (according to Doble & Caron-Santha's (2008) exploration of the concept of occupational wellbeing). Furthermore, occupational balance has been explored by literature reviews by Håkansson *et al.* (2006), Matuska & Erickson (2008), Stamm *et al.* (2009), Matuska & Christiansen (2008), and Wilcock (2006) amongst others. Consequently, Wada *et al's.* (2010) literature review discussed four perspectives of occupational balance, including quantitative time allocation or ratio, the extent of congruence between occupations and beliefs, values, interests and/or aspirations, competence to fulfil the demands of role or occupations compatibility to time allocation, location, energy required to participate. Whilst, Backman's (2004) national conference presentation, suggested that balance occurred in response to an individuals choices about spending time on valued, mandatory and optional activities. Christiansen's (1996) book chapter postulated that time use, chronobiological balance, and relationships among occupations could need to be compatible across the whole, to generate a sense of occupational balance. Furthermore, Westhorp's (2003) *literature* review suggested that a balance of occupations could express and develop capability and transferable skills. Wilcock (2006) talked about a balance of occupations in terms of a balance of physical, mental, and social occupations, selected and compulsory occupations, arduous and relaxing occupations and between doing, being and becoming (Wilcock, 2006). Arguably, only doing a favourite occupation is preferable to a balance of occupations. However, occupational science has explored how occupational balance influences health and wellbeing and vice versa (Håkansson *et al.,* 2006; Matuska & Erickson's (2008) literature review ; Stamm *et al.,* 2009), whereas occupational imbalance feels similar to overload (Håkansson *et al.,* 2006). Occupational-engagement can include elements of complexity, motivation, self-determination and a balance between challenge and skill (Law *et al.,* 1998). If an occupation is meaningful to the individual, and their usual experience is similar to the situation in the non-stimulating and non-demanding control condition observed in chapter five, the participants could prefer to engage in any occupation to achieve a sense of occupational balance, rather than doing nothing at all. Novelty could also influence engagement.

7 Novelty

Some individuals could seek out experiences that provide experimentation, sensation, novelty, and optimal experience (see for example Sharp et al's. (2011) experimental study of adolescents leisure experiences). This could be especially true during leisure where exploration, novel experiences, and sensation seeking could be expected (Sharp *et al.,* 2011). It could also be especially true for adolescents who could be seeking optimal sensation and novelty as part of their transition into adult hood (Sharp *et al.,* 2011), but could also be true where another transition is taking place i.e. transcending negative life events (Kleiber *et al.,* 2002, 2008).

However, Larson and Von Eye (2010) suggested that novelty required a higher level of perceptive processing, thereby generating a perception of time being shorter or passing more quickly. Conversely, occupations that are too challenging could overwhelm the individual, making time seem to pass slowly. This could explain why Kishida and Kemp (2006) suggested that their sample was more engaged in routine occupations than in the unusual ones offered to their sample. McLean's (2005) practical suggestions article reinforced this with the finding that participants demonstrated a lack of interest in joining in with non-routine occupations. This contrasts with Berlyne's (1966) proposal that novel situations would be more engaging. Berlyne's conclusion would lead the reader to anticipate that unique leisure opportunities would be more engaging than the more regular ones. Berlyne's (1966) study would also suggest that frequent opportunities e.g. Sunday concerts such as the visit by Vengerov (reported in the newspaper by Morrison, 2007) to the home – were less engaging.

Psychological ownership may have a positive impact on human performance, in that individuals care more for things that they have chosen themselves and that they feel a sense of ownership about (according to Avey *et al's.* (2009) review of the literature). This ownership issue was reinforced by Deci & Ryan (2008); Ryan & Deci (2000, 2006, 2008) findings that intrinsic motivation derives from self-determination and freedom of choice, which are at the very heart of the definition of what makes something into a meaningful, autonomous leisure occupation, as opposed to a necessary or purposeful occupation. After all according to Guidetti *et al's.* (2009) interview data and studies by Kuhl & Fuhrmann (1998), Christiansen (1999), Phelan & Kinsella (2009); a synthesis of the meaning and the context of an occupation could influence its potential for interest and excitement, thereby enhancing performance, persistence (Deci & Ryan (2008); Ryan & Deci (2000, 2006, 2008)) and potentially engagement. Kishida and Kemp's (2006) findings suggested that their sample were most engaged in routine occupations, with the lowest engagement category being in imposed occupations as opposed to self-determined ones. This implies that occupations imposed to kill or fill time, are less engaging than those chosen by the individual. This highlights the importance of regular but self-determined leisure opportunities.

Furthermore, Kishida and Kemp (2006) highlighted differences in the comparative merits of different types of occupation in promoting engagement. The difficulty posed by this concept is the capacity of individual participants to arrange their own leisure occupations. Therefore, the home has a Recreation and Leisure Team who organise large-scale leisure opportunities, as well as residence staff who organise more local residence-based leisure occupations. It would seem that a mix of regular and novel leisure opportunities would be ideal, but that self-determination is also crucial to engagement. Since

the occupations that offered novelty in this study are towards the higher levels of sensory attributes, the element of novelty along with complexity could help to maintain the participants' engagement.

8 Complexity

Stebbins (2011) book suggested that complexity could make an occupation more rewarding, more highly valued and more motivating, and thus more likely to initiate a state of 'flow'. He suggested that by their very nature serious leisure occupations were likely to be more complex that casual leisure occupations since they involved gathering knowledge, skills and experience, and as such could influence the individual's personality, sense of self-efficacy and self-identity. In addition to self-perception, Mackenzie's (2011) book chapter suggested that engaging in complex leisure occupations could also amplify intellectual functioning. The complexity of an occupation could include the individuals' perceptions and experiences of all (but in particular the current) occupations (according to Cook's (2001) book about qualitative research in occupational therapy). Therefore, a greater complexity or level of stimulation could lead to a perception that more time has passed (Sackett *et al.,* 2010), or of loosing track of time (Stebbins 2011) because the occupation was more engrossing. However, tasks that are more complex could require the participants' full attention to the task, rather than attending to the passing of time, so that the participant loses track of time (according to Stebbins' (2011) book and Thomas & Weaver's (1975) experimental study).

Similarly, the periods when the complexity of stimulation increases, or where a deeper level of processing is required, may appear shorter (Larson and Von Eye, 2010). This phenomenon appears to be similar to "Flow", where at the optimal engagement category the match between skill and challenge may make the participant lose track of time passing (according to Stebbins (2011), and also Csikszentmihalyi & Csikszentmihalyi's (1988) book about studies of flow. Stebbins (2011) also suggested that less complex casual leisure occupations could do little or nothing for motivation, 'flow', self efficacy and self-identity, which Kleiber's (2012) examination of flow and serious leisure, refuted vehemently. Kleiber (2012) stated that Stebbins position undervalued the balancing effects of casual leisure. The researcher also, finds this lack of value stance limiting. Some casual leisure occupations form part of a lifespan of themed activities, which therefore could contribute to the individual's self-identity purely through perseverance and repetition (which could perhaps be based upon liking or even devotion) (see chapter five). Kleiber suggests several reasons not to take leisure seriously namely:

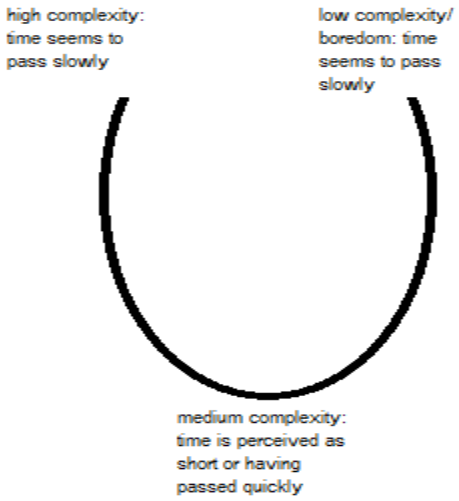
- commitment which could over rule other opportunities when a choice has to be made,
- the protestant work ethic means that a large proportion of westernised societies do not value non productivity and therefore casual leisure could be seen as of lesser value,
- the value of appreciating another's performance or the effort that they put in to allow someone else to spectate (although the researcher is writing against the background of the gold medal fever which seems to have swept the UK during the London 2012 Olympics),
- The Olympics also illustrate how a casual leisure occupation could offer a shared identity to sports spectators who are supporting their team.

All of which run counter to Stebbins 1997 definitions of serious leisure and to what kleiber (2012) sees as an excessive focus on serious leisure, by leisure science. Put this way, Stebbins stance that less complex leisure occupations not

motivate, could detract from self-efficacy and self-identity was problematic, even though he was building on previous publications. These publications had suggested that spectating passively or remaining unengaged for intervals of time, could also lead to a sense that time has passed more slowly, resulting in an experience similar to boredom. This view upholds Hicks & Brundige's (1974) study of students verbal estimations of temporal durations during occupational performance, and also by Thomas & Weaver's (1975) experimental study of temporal and non temporal information processing and subsequent proposal of a model according to which attentional resources are limited.

Occupations of moderate or low complexity could lead to an inversion of the linear relationship between complexity and perceived duration. At a certain point, the complexity of the occupation could challenge the participant's ability, leading to a perception that time has passed slowly. Therefore, a U-shaped relationship (see Figure on following page) between levels of complexity and perceptions of time passing may (Glicksohn, 2001), with optimal engagement including a sense of losing track of time (according to both Tzanidaki & Reynolds' (2011) semi-structured interview data about the meanings of making traditional arts and crafts, and Csikszentmihalyi & Csikszentmihalyi (1988). Furthermore, Keen's (2009) literature review about the use of the term engagement suggested that the complexity of the social environment could influence individual engagement – for example, the effects of supporter responsiveness, the effect of group size, supporter-to-participant ratios, and willing engagement versus coerced engagement.

The relationship between perceptions of time passing and complexity of occupations



Other factors that could influence engagement could include attention, absorption, and psychological depletion and enrichment.

9 Attention, absorption, depletion and enrichment

Engagement involves not only performance, but also the subjective experience according to Yerxa (1980) during her national conference presentation, additionally Rothbard's (2001) survey data suggested the involvement of attention, absorption, depletion and enrichment. Attention and absorption could be limited by cognitive and awareness limitations that can result from NPC. Attention includes concentration on selected aspects of the environment, and the blocking out of other stimuli to focus on an occupation (Rothbard, 2001). Absorption, similar to a state of 'Flow', requires the individual to be assimilated into the occupation ((Tzanidaki & Reynolds (2011); Csikszentmihalyi (1982, 1990)). Attention and absorption appear to be similar concepts, although attention is a resource and absorption an intrinsic motivation for engagement (Rothbard, 2001). Their presence facilitates goal attainment and their absence could be demotivating in relation to occupational-engagement (Rothbard, 2001).

Depletion and enrichment, on the other hand, describe the allocation of finite psychological and physiological capacities, so that depletion and enrichment can influence an individual's engagement in occupations. Finite resources such as physical, cognitive and communication abilities could be exchanged to enhance engagement putting resources (limited by

NPC) under pressure (Rothbard, 2001). This could be especially true where the demands of the occupation further reduce functioning, making goal achievement difficult (Rothbard, 2001).

In contrast, transferable skills could also enhance or enrich engagement in another occupation. Enrichment could enhance attention, skills and energy, but could also lead to information overload. So that careful consideration of occupational enrichment Cronin - Davis *et al.,* 2004) is needed with individuals who are at risk of sensory-overload, since the benefits could outweigh the drawbacks, and leading to a higher level of satisfaction or vice versa leading to stress and distress. Danzl *et al.* (2012) literature review suggested that engagement could enhance neuroplasticity, when recovering from a brain injury. To come to this conclusion they suggested a connection between attention and environmental enrichment (Cronin - Davis *et al.,* 2004). They also suggested that an enriched environment could promote enhanced brain function with long-term potentiation and neurogenesis resulting from enriched environments and enriched occupations. One form of enrichment already suggested is increased complexity, which requires involve increased attention (Cronin - Davis *et al.,* 2004; Danzl *et al.,* 2012). Depletion and enrichment therefore could be associated to engagement and the ability to connect engagement in one occupational role with participation in another could be a factor (Rothbard, 2001). Another factor that could influence engagement could be the occupational role offered to the individual.

10 Occupational role: Participating versus spectating

According to Creek (2010) occupational-engagement is about the degree or level to which an individual is occupied, participating or involved. Creek (2010) suggested that occupational-engagement could be direct involvement (doing it), peripheral (commentating or supportive role), or spectating. Distinctions have been drawn between active and passive engagement (according to Hitch's (2009) semi-structured interview data; and Harvey's (1982) study in the context of media broadcasting), which both highlighted the complicated nature of engagement (as did Pieris & Craik's (2004) semi-structured interview data); and between serious and casual leisure (Stebbins 1997, Kleiber 2012). Lockwood and Lockwood (2007) all suggested that individuals with disabilities, especially those with high support needs, tend to prefer to participate in spectator occupations where they can be independent, rather than engaging in active leisure occupations which require support from others. The residents' of the home also pursue leisure occupations that tend to be passive. Passive and solitary leisure (Pollock & Stewart, 1990; O'sullivan & Chard, 2010) offers them independence (and therefore a sense of capability), rather than requiring support to engage in more active leisure occupations. Furthermore, Winkler *et al's.* (2011) comparison of time use between healthy and brain injured adults described living in a home as being incompatible with optimum quality of life. Consequently, the participants' profound level of disability may limit their experience of physically active leisure (according to Goodman's (1996) report about coaching wheelchair athletes and Saebu & Sørensen's (2011) cross-sectional survey data. In part, this is because the options for occupational participation decreased as the complexity of disability increases, leaving only the occupations with a passive/spectator role as do-able (Stanley & Dolby, 1999; O'sullivan & Chard, 2010). Unconstrained leisure choices should therefore include participants being able to choose between taking an active or passive role – i.e. either watching or doing – across the whole range of their occupational-engagement. However, disability in combination with an

unadapted occupation could limit this choice (Bier *et al.,* 2009), leading to a leisure repertoire that predominantly includes one role or the other, rather than a combination of the two roles.

Occupations and the roles undertaken could also reflect the individuals' culture, routines and habits (according to the CAOT's (1997) book and Wall's (2012) book review). The occupational roles undertaken will influence what individuals do each day and therefore who they perceive themselves to be (as suggested in Polatajko's (2004) book chapter). Furthermore, occupational-engagement could be different from commitment to and/or identification with a role, because identification could be about the meaning of an occupation, while commitment could be about the attachment of the individual to the occupation (Rothbard 2001).

The profound level of disability experienced by the participants limits what they can get involved in, especially when combined with a lack of positive collaboration and timely adaptation of leisure occupations to make them accessible. The relative merits of role preference versus the role offered by the leisure occupations could be another factor. There also appears to be disconnected expectations between role preferences as perceived by staff, participants and family members (according to Bigby *et al's.* (2011) focus group interviews). Staff and family members appeared to expect the majority of participants to prefer spectating, fewer to prefer a choice of role as dictated by the occupation, with little expectation that the individual would prefer to be an active participant. However, participants themselves had the highest preference for spectating, followed by active participation and finally either role; their preferences appearing evenly spread across the range of roles (Royal Hospital for Neuro - disability, 2007). Opinion surveys (such as RHN, 2005) have suggested that there could be a discrepancy between relatives and individuals' views.

Goodman (1996) and Shields *et al's.* (2011) systematic review (of the barriers and facilitators to active leisure) suggested that because of the barriers they encountered, individuals with disabilities engaged in very few physically active leisure occupations. Liverton's (1994) text for example, suggested that individuals with neurological disabilities could wish to participate in a diverse range of unmet leisure experiences, such as scuba diving, skating, sexual activity and intimate relationships, hang gliding, travel and gardening. This desire for more challenging occupations mirrors audits of leisure satisfaction of homes such as the one studied here (RHN, 2007). Spectator leisure occupations seemed to dominate the experiences of home residents, although some individuals did participate in occupations away from their "home space" and get actively involved in them. Another factor that could influence engagement could be the participant's mood.

11 Emotions and mood

When discussing occupational deprivation, Whiteford (2000) suggested that limitations to freedom and worry about an uncertain future could lead to fear, anxiety, stress and depression, which could further reduce an individual's occupational-engagement. Furthermore, the attitudinal environment could prevent social reintegration, because of fear as well as lack of understanding or acceptance from others around the individual (Royal Hospital for Neuro - disability, 2006). Heller's (2002) book defined sensory defensiveness as fearfulness and withdrawal from an overloading environment and its associated stress, leading to fatigue and depression, sleep difficulties, headaches, tense muscles, decreased memory and inability to

concentrate, all of which could influence occupational-engagement. In fact, within this thesis mood and fear could contraindicate participating, for example in the Aquability sessions (see section 5.2.4.2.8). Similarly, Evans (2008) dissertation suggested that some of the factors that contribute to the occupational context could include fear and anger, and Dunn (1997) suggested an overlap in behavioural and neurological thresholds, which could influence engagement. Furthermore, Rothbart and Derryberry's (1981) book chapter, and Brock *et al's.* (2012) experimental study suggested a link between temperament and the individual's responsiveness to sensory stimuli. Glicksohn (2001) also suggested that emotional experience during participation could contribute to losing track of time when engrossed in an occupation, which Tzanidaki & Reynolds's (2011) semi-structured interviews and Csikszentmihalyi and Csikszentmihalyi's (1988) book suggested to be a sign of optimal engagement. Moreover, Snyder *et al's.* (1998) literature review about occupational deprivation suggested that impoverished children could not have adequate financial and social opportunities, for exposure and engagement in leisure occupations, could manifest increased involvement in non-legitimate occupations, e.g. vandalism and gang activity. These could offer alternatives to meet their social, leisure and relaxation needs.

Appendix ii Discussion of the Human Costs of Occupational Deprivation in Non-Neuropalliative Individuals

Being unable to engage in occupations may lead to costs, such as longer periods asleep, altered life satisfaction, lack of social status, diminished sense of self-efficacy, atrophied occupational capacities, loss of self-identity, social exclusion, altered patterns of time use, and imposed dependence (Wilcock, 2006; Whiteford, 2009). Turner's (2002) book chapter discussed how further occupational dysfunction results from the deleterious effects of occupational deprivation, since the resulting loss of ability and opportunity could be "devastating and widespread", with associated loss of roles and routines. O'Sullivan and Hocking (2006) and Hearle *et al's.* (2005) narrative study described the insidious effects of occupational deprivation, whereby as individuals do less, they lose capacity, and therefore it becomes harder to do things. When doing requires too much effort, occupations become less rewarding and individuals are less motivated to try. However, because occupational deprivation is externally controlled, there was little research (at the time of data collection) about occupational deprivation in individuals with NPC. A study conducted by Rambeau (2010) on adolescent refugees suggested that war-related trauma and being deprived of any type of meaningful occupation risks the development of significant difficulties on the individual's functional abilities. Therefore, the literature reviewed in sections 2.3.5, Appendix ii and 2.3.6 will investigate parallels from a refugee camp and a prison, and situations of geographical isolation, under/employment and sexual role stereotyping, to illustrate the effects of limitations to occupational experience and why occupational deprivation should be avoided. One such effect is spending longer periods asleep.

Longer periods asleep

Given that humans are occupational beings (Wilcock, 2006), and is only truly human when occupationally engaged (Yerxa *et al.,* 1989), being unable to engage in occupations could lead to maladaptive behaviour such as spending longer periods of time asleep (Whiteford, 1997). Sleep has been defined by Whiteford as maladaptive because western society views time spent sleeping as time wasted (see for example Howell & Pierce's (2000) literature review based argument), while occupational-engagement occurs during the rest of their time awake (see Kielhofner & Burke's (1985) and Farnworth's (2004) book chapter's. Sleeping could have become an avoidance mechanism (against negative thoughts and spiralling demotivation, boredom, lack of social status, diminished sense of self efficacy, imposed dependence and altered self-identity and so forth, which could all result from occupational deprivation), or it could be a habit to use up unengaged time (Whiteford, 1997). Sleep could a common response to boredom, and is a way of using time in the absence of meaningful occupations (Farnworth, 1998, 2004; Whiteford, 2000).

Occupational-engagement and sleep could be at two ends of the same continuum (Wilcock, 2006). Therefore, over occupation/stimulation could result in reduced opportunities for sleep (and lead to burnout), while a reduction in occupations could leave further free time to fill. One could argue that sleep could reinvigorate after a period of energy expenditure resulting from the effort of completing necessary tasks or worrying about the future. However, one could also argue that

sleep could offer a way of drawing away from the world and a negative self-image (Jensen & Allen, 1994), to enable the individual to exercise some control over some part of their life.

Minato and Zemke (2004) reported a study (of 89 individual's time use diaries) of occupationally deprived individuals who spent long periods sleeping, or being passive to fill their time. Pentland *et al's.,* (1998) cross sectional study of time use by 312 adults with spinal injuries revealed that the mean amount of time spent in sleep over a twenty-four-hour period was 8.5 hours, and the time spent in leisure was 7.2 hours. Both of these were far higher than the time spent in personal care (3.7 hours) and productivity (4.7 hours). Shimitras *et al's.,* large study (2003) involved data from 528 participants to suggest suggested that few individuals with mental health problems were able to engage in work, active leisure, education, or volunteer occupations. They suggested that sleeping, personal care and passive leisure were the most prevalent sources of engagement for these individuals. Furthermore, Weeder's (1986) experimental study and Eklund *et al's.,* (2009) systematic review (which included Weeder's study) of studies of time use patterns among adults with mental illnesses suggested that they spent more time in sleep and passive leisure and less time in productive occupations than average. Despite the evidence presented, Arguably, the greater effort involved in moving and the continued stress and pain of NPC are the cause of the longer periods asleep witnessed by the researcher. However, this view ignores the concept of depriving man (an occupational being), of opportunities to engage in the most complex occupations occurring in the animal kingdom (Wilcock, 2006; Yerxa *et al.,* 1989). A second feature of occupational deprivation is poor quality of life.

Altered Life Satisfaction

Whiteford (1995, 2004) suggested that occupational deprivation, or the absence of opportunities for occupational-engagement (Townsend & Wilcock, 2004), can lead to an inability to be fully part of the world, because it is through interaction with our environment that the individual understands themselves and their relationship to the world. Furthermore, Hearle *et al.* (2005) suggested that prolonged inactivity could result in feelings of helplessness and a decrease in psychological wellbeing. Being unable to engage in occupations could lead to reduced life satisfaction (Whiteford, 1997, 2004, 2010) because of a diminished sense of self-efficacy, social status and self-identity, social exclusion, and imposed dependence.

Occupationally deprived individuals appear to have a higher rate of suicide attempts than average because of their compromised self-identity and reduced sense of self-efficacy (Whiteford, 2000). Similarly, the restrictions to their freedom and the worry experienced by Whiteford's (2000) sample about an uncertain future and coping with an NPC could lead to fear, anxiety, stress and depression. The World Health Organisation (2001) has recognised occupational limitation as a measure of disability, while Szalai's (1980) conference paper and Frisch's (2012) book chapter suggested that it could be an indicator of life (dis)satisfaction. Furthermore, Pentland *et al's.* (1998) cross sectional study, Pentland & McColl's (1999) book chapter and Sandqvist & Eklund's (2008) interviews with Forty-four female participants, suggested that satisfaction with the balance of individuals' use of time had a significant influence on adjustment to disability, and could have had a strong predictive relationship with life satisfaction, and perceived health and adjustment to disability. Pentland *et al.,* 1998, Pentland & McColl, 1999, Larson's (1990) small questionnaire based study, Osberg *et al's.* (1987) study of 97 recently discharged elderly

participants with disabilities, and Frisch's (2012) book chapter also suggested that time spent inactive or carrying out passive occupations was negatively associated to life satisfaction and was not conducive to health (Passmore, 1998). Therefore, it is of concern that many researcher's have described how individuals with disabilities withdraw from all but the most physically passive occupations (see for example Farrow & Reid,'s (2004) qualitative investigation of the experiences of sixteen stroke survivors; Parker *et al's.* (1997) rationale for making leisure engagement a rehabilitation goal; and Pound *et al's.* (1998) qualitative interviews). This withdrawal, because of their limitations, could reduce occupational satisfaction, which in turn could result in depression.

Meaningfulness, challenge, occupational-performance or satisfaction have all been suggested to compensate for occupational imbalance by researcher's such as Wilcock (1993, 2006), Farnworth (2004), Pentland *et al.* (1998), Pentland & McColl (1999) and Yerxa and Baum's (1986) study comparing community-based spinally injured and healthy adults using a matched pairs methodology. One could argue that the link between depression and time spent inactive could be the result of the depression, given the impact of chronic symptoms on sickness behaviour. This inactivity could have led to occupational alienation at best and occupational deprivation at worst. Experimental studies such as those by Mishara (1999), Lippert-Grüner *et al.* (2006), Degeneffe and Lynch (2006) and Baudic *et al.* (2006) all suggested significantly higher levels of depression and suicide in individuals with NPC when compared with individuals suffering from other long-term conditions (e.g. blindness). However, these studies took a biomedical model view of the causes of their depression, attributing it to a chemical imbalance in the body or to the limitations caused by disability (Alderfer *et al's.* (2005) proposed practical approach to the evaluation and treatment of this depression after head injury). These researcher's all suggested that depression could be due to the physiological effects of disability itself, rather than being a side effect resulting from altered occupational capacity. This view would suggest that depression makes the individual less likely to engage in occupations, focusing instead on (safe) independence as a passive spectator, in contrast with (the risk of requiring) support as a physically active occupational participant. However, the link between occupational deprivation and reduced life satisfaction reinforces the belief that humans are occupational beings (Wilcock, 2006), most true to his humanity when occupationally engaged (Yerxa *et al.,* 1989), and who becomes stressed when occupationally deprived. Another feature of occupational deprivation is a lack of social status.

Lack of social status

Social status results from the characteristics, knowledge, ability and/or skills required to maintain a social role (Bullock, 2010). If paid employment or an occupational role is regarded as defining an individual's identity, social status (Whiteford 2009), then the converse could also be true – lack of or under-employment or occupational deprivation could influence the individual's occupational choices and social role, thereby influencing self-identity. O'Sullivan and Hocking (2006) described how as individuals do less, they become less skilled, which in turn makes participation more difficult. As they become less accomplished, their social status could decline, reducing their belief in their own self-efficacy.

According to the UK Home Office (2006), occupational deprivation affects social status, identity and self-worth. The effects of occupational deprivation can become a further barrier to community reintegration because the individual could

become accustomed to a negative picture of their self-image, low self-esteem, and low self-efficacy. They could develop an inability to judge the passing of time, losing the ability to gauge the time span required for an occupation, and therefore their occupational skills could deteriorate (Whiteford, 2000). The social/attitudinal environment may form a barrier to reintegration, because of fear, lack of understanding or acceptance (Suto, 1998, 2004; Scanlan *et al.,* 2010).

Paid employment is believed to have assumed a central position in identity construction in western society (Whiteford, 2009), thereby influencing social acceptance, self-identity and social status (according to Salmond *et al's.* (2006) Index of Socioeconomic Deprivation). One could argue that individuals lose their social status because humans dislike and are prejudiced against difference (as suggested in Brown's (2006) book which argues that freedom lies within power relations, with the result that those who are different may experience less freedom to choose). However, occupational science proposes that individuals who are unable to "do" are at risk of losing any social identity gained through their occupational roles, their productivity and their relationships. That is, they would be unable to view themselves as unique occupational beings if occupational deprivation deprived them of these roles and relationships (Wilcock, 1999, 2006). A diminished sense of self-efficacy could also be a feature of occupational deprivation.

Diminished sense of self-efficacy

Self-efficacy is a judgment about engagement in occupational-performance (according to Salbach *et al's.* (2005) experimental study). Christiansen (1999), Phelan & Kinsella (2009) described identity relation to occupational-engagement, suggesting that successful performance enhances self-efficacy, which in turn helps to develop a positive identity, and vice versa. On the other hand, any impediment to presenting an image of competence threatens our self-identity. This happens because as individuals do less, they lose occupational capacity and so participation becomes harder, less rewarding and belief in self-efficacy declines (O'Sullivan & Hocking, 2006).

If occupational-engagement leads to a sense of competence and therefore influences the choices made, the effort expended, and persistence towards outcomes (Whiteford, 2000), the overall result could be an enhanced ability to cope with disability (Edwards *et al's.* (2001) study of self - efficacy). A diminished sense of self-efficacy, as a context-specific outcome of occupational deprivation leading to low expectations and feelings of futility, could dissuade individuals from further attempts to participate (Bandura, 2004; Whiteford, 2000). Sarda *et al.* (2009), Buckelew (1995), Lackner *et al.* (1996), Grossman (1987), Bartholemew *et al.* (1993), Schwartz *et al.* (1996), Dahlbeck & Lightsey (2008), Wigal (1991) and Rinat *et al.* (2011) have all suggested that self-efficacy beliefs influence adjustment to chronic circumstances and symptomatology (e.g. the severity of pain) as well as disease progression (Edwards *et al.,* 2001). Therefore, if occupational-engagement leads to an enhanced ability to cope with disability, then occupational deprivation could lead to a sense of futility, and negative adjustment to disability.

Whilst one could argue that disability could lead to a sense of reduced ability, there is also evidence that regained occupational roles lead to a sense of capability (Vrkljan & Miller Polgar, 2001). Kagawa-Singer (1993), Ashing-Giwa & Kagawa-Singer (2006) suggested that meaningful occupations enabled individuals with a life-threatening illness to perceive

themselves as well. Kawaga-Singer's (1993) study used semi-structured interviews to describe participants' perceptions of living with cancer. The data was analysed using content analysis, and the theories that emerged suggested that a sense of capability and self-integrity could contribute to the concept of health. This study examined the effects that cultural beliefs had on the coping capacity of individuals with chronic and life-threatening diseases (see for example Vrkljan & Miller Polgar (2007), and Lyons *et al's.* (2002) studies of occupational experiences which suggested a theoretical framework to define health. Kagawa-Singer (1993), Ashing-Giwa & Kagawa-Singer (2006) emphasised the importance of social identity, suggesting that it exerted a greater influence than the study participant's actual health status.

Lockwood & Lockwood's (2007) literature review suggested that individuals with high support needs tended to participate in spectator occupations rather than participating actively in occupations with support from others, which could have been a response to pressure to be independent rather than autonomous. Lockwood and Lockwood's earlier (1991) study concurred (as did Creek 2010), suggesting that an individual's awareness of their reduced occupational capacities and a wish to prevent further dependence on others could have led to a preference for spectator occupations, rather than being an active but supported occupational participant. This choice could have further atrophied their occupational capacity (Wilcock, 1995, 2006).

Atrophied occupational capacities

Turner (2002) suggested that occupational dysfunction is an outcome of occupational deprivation. O'Sullivan and Hocking (2006) described how as individuals do less, they lose occupational capacity and so participation requires gets harder, less rewarding, and motivation declines. Occupational dysfunction, which leads to loss of skills and reduced occupational capacity, could in turn lead to unfulfilled needs, roles and responsibilities (Turner, 2002).

Individuals with NPC could have difficulty engaging in occupations because they do not have the ability to do so, or because the opportunities to participate are limited due to a lack of enablement. Whiteford (2000) and Wilcock (1995, 2006) suggested that "atrophied occupational capacities" resulted from occupational deprivation. The human drive to use occupational capacities was evident from very early in evolution, with the development of upright walking, hand dexterity, stereoscopic vision, language and society being prime examples (Wilcock, 1995, 2006). Our range of occupational capacities has resulted from evolution, culture, genetics and self-identity. These capacities need to be flexible and adaptable to cope with complex activity (Wilcock, 1995, 2006). However, having achieved these skills, individuals who have subsequently gone on to develop NPC could have lost their occupational capacities. For example, consider the individual with advanced Friedreich's Ataxia, who cannot walk safely or use an electric wheelchair because of their condition. This individual's coordination of mouth and tongue muscles could make swallowing a life-threatening activity, and make speech difficult, but it is necessary because their ataxia could also render their use of assistive technology even more challenging.

Occupational potential could build on learning about, or erode (because of disuse), occupational capacities (Wicks, 2005). According to O'Sullivan and Hocking (2006) and Wilcock (1995) atrophied occupational capacities and diminished self-efficacy beliefs could lead to skill degradation and restricted role repertoires. A loss of role repertoires, in turn, could

negatively influence integration into the community, reducing opportunities to engage in occupations and thereby compounding the skills degradation spiral. Whiteford (2000) described this as a “dehumanising phenomenon”. Consequently, whilst one could argue that disability reduces engagement or performance, occupational science proposes that a lack of opportunities offered by the social and physical world is what disables, rather than limitations caused by the disability. Theoretically, this lack of opportunity is unnecessary (Whiteford, 2004, 2010). Another result of occupational deprivation is loss of identity.

Loss of Self-Identity

Not being able to perform an occupation could change an individual's self- identity and self-image (according to Reed *et al's.* (2010) hermeneutic phenomenological study). Self-identity includes a mixture of past, present and future experience of occupational-performance (Kielhofner *et al.,* 2002). Since Kielhofner *et al.* (2002) suggested that this experience could include knowledge about ability, self-identity, especially if the individual finds him- or herself less able to participate in the present than in the past. They could also face uncertainty about their future, and could therefore have uncertain expectations of their future engagement. Kielhofner *et al.* (2002) also suggested that self-identity could include knowledge about commitments, with self-identity altering with different levels and types of commitments – e.g. self-care occupations taking up a greater proportion of time than previously, or having free time thrust upon them because there is nothing that they can engage in.

Additionally, the individual could experience different occupational contexts that could alter the meaning of an occupation (Kielhofner *et al.,* 2002). Being in residential care could lead to a change of occupational habits and routines similar to occupational apartheid (Phelan & Kinsella 2009) (which could alter the meaning of the occupations engaged in), and therefore could influence their self-identity. Additionally, the individual’s preferences for occupations and the roles they want to undertake could have been altered as part of the catastrophic reaction (Martelli *et al.,* 2008) involved in adjusting to neuropalliative disability (Kielhofner *et al.,* 2002).

Christiansen (1999) and Phelan & Kinsella (2009) both explored the link between self-identity and occupational-engagement, based around the human need to express individual identity to experience a meaningful life. The literature search strategy was missing. However, the literature included was relevant and comprehensive regarding the topics covered, although there was no critical appraisal of the quality of the literature. The literature review suggested that self-identity influences how humans think, act and feel, and is central to coherence, meaning and wellbeing (Christiansen, 1999; Phelan & Kinsella, 2009). Self-identity results from feedback from others (according to Unruh's (2004) study of occupation & identity) and the interrelationship between the individual and others (Christiansen, 1999; Phelan & Kinsella, 2009). Both Whiteford (2000) and the UK Home Office (2006) suggested that a loss of self-identity could result from occupational deprivation. Additionally, feedback from a persistent lack of achievement in an occupation may influence any self-identity based on that role (Kleiber & Kirshnit, 1991; Tinley, 2012). The individual could be likely to attempt to engage in their previous occupations (according to Stryker's (1987) book chapter and; Kleiber *et al's.* (2008) literature review), but because of repeated failure, their self-identity could be eroded further (Whiteford 2000; Palmcrantz *et al.,* 2012).

Disability presents the individual with many challenges and lifestyle changes beyond the symptoms of the condition, including becoming unemployed, altered social networks, new roles, and increased dependence on others (according to Reynolds' (2003) thematic analysis of interview data). All of these challenges could threaten the individual's sense of self and identity, bringing about what Mattingly's (1998) book describes as the concept of "narrative suspense" or stalling of the life story as also discussed by Frank (2008). Individuals experiencing narrative suspense avoid or delay reconstructing their self-identity around their disability until they have exhausted all other possibilities and have learnt repeatedly that they have changed. This can lead to identity alienation – a self-image that is not consistent with their current situation (Charmaz, 2002). Identity alienation may result from unfamiliar clothing and changes to movement patterns, posture, and appearance (Seymour, 1998), to being able to join in (because of limiting disabilities (according to Smiler & McKee's (2007) interview data and Hahn & Belt's (2004) survey data from demonstrators with a disability). Additionally, it could combine with impaired self-awareness, impeding their adaptation to their "new self" still further (Jensen & Allen, 1998). All these factors could combine to isolate them from reality.

One could argue that cognitive deficits could deprive the individual of their past and therefore impact on their recollection of who they were. However, without occupational-engagement to bolster and create an image of an occupational being, occupational deprivation could also influence institutionalisation and self-identity, since Lawton & Rubenstein's (2000) book suggested that the culture in residential homes could reinforce dependent behaviour. Wilcock (2007) added belonging to the benefits of doing, being and becoming an occupational being (Wilcock, 1999). Anderson and Brown Kress's (2003) book, Wendelborg & Kvello (2010) explorations of children with disabilities and their parents about social participation, Kvello's (2006) PhD thesis, and Asbjørnslett *et al's.* (2011) interview data amongst others have suggested that leisure-based social relationships with role models could influence the image of an occupational being and help with adjustment to a disability. Additionally, engagement in leisure occupations may influence mental and physical health, support relationships, and maintain a positive sense of self (Corring, 2006). Another aspect of occupational deprivation is prolonged social isolation and social exclusion.

Prolonged social isolation and social exclusion

Dorer *et al's.* (2009) descriptive survey, suggested that individuals with cognitive and mental health problems experienced limited occupational-engagement alongside social exclusion. This situation can arise if an individual's social relationships build upon their occupations and roles – e.g. dog owners who meet when out walking, parents who meet at the school gate or crafters who meet at exhibitions. Being unable to engage in these occupations, could result in social isolation or exclusion because of a lack of participation in occupations leading to and resulting in the opportunity to meet others, gain social acceptance and portray a positive self-image.

Friendship and social interaction may provide a source of feedback about who we are, providing information about social approval and how others perceive us, (forming a benchmark) (Whiteford, 2009; Asbjørnslett *et al.* (2011) Lobo, 1999). Social interaction for individuals with NPC could be restricted. Additionally, whilst assistive technology facilitates social

interaction (Asbjørnslett *et al.,* 2011), its use could be difficult for others to understand. The individual could only be able to communicate easily with selected individuals, such as staff, rather than being able to interact with friends and family members, which could lead to selective social isolation. Therefore, the type and attitudes of individuals available to communicate with could influence social engagement.

Lobo's (1999) much cited review of the literature explored the interrelationship between work and leisure, and suggested that leisure offers opportunities for experimentation, risk taking and challenge. The literature search strategy was absent, although it was relevant to the aim of the paper and comprehensive with regard to the topics covered. Lobo described how un- and underemployed individuals could become socially excluded and demoralised, and could use leisure as a coping/escaping strategy. Additionally, he explained that individuals with higher levels of education could lack a demarcation between work and leisure because they feel morally impelled to use free time. However, others participate in very different leisure occupations from their work roles. He also discussed how the facets that make paid employment meaningful can be substituted by their engagement in leisure, e.g. via a change of location.

Whiteford's (2004) illustrations of occupational deprivation included "prolonged isolation", such as that experienced by someone with communication difficulties, and confinement, such as that experienced by an individual with quadriplegia. Prolonged isolation and confinement were both suggested to result in the person becoming uncreative, unmotivated and fatigued (according to experimental studies by Connors *et al.,* 1985; Salam, 2012). Prolonged isolation and confinement have also been associated with feelings of being powerless, and with impaired social interaction abilities (according to Pope & Rogers' (1968) clinical records of a scientific expedition to the Antarctic as well as Connors *et al.,* 1985; Salam, 2012;). Rohrer's (1961) book chapter and Leon *et al's.* (2011) experimental study identified some aspects of the reaction to prolonged but time-limited isolation and confinement. Individuals may move from a state of heightened anxiety to depression, before moving on to emotional outbursts, aggressiveness and challenging behaviour (because of sensory-overload). Social interaction may act as a source of feedback about the individual's self and social-identity (Whiteford, 2009). However, feedback could be restricted because of language, comprehension problems or aphasia, which could be part of an NPC.

One could argue that social isolation is a result of the clinical condition itself. However, occupational science proposes that social relationships, social identity and social roles result from and develop through occupational-engagement. Therefore, occupational deprivation could lead to limitations in opportunities to develop, maintain or reinforce social relationships, social identity and social roles. Another aspect of occupational deprivation includes altered patterns of occupational-engagement.

Altered occupational patterns and time use

The relationship between time use, sense of efficacy and identity appears compromised by prolonged occupational deprivation (Whiteford, 1997; Farnworth, 2004, Cronin - Davis *et al.,* 2004, Long, 2004). This could be a response to the lack of self-determination over occupational choices that results from incarceration. Similarly, Stewart and Craik's (2007) questionnaire data; Helbig's (2003) qualitative study; Farnworth (2004); and Farnworth *et al.* (2004) all suggested that time-

use in residential care could predominantly include personal care, passive leisure and rest, with limited engagement in active or productive occupations. These two situations could result if an individual is dependent on others for permission or support to engage in occupations. Instead of choosing occupations for themselves, they could find themselves experiencing the occupations that others deem appropriate (Suto, 1998, 2004), think they have earned (Scanlan *et al.,* 2010), or are available (Suto, 1998, 2004). This could not be how they would choose to spend their time given a free choice, and therefore they experience an altered pattern of time use through being dependent on others. Additionally, this could influence the meaningfulness of how their time is used – i.e. killing or filling free time (Lobo, 1999; Stebbins, 2009) with what was once a leisure occupation feeling imposed. Additionally, an individual's abilities govern the choices about potential occupations, the opportunities available, and cultural value judgements by the individual and those around them (Larsson *et al.,* 1995; Wall, 2012).

Whiteford (1997), Cronin - Davis *et al.* (2004), Long (2004) and Farnworth, (2004) all suggested that altered occupational patterns and time use could result from occupational deprivation. Individuals with disabilities have more free time (Pentland *et al.,* 1998, Pentland & McColl, 1999, Farnworth, 2004), but less energy or opportunities to use it given their reliance on supporter facilitation and positive collaboration, assistive technology, and adaptation of the environment. Having less to do (and particularly a lack of goal directedness and challenge) could affect their perception of time passing (according to Zauberman *et al's.* (2010) experimental study.

Substantial differences occur between the occupational patterns and time use of individuals with and without a disability (Pentland, 1998; Cronin - Davis *et al.* (2004), Long (2004) and Farnworth, (2004)), which could lead to reduced performance and wellbeing (Whiteford, 2009). These differences could include time spent on self-care, but less time for productive occupations, and having more 'free' time (Pentland *et al.,* 1998, Pentland & McColl, 1999) Farnworth, 2004)). These researcher's also suggested that a little time spent doing a satisfying occupation contributes to health and wellbeing more than a long time spent doing a minimally satisfying occupation.

What is important about a leisure occupation is not what it is, but why it is carried out (according to the Chan et al's (*2012)* analysis of interview data about the meanings of leisure and the meaningfulness of its pursuit; and Pereira & Stagnitti's (2008) small semi structured interview dataset. Both Suto (1998, 2004) and Lobo (1999) challenged the belief that free time equates to leisure when it is "imposed" because of having nothing else to do. Un- or underemployed individuals could therefore perceive their uncontracted time as endless unfilled time (Lobo, 1999). This coincides with Stebbins' (2009) view that freely chosen free time leisure occupations, occur within the context of an individual's personal, cultural, and historical background. Boredom occurring in free time could be a chosen but unwelcome experience, and so is leisure (Stebbins, 2009). Additionally, activities imposed to kill or fill free time (Lobo, 1999 cannot be defined as leisure (Stebbins, 2009). Another aspect of occupational deprivation is imposed dependence.

Imposed dependence

The boredom resulting from not being able to engage and having nothing else to do could result in an individual being pleased to engage in whatever occupations come their way. This dependence on what others deem suitable (Suto, 1998, 2004), earned (Scanlan *et al.,* 2010) or available (Suto, 1998, 2004) could mean that leisure activities serve as a means of killing or filling time, rather than as a meaningful occupation. Dependence on others could result from a lack of self-determination over occupational choices, resulting in turn from being limited due to atrophied occupational capacities. Similarly, Stewart and Craik (2007), Helbig (2003) Farnworth (2004) and Farnworth *et al.* (2004) all suggested that time-use in residential care could predominantly include personal care, passive leisure and rest. This could influence the meaningfulness of how time is used, and of the occupation (Lobo, 1999; Stebbins, 2009).

Physically constrained and occupationally deprived individuals (Whiteford 2004, 2010) such as prisoners (Whiteford, 1997), refugees (Whiteford, 2000) and residents in care environments (French, 2001) could share a sense of dependence or lack of control with individuals with NPC. The concept of occupational injustice suggests that some individuals have the freedom to choose and organise their time, place, or occupation, whilst others have little or no occupational choice (according to Zemke during an (2010) online discussion). For example, a lack of control over time and space could mean that asylum seekers have very limited possibilities for meaningful occupations within the limitations provided by a facility; they experience little or no structure of space and time, wanting simply to "kill time" (Zemke, 2010). This occupational injustice, Zemke (2010) suggested, is one of the reasons why occupationally deprived individuals experience a higher incidence of ill health than average.

Lack of control over occupations (Whiteford, 2000, 2004) is also an issue for individuals with NPC, possibly affecting their sense of time passing. This could arise because of the structure of the day imposed by a residential facility. The structured use of time could reflect an individual's perceptions of time spent between occupations, as opposed to the actual time spent (Christiansen, 1996; Farnworth, 2004; Farnworth, 2003). Zemke (2004) also suggested that humans depend on times and places to allow "being" and "doing" their self-identity through their occupations (Zemke, 2004). Therefore, limitations on the control of activity could lead to imposed dependence and identity. In the case of a home, one could argue that this imposed dependence could lead to institutionalisation because of a reduced opportunity to access the requirements necessary to engage in occupations.

Lack of opportunity to access the tools required to engage in occupations

Disability or incarceration could restrict the opportunities for an individual to engage in occupations. In the case of a prisoner, this could be part of their punishment (Whiteford, 1997). However, in the case of an individual with an NPC, limitations could result from their combination of limitations (according to Collier & Truman's (2009) discussion of the issues around MSE use for leisure purposes). Restricted access to opportunities could result in an individual losing the skills to engage in occupations, which is a hypothesis supported by O'Sullivan and Hocking (2006) and Hearle *et al.* (2005), who both described the insidious effects of occupational deprivation. They suggested that as individuals do less, they lose capacity. As

they lose capacity, it becomes harder to do things. When doing things requires effort, occupations become less rewarding, individuals are less motivated to try, so they do less. This means that the atrophy of occupational capacities could lead to a lessening of the ability to use the tools required to engage in occupations. The effects of prolonged occupational deprivation were suggested by Sviden and Borrell's (1998) interview data and Helbig & McKay's (2003) discussion about addictive behaviours from an occupational science standpoint to include failing to gain sensory stimulation from the environment, or failure to capitalise on such stimulation when it is available. Equally, a lack of sensory stimulation could lead to occupational deprivation (according to Heuchemer & Josephsson's (2006) interviews of two formerly homeless women recovering from drug addiction. These researcher's considered the resulting lack of engagement to be sensory-deprivation, even though they were studying the effects of occupational-engagement. However, the researcher wonders whether this could be another example of lack of opportunity to access the tools required to engage in occupations, resulting from long unfamiliarity with the experience of engagement. Equally, attitudes could force the individual to be dependent on others for permission or support to engage in occupations, depending on what is deemed appropriate (Suto, 1998, 2004), earned (Scanlan *et al.,* 2010), or available (Suto, 1998, 2004). The individual could experience a lack of opportunity to access (even unsuitable) occupations, or a lack of access to the materials and tools required.

Turner (2002) suggested that the loss of the ability to use the tools to undertake occupations was an outcome of occupational deprivation. One could argue that profound disability limits an individual's occupational performance. However, occupational science proposes that the lack of access to opportunities for hand use leads to a 'use it or lose it' cycle, in turn leading to the atrophy of occupational capacities. Whiteford (1997, 2004, and 2010), Molineux, and Whiteford (1999) suggested that limited access to hand or tool use results from occupational deprivation. Disability could also render individuals less able to use their hands or tools to engage in occupations, thereby depriving them of the opportunity to engage in occupations just as much as external barriers such as a refugee camp, a prison, geographical isolation, unemployment or sexual role stereotyping. Thus, the disability is acting as a source of occupational deprivation, by depriving the individual of their ability to use tools. Therefore, the residents appear to be more vulnerable to occupational disruption, imbalance, and alienation (initially) and deprivation (as their clinical condition progresses) than other clinical groups could be.

Molineux and Whiteford (1999) explored the experience of prisoners, providing an overview of the issues arising from occupational deprivation. They reviewed a range of literature about the effects of incarceration to promote their argument that prisoners experience occupational deprivation. Their article is relevant to this thesis because the institutionalisation that results from being a prisoner (on the one hand) or a resident with profound disabilities (on the other) could have many similarities. The prisoners experienced limitations to support, privacy, safety, structure, emotional feedback, social stimulation, activity and freedom. The study is relevant because disabilities such as Locked-in Syndrome imprison individuals within their own bodies, as indicated by Bauby when he chose to title his book "*The Diving Bell and the Butterfly*" (McCammon, 2008).

The association of concepts, sensory perception and communication has contributed to human evolution towards expert hand use (Wilcock, 2006). Thus, the prisoners in Molineux and Whiteford's (1999) study and the refugees in Whiteford's (2000) research all found themselves unable to access and therefore use tools, and they all experienced

occupational deprivation (Whiteford, 2009). Other reasons for inability to use tools could include paralysis, choreaform movements, cognitive impairments, or the reduced awareness of an individual with low awareness.

Appendix iii Issues around Leisure Activities at the home

There is a varied range of recreational and leisure occupations available to the residents, arranged by themselves or their visitors, staff or residence/ department staff, or Recreation and Leisure Service team.

Some of the challenges experienced when participating in or facilitating recreational and leisure occupations for the residents of the home include:

Active engagement/ flow:

Both Passmore (1998) and Csikszentmihalyi (1990) regard this as an important factor for an occupation to be meaningful, satisfying and positive in terms of mental health. However, Csikszentmihalyi (2002) raises concerns about whether a "flow" state is possible for individuals with sensory gating deficits.

Csikszentmihalyi (1990) described the state of "flow" and concluded that enjoyment could be obtained through diverse routes or occupations. Comparing enjoyment to pleasure he noted that pleasure lacked the sense of achievement or active contribution which was present in enjoyment. He found that individuals were generally unhappy/ frustrated by "doing nothing" which reinforced Wilcock's (1993) point that humans are occupational beings.

Passmore highlighted three types of leisure occupations that contribute to personal growth, mental health and wellbeing:

* Achievement leisure - provides challenges, and is demanding, requiring commitment e.g. sports, creativity and music performances;

* Social leisure - where engaging in leisure is primarily about being with others, such as a tea party;

* Time-out leisure - includes TV watching, isolated reflecting or listening to music - occupations that tended to be more socially isolating, less demanding and frequently physically passive.

Occupation adaptation:

Equipment tends to be quite specialised for games, making music and sports etc and includes switches, large pieces and individualised handles. This can add to the cost for the organisation, or the individual and put off residents from trying a new occupation if they look unsightly or childish

When approaching the adaptation of recreational and leisure occupations for any individual an Occupational Therapist conducts an activity analysis and compares this with an assessment of the individuals abilities and needs. At the other end of the spectrum is the menu option of picking occupations that have already been tailored to or tried with individuals with disabilities (however different from the needs of the individual in question). Less skilled staff, who do not appreciate the need for analysis of the individual and the occupation and enabling a fit between the two, usually carry out this more rigid style of occupation selection.

The latter approach is more appropriate for group occupations, and appears to be the approach of staff who do not regard recreational and leisure occupations as central to the lifestyle of an individual, than for individual occupations.

Constraint:

Stroke survivors reported 80% deterioration in leisure domains (Bhogal et al 2003). Backman (1991) considered that the main reason for the decision to discontinue an occupation was a perception of constraint. Constraint could be related to loss of interest, lack of facilities, unfitness and physical disability, or lack of time. Discontinuing a previously enjoyed leisure occupation could occur when the skill or abilities required are now is greater than challenge or if the skill or abilities required is lesser than the challenge.

Accessibility:

Because of the nature and severity of neurological disabilities, physical access to an occupation especially off the hospital site could present substantial challenges. For example, a wheelchair user who needs to tilt in space and is dependent on a ventilator could need a far bigger chair than a basic attendant propelled chair. The wheelchair use could also require an experienced and trained attendant to support their occupation in case the ventilator needs attention, this will influence the staff left behind on the residence.

Away from home space

Lobo (1999) and Ross (2008) noted the value of a change of environment when carrying out different types of occupations. To replace the routine and change of location involved in going out to work, or going out shopping; recreational and leisure occupations could be carried out in different locations, away from the individuals "home space"

However, a balance is required to ensure that some occupations can be carried out in the public rooms of the hospital or residence, some in a drop in leisure facility, others in the grounds, and some in the individual's "home space".

Choice and flexibility of context

Kjellberg (2002) points out that in recreational and leisure occupations, the self-determination, control, choice opportunities vary between different occupations and contexts.

Understanding leisure contexts is important because of its impact upon quality of life (Devine 2004), especially for individuals with disabilities (Bedini 2000, Devine & Lashua 2002) context has been found to be important factors in the meaning individuals assign to leisure, and includes:

Physical space and aspects of place

Tone or atmosphere

Meanings individuals assign to behaviours, objects and language

Participants themselves (Devine 2004)

Having a designated place where particular (e.g. creative, games) occupations were available constantly during specified hours would enable individuals to control the timing of their occupations.

Environmental control/ possum

Control of the environment either by communicating the individuals request to staff or via switch control is important for the individual's engagement with the occupation and comfort. This could involve the selection of

background music, windows being open or closed, lighting levels, access to appropriate materials and tools such as paper or paint, mouth stick paintbrushes etc.

Family factors (*previous interests in recreation)*

Different families use free time in different ways. Not all individuals therefore will be used to using free time for leisure occupations. This will affect the family's support for the individual's recreational and leisure occupations. It will also affect the individual's own choice of occupations (as will other family influences such as beliefs, ethnicity, religion etc).

Supporter issues (*and surrounding individuals):*

Attitudes and levels of commitment to recreational and leisure have a major impact on prioritising leisure opportunity provision.

McLean (2005) demonstrated that a lack of interest by individuals in taking part in any occupations and a lack of motivation to join in something outside the routine was not unusual. She advocated that creative occupations and aspects of reminiscence could be included in any occupation, to raise individuals' self-esteem and raise awareness of individual characteristics. Interestingly women and individuals with a high educational attainment level are least likely to engage in recreational and leisure occupations post stroke (Bhogal et al 2003).

Escorting individuals on holidays and out of hours outings appears to be reliant on the good will of staff to offer their off duty time free of charge and requires a member of staff who is able to respond to emergencies on their own. It also involves caring for the individual during the entire day and evening and also during the night.

At the residential care, home staff appear more willing to escort individuals to and participate in occupations that interest the staff member. The enthusiasm of the staff member is reported as having a great impact on the engagement of the individual in the occupation. Therefore, if a group is perceived as childish or inappropriate (in the observer's perception) it is hard to gather escorts for individuals to attend.

Funding Issues:

Can individuals with neuropalliative conditions afford the outings and holidays when they have little or no income? Occupations for disabled are always more expensive because of:

* Staffing levels

* Adapted and individual equipment

* Specialist transport requirements

Skills of facilitators:

Assessment of the individual's skills and an activity analysis is required to adapt an occupation to the individual's needs and abilities.

The following skills are just a few of those covered in a (US) national certification council for occupation professionals course. This list demonstrates the need for underpinning knowledge and analysis of both individual and occupation to facilitate a truly client centred recreational and leisure occupation.

Occupation analysis	Knowledge of the models of disability
Client assessment	Leisure satisfaction auditing/ Evaluation Techniques
Creative occupations	Supportive techniques
Dealing with Challenging behaviours	Musical occupations
Educational occupations	Off site occupations
Empowerment	Open minded about festivals, games, creative occupations with which they are not familiar
Entertainment occupations	Outdoor occupations
Exercise occupations	Problem Solving
Creative expression	Professional attitude to individuals
Grooming occupations	Program Implementation
Interdisciplinary Team working	Program Planning
Knowledge of the impacts of diagnoses on individuals	Reality Awareness occupations
Sensory occupations	Religious occupations
Social occupations	Individual Planned occupations
	Individuals with special needs

Choice:

In an home, there is a danger that residents will be offered little choice of location and timing for their occupations because they are organised on a group basis unless there is a drop in leisure facility.

Attitudes:

The attitudes of staff and carers have a profound impact on the quality and quantity of leisure occupations that an individual engages in. Nolan et al (1995) portray the organisation of leisure and social interaction as a core responsibility for staff in continuing care environments. A failure to provide for such needs being as Crump (1991) puts it “tantamount to abuse”. If staff and carers do not value the importance of leisure in the lives of individuals, this can discourage or fail to facilitate the individual to attend or join in. Herbert (2000) noted that staff who had knowledge of occupation adaptation and competence regarding disability issues tended to have positive attitudes towards providing services for individuals with disabilities.

Additionally, the attitudes of those who are around the individual e.g. fellow audience members, other shoppers, sports centre instructors etc can have a major affect on the opportunities offered. Much of the awkwardness displayed by able-bodied individuals towards individuals with disabilities is the result of ignorance, fear and lack of familiarity than outright prejudice; however, it can manifest itself as abusive or patronising behaviour or avoidance of contact. The Recreation and Leisure Service team have described instances of real abuse from members of the general public who have been offended by the presence of an individual in the audience. This has influenced the individual who could be less willing to participate in outings in the future.

Staff enthusiasm to escort an individual to an occupation depends as much on the staff members’ interests in the occupation, as the needs of the client. Occupations which are interesting to staff appear to motivate them to escort individuals to occupations more than those which are not.

Stamina/ tolerance:

Due to pain, physical or psychological fatigue, or the care of decubitus ulcers, an individual could only be able to tolerate/ participate in an occupation for a limited period of time. This will mean that either they can participate in time limited occupations or that other participants are disturbed when the individual has to withdraw.

The occupations should also allow/ enable individuals who need to shift their weight, move, stretch etc to do so throughout the occupation.

Occupational tolerance can vary considerably between individuals, due to the effort (physical, cognitive etc) involved as well as pain and sitting tolerance. A balanced programme of occupations therefore, should include short occupations (counting the time taken to get there and the time waiting for the occupation to begin) as well as ones, which can last longer.

Behaviour:

Challenging behaviour in individuals with cognitive deficits are often signs of unmet need and are particularly likely to occur in periods when the individual is unoccupied or bored according to Kolanowski et al (2001). Recreational and leisure occupations are suggested to can reduce such behaviours.

Behavioural difficulties such as aggression, non-compliance, self-injury, impulsiveness, or disinhibition could make social inclusion and re-integration difficult because of the safety of others and difficulties with engaging in occupations with others. This behaviour can be distracting to others, offensive, out of context or unpredictable, which is why Wellesley ward send an escort with each individual participating in occupations off the ward.

An individual's behaviour can sometimes be the most prominent symptom of a neurological disability to the lay individual. Other individual's reactions to this behaviour can in turn cause more problems than the behaviour itself.

Cognitive Function:

A cognitive impairment could result in changes in how an individual thinks, reacts to emotions, or behaves. It can affect the ability to concentrate, formulate ideas, reason and remember. It occurs because of a reduction in the ability to process, learn, and remember information. Impaired attention/ cognitive function impacts on the ability to develop, retain, and transfer skills and learning/ persistence especially if the individual is easily distracted. Cognitive deficits also make social skills harder to use and interpret which impacts on social occupations.

Individuals who are cognitively overwhelmed could exhibit impaired social skills including disruptive, offensive behaviour, or physically passive disinterest. Cognitive impairment can manifest itself as rigidity, an insistence on doing things "my way," and a refusal to try something new. Some individuals could demonstrate an increase in symptoms such as agitation, depression, or aggression. This could be a result of over stimulating/ challenging the individual with a task too difficult for him or her to complete successfully. Some individuals are unable express feeling overwhelmed and will only act out physically and/or emotionally. Individuals who appear disinterested could also be over challenged due to an inability to plan, organise and initiate taking action.

Communication:

Communication is the process of expressing and understanding messages. Communication problems can depend on many factors that include an individual's personality, previous abilities, and the severity of the neurological damage; all of which can lead to difficulties in finding words, processing the message, expressing the message, or receiving the message.

Language problems often include word-finding difficulty, poor sentence construction, and lengthy and often faulty descriptions or explanations. Individuals could have difficulty understanding multiple meanings in jokes, sarcasm, and adages or figurative expressions. Individuals can be completely unaware of their errors and become frustrated and place the blame for communication difficulties on the individual to whom they are speaking.

Speech that is slow, slurred, or difficult to understand impacts on communication. Many individuals use communication aides such as light writers or eye pointing, which demands skill from the receiver of the communication to interpret. Social occupations therefore could require an interpreter if the two individuals use incompatible or unfamiliar communication methods.

Emotional Lability:

Emotional lability is the term for the drastic and rapid swings of emotion that can result in outbursts of tears, laughter and sometimes anger. The emotional reaction of some individual's matches how they are feeling but is greatly exaggerated. In others, the exaggerated laughing or crying is out of place and inappropriate to the situation they are in. Individuals affected by emotional lability can also switch rapidly from one to the other, crying for no reason then laughing inappropriately. In either case, emotional lability is not easily controlled.

Emotional lability and unpredictability of reactions can affect interpersonal relations if the individuals around the individual are not aware of it, its causes and the effect that it has on the individual. It can cause distress and embarrassment to both the individual and those around him. It can be distracting during an occupation, affecting the concentration of all parties.

Physical abilities:

The individual's ability to hold or manipulate tools and materials could be severely limited by their disability. Therefore, it could be easier for the individual to participate using assistive technology or adaptations to the occupation to increase, maintain, or make a particular occupation less strenuous. Assistive technologies can include mechanical, electronic, and microprocessor based adaptations such as switch controls or levers, as well as non-mechanical and non-electronic equipment such as a ramp.

Reaction times and the ability to move quickly or in a coordinated way to catch something unpredictable or to hit a target such as a ball with a bat could also be affected.

Appendix iv Literature Search Strategy

The search included:

Publication Type: Journal Article;

Published from: 01/011990-28/03/2012;

Peer Reviewed;

English Language;

Population Group: Human;

Furthermore, it used the Boolean/Phrase Search terms listed below:

Search terms used	Results
TX "symptoms of sensory-overload"	0
TX "signs of sensory-overload"	0
TX "signs of sensory-overload" OR TX "symptoms of sensory-overload"	0
TX facilitation AND TX "positive collaboration" AND TX help	0
TX "sensory regulation" AND AB disability AND TX neurological	0
TX "sensory habituation" AND AB disability	0
TX "History of Occupational science"	1
TX "sensory adaptation" AND AB disability AND TX neurological	1
TX "Sensory regulation" AND AB disability	1
TX "being fully human" AND (TX leisure OR TX occupation)	2
TX "sensory gating" AND AB disability AND TX neurological	2
TX "sensory-overload" AND AB disability AND TX neurological	2
TX "sensory-deprivation" AND AB disability AND TX neurological	3
TX "sensory habituation" AND TX neurological	4
TX "Sensory-overload" AND AB disability	4
TX "preventing boredom" AND (TX leisure OR TX occupation)	5
TX "Sensory-deprivation" AND AB disability	5
TX "occupational deprivation" AND TX neurological	6
TX "barriers" AND TX "leisure engagement"	8
TX "occupational deprivation" AND AB leisure	9
TX "sensory adaptation" AND AB disability	9
TX "sensory gating" AND AB disability	9
TX "History of Occupations"	10
TX "sensory-overload" AND TX behaviours	13
AB "sensory environment" AND AB care NOT dentist NOT multi-sensory NOT multisensory	14
TX "sensory stimulation" AND AB disability AND TX neurological	22
TX Attention AND TX absorption AND TX depletion AND TX enrichment	24
TX "being fully human"	24
(TX "occupational therapy" or TX "occupational therapist") AND (TX "adjustment to disability") AND (TX occupation OR TX leisure)	26
(TX "occupational therapy" or TX "occupational therapist") AND (TX "adjustment to disability") AND (TX occupation OR TX leisure)	26

TX "rhythm of life" AND (TX leisure OR TX occupation)	27
TX "leisure occupation"	31
TX leisure AND TX "meaning of occupation"	34
TX "sensory diet"	35
TX "occupational deprivation" AND (TX effects or TX costs)	39
(TX "occupational therapy" or TX "occupational therapist") AND (TX diversion) AND (TX leisure)	39
TX "occupational balance" AND TX neurological	40
TX "occupational deprivation" AND TX disability	43
TX "neuropalliative" OR TX "neuro-palliative" OR TX "neuro palliative" AND conditions	72
TX "occupational roles" AND TX neurological	74
TX neuropalliative OR "neuro palliative" OR "neuro-palliative" OR TX "complex neuro-disability" OR TX "complex neurodisability" OR TX "complex neuro disability"	89
TX "Sensory stimulation" AND AB disability	91
TX "occupational deprivation"	94
TX "meaning of occupation"	99
TX leisure AND TX "occupational roles"	159
TX "Types of Occupations" AND TX "occupational"	164
TX "individual growth" AND (TX leisure OR TX occupation)	167
TX "rhythm of life"	181
TX leisure AND TX flow AND TX csikszentmihalyi	188
TX leisure AND (TX "occupational-engagement " OR TX "occupational-engagement " OR TX "participation in occupations" OR TX "occupational participation")	210
TX "Types of Occupations"	217
TX "influences on engagement" OR TX "influences on participation"	232
(TX "occupational therapy" or TX "occupational therapist") AND (TX "self-determination" OR TX "choice of occupation" OR TX control) AND (TX occupation OR TX leisure)	236
TX "goal orientation" AND (TX leisure OR TX occupation)	259
(TX "health and wellbeing" OR TX "health and well-being" OR TX "health and well being") AND TX capability AND (TX leisure OR TX occupation)	271
(TX occupational) AND TX belonging AND TX leisure	420
TX "effects of leisure" OR TX "benefits of leisure"	427
TX "self expression" AND (TX leisure OR TX occupation)	488
TX "occupational performance" AND TX neurological	509
TX leisure AND TX "occupational performance"	569
TX "sensory environment" OR TX "sensory context"	634
TX "occupational-engagement " OR TX "occupational-engagement " OR TX "participation in occupations" OR TX "occupational participation"	767
(TX occupational OR TX recreational OR TX diversional) (TX therapy or TX therapist) AND (TX capability)	773
(TX "occupational therapy" or TX "occupational therapist") AND (TX accomplishment OR TX achievement) AND (TX occupation OR TX leisure)	918
TX "occupational environment" OR TX "occupational context" AND (TX leisure OR TX occupation)	953
TX "occupational role" OR (TX spectator AND TX participant) OR (TX spectating AND TX participating)	2110
TX creativity AND (TX leisure OR TX occupation)	2221
(TX occupational) AND (TX wellbeing OR TX well-being OR "well being") AND TX leisure	2522
TX "occupational science"	2704
TX "occupational performance"	3353
(TX "health and wellbeing" OR TX "health and well-being" OR TX "health and well being") AND (TX leisure OR TX occupation)	3436
TX "belonging" AND (TX leisure OR TX occupation)	3574
(TX "occupational therapy" or TX "occupational therapist") AND (TX purpose OR TX meaning) AND (TX occupation OR TX leisure)	4263
TX "self-identity" OR "self identity" AND (TX leisure OR TX occupation)	7296

TX "sensory gating" OR TX "sensory processing" OR TX sensoristasis	9168
TX "health, wellbeing and capability"	9744
(TX "influences on " OR TX "influenced by") AND (TX participation OR TX engagement) AND TX occupational	10172
(TX purpose OR meaning OR importance) AND (TX leisure OR TX occupation)	38582
TX "self-efficacy" OR "self efficacy" AND (TX leisure OR TX occupation)	77212
TX facilitation OR TX "positive collaboration" OR TX Help	1137312

Key:

TX =in the text of the article

AB =in the abstract of the article

"" =phrase in speech marks sought as a whole

() =text in brackets sought before the rest of the Boolean phrase

And =combines search terms so that each search result contains all of the terms.

Or =combines search terms so that each search result contains at least one of the terms.

Appendix v Examples of the data collection format used for the time sampled observations of engagement and a completed example published in Fenech (2009)

May 2006
Interactive Drama Project

Senses involved:
Hearing and seeing, touch, proprioception, vestibular stimulation

resident	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	Minute 50 - 51	Minute 55-56	Field notes
	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	
	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	
	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	
	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	
	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	
	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	

Downloaded By: [Fenech, Anne] At: 21:38 16 January 2009

	Minute 1–2	Minute 5–6	Minute 10–11	Minute 15–16	Minute 20–21	Minute 25–26	Minute 30–31	Minute 35–36	Minute 40–41	Minute 45–46	Minute 50–51	Minute 55–56	
1	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	No engagement, no reaction
2	ae	ae	ae	pe	ae	pe	ae	ae	pne	pne	pne	pne	Typed yes in answer to question, laughed when Juliet (her daughter) didn't want to marry her choice × 2, tracking, laughed when accused of misdemeanour, looked up and around audience, tracking lady actor when describing kittens, tracking, sleep
3	pe	ae	pe	ae	ae	pe	pne	pne	pne	pne	pne	pne	Not tracking, nodded when thanked for attending ball, head down/ tracking alternately, laughed at nurse being accused of drinking all the wine, laughing at servant who was trying to run off with Lady Capulet, head down, no engagement
4	ae	pe	ae	ae	ae	ae	ae	ae	ae	pe	pe	pe	Shook hands with male actor when he spoke directly to him and made eye contact, tracking, danced with lady actor, smiling, laughed when offered wine, holds hands to be shaken when introduced to future wife, spontaneously, eye contact with lady actor speaking to him, laughing at drunk servants, tracking
5	ane	ae	pe	ae	ae	ae	ae	pe	ae	ae	ae	ae	Looking away – not engaged laughs when actor speaks directly to him, tracking male actor after he is directly approached, tracking, laughed at tongue twister, 'you look nice, nice face' spontaneous comment directly to male actor
6	pe	pe	ae	pe	pe	pne	pe	pe	pe	ae	pe	pe	Tracking dancers, tracking male actor when speaking to him, responds to male actor when spoken to, tracking on and off, no reaction
7	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	
8	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	Removed to back to be PEG fed
9	pe	pe	ae	pe	pe	pe	pe	pe	pe	pe	pe	pe	
10	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	Eye contact with male actor when he speaks to him × 2, leans towards him, tracking male actor, tracking most of the time
11	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	Head down, All through
12	ae	ae	ae	ane	ae	ae	ae	ae	ae	ae	ae	ae	
13	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	pne	Brought her self up from making music group to see performance, spoke spontaneously to both actors, tells male actor that she speaks 5 languages and likes ballet, trained dancer, laughing at nurse character being a fool, teaching male actor phrases in Hungarian, tracking, responds to question from actors, further conversation about ballet, liked dancing Copelia
14													Not tracking, no eye contact, eyes down

Active engagement Ae: Participation with the environment appropriately/manipulating materials or vocalizing.
Passive engagement Pe: Individual interacts with the environment without manipulation or vocalization.
Active non-engagement Ane: Interacts with the environment in an inappropriate manner by manipulation/movement and/or vocalization.
Passive non-engagement Pne: Does not interact with the environment and does not do what is expected during the activity.

Appendix vi the statistical tests used for the data analysis?

The data and the variables

The second research question was 'How does engagement in casual leisure occupations (by individuals with NPC) alter with different levels of sensory attributes'? In this instance, the purpose of analysing the data is to describe and summarise it, identifying relationships, patterns, and comparing the effects of the addition of sensory attributes to engagement in the casual leisure occupations.

Variables are attributes which change between participants, time, location (Field, 2009). Independent variables include the proposed cause, a predictor variable or the variable being manipulated (such as the number of sensory attributes offering sensory stimulation to the participant) (Field, 2009). During the marginal participant observations, the researcher was looking for signs of engagement. Dependent variables (the engagement categories) may respond to changes in the independent variable, they are an outcome or the proposed effect, i.e. they are the item measured but not manipulated (Field, 2009). These were coded against Kishida & Kemp's (2006) ICER; this meant that the dependent variable under consideration was engagement. The data produced were categories relating to the five engagement categories defined in the ICER. These were active engagement, passive engagement, undifferentiated engagement, passive non-engagement and active non-engagement. Evidently, the categories might not be equidistant, even if given an alternative numerical code.

Is the data continuous or categorical?

Data is either continuous or categorical (Field, 2009). Continuous data can have a distinct score, e.g. equal differences or intervals data (interval variable) or equal intervals but with relative or ratio differences to differentiate the data (Field, 2009). Whereas categorical data can be divided into distinct categories (Field, 2009). Table 7 contains binary data i.e. only two categories; in this case 1&0. Nominal data might fall into more than two categories which might all be on a theme but do not have an order of progression (Field, 2009). Ordinal data also adheres to a theme (in this case engagement category) but Furthermore, the categories have a logical order of progression (Field, 2009). Appendix vii3, (1120 data points) presents the raw data gathered from observations of engagement using the ICER. The data is categorical and continuous, and the words in the category titles converted to a number in order of increasing or reducing engagement. The ICER ranks the different engagement categories across a range from active engagement (5), passive engagement (4), undifferentiated engagement (3), passive non-engagement (2), to active non-engagement (1). Therefore, the data does not necessarily have the same distance between the categories, so that it might have unequal intervals.

The tests used to test the statistical significance of the differences in engagement included a Friedman test and a series of Wilcoxon signed-rank tests. Both techniques are non-parametric and suitable for repeated measures (with related samples) and ordinal data. In this thesis, the Friedman's ANOVA test compared seven leisure occupations with a control condition, each carried out by the same participants where a normal distribution could not automatically be assumed. It was used with continuous data which has resulted from several variables (number of sensory attributes of casual leisure occupation) which has produced categorical data (from the ICER categories of engagement) when comparing data from a core

group of participants (common to all occupations). This was possible because the ICER produced ranked (ordinal) categories in relation to the engagement categories and therefore the differences between them were observed.

Given the non-equivalence of the distance between the categories, medians or middle values have been presented because the categories are what is important, not the code value itself (and not the frequency of the values attributed to the individual participants, because the case is an entire occupation, not each individual participant). The rank position relates to the position of the piece of data collected in the hierarchy. Statistical ranking takes account of data with the same score or value when assigning the rank position. Non-parametric statistics are based on these rank positions, rather than on the actual values. This corrects for bias and distortion, outliers and other anomalous distributions, as well as unequal intervals between points on a scale, as found in ordinal data (Walker & Almond, 2010). Therefore, bar charts will be used to provide a visual representation of the data, accompanied by tables and a description of the data (Walker & Almond, 2010), rather than placing reliance only on statistical significance.

Analysis of variance

An analysis of variance (ANOVA) might establish whether the means of several groups are all equal, so that the results can be generalised a more than two groups. This could compare the mean engagement categories of each participant in an occupation and then to compare these with all others involved in the case. However, this study did not set out to compare individual participants with each other, since the focus was on the occupations and their sensory attribute level. Doing multiple two-sample t-tests would result in an increased chance of committing a type 1 error (a false negative that might, for example give the illusion of good health and not requiring treatment when in fact they had a serious condition which required treatment). To avoid this false negative result, ANOVAs compare at least three group means e.g. comparing group means for each case. Several models are used in the analysis of variance. However, it was the fixed-effects model of analysis of variance, that would have been applicable to this thesis, had this option been necessary. It applies to situations in which the researcher applies one or more treatments or levels of sensory stimulation to the participants data to see if the response changes and to estimate the ranges of responses that the treatment would generate in the population as a whole. An analysis of variance assumes that the variables are independent, normally distributed with an equal and constant distribution of their effects. Some popular ANOVA designs include:

- One-way ANOVA tests for differences among two or more independent groups (means), e.g. different levels of sensory stimulation applied to leisure occupations.
- Factorial ANOVA studies the interaction effects among the treatments.
- Repeated measures ANOVA test the same subjects for each treatment.
- Multivariate analysis of variance study multiple response variables.

Parametric or non-parametric tests?

Generally, parametric methods make more assumptions than non-parametric methods, but if the assumptions prove correct, produce more accurate and precise results that have statistical power (Corder & Foreman, 2009). However, misleading results might appear if the assumptions prove incorrect (Field, 2009). When data are distributed normally, or equidistant; there is likely to be a nonparametric equivalent test, used to analyse ranked data, to use instead (Field, 2009). This was true in this thesis, therefore non-parametric statistical methods were used to analyse the engagement categories

with each level being given a numerical code ranging from 5 to 1 (Robson, 2002; see raw data in Appendix vii3). The use of non-parametric methods was necessary because despite the ICER producing data about the ranking of the individual's engagement, there can be no clear numerical interpretation of these levels or the differences between them. Another reason for choosing to use non-parametric methods of statistical analysis was that they are usable with less well-known data collection scales such as the ICER (Field, 2009). Furthermore, non-parametric statistical methods could be considered easy to administer (to someone of a mathematical mind), and to produce robust and understandable results (Gibbons & Chakraborti, 2003). Although, Robson (2002) suggests that non-parametric and parametric tests might not test exactly the same thing as their counterpart. In this instance because the categories in the ICER are defined by words such as active engagement, passive engagement, undifferentiated engagement, passive non-engagement and active non-engagement, and because the difference between the categories cannot be guaranteed to be the same, the decision was taken to use non-parametric tests.

The non-parametric tests

This section expands upon the figure on the next page which shows the similarities and differences between the Wilcoxon signed rank test, Friedman test and Kruskal-Wallis Tests, all of which are non-parametric. Non-parametric tests have been suggested to be suitable for comparing whether the differences between two sets of data (whether independent or dependent) are significant, include the Mann-Whitney, and the Wilcoxon rank-sum tests and the Wilcoxon Signed-rank test (Field, 2009). Furthermore, the Kruskal-Wallis test and the Friedman's test compare the differences between related and non-related groups of data. While, the Mann-Whitney/Wilcoxon rank-sum tests, compare two independent groups of categories generated by different groups of participants each time (Field, 2009). This thesis gathered data from a core group of 14 participants, who all participated in each casual leisure occupation; Consequently these tests were not used (Field, 2009).

Figure showing the similarities and differences between the Wilcoxon signed rank test, Friedman test and Kruskal-Wallis Test

<table>
<tr><th>Number of variables</th><th>Type of outcome</th><th>Number of independent variables</th><th>Type of independent variables</th><th>How many categories</th><th>Ranked categories</th><th>Same or different participants</th><th>can compare the differences between related and non-related groups of data</th><th>Comparison of</th><th>Data meet assumptions for parametric tests</th><th></th></tr>
<tr><td rowspan="3">One
=
engagement</td><td rowspan="3">Continuous
=
Difference in engagement between cases</td><td rowspan="3">One
=
number of sensory attributes</td><td rowspan="3">Categorical
=
Category of sensory attribute</td><td rowspan="3">More than two
=
The ICER ranks the different engagement categories across a range from:
active engagement (5),
passive engagement (4),
undifferentiated engagement (3),
passive non-engagement (2),
to active non-engagement (1).</td><td rowspan="3">Yes
=
The ICER produced ranked (ordinal) categories.</td><td rowspan="2">same</td><td>No</td><td>paired observations</td><td rowspan="3">no</td><td>Wilcoxon Signed-Rank Test:</td></tr>
<tr><td rowspan="2">yes</td><td rowspan="2">several populations i.e. analysis of variance with ranks</td><td>Friedman Test: Repeated measures (- A Nonparametric Alternative to Two-Way ANOVA).</td></tr>
<tr><td>Different (just in case)</td><td>The Kruskal-Wallis Test - A Nonparametric Alternative to One-Way ANOVA</td></tr>
</table>

The Wilcoxon signed rank test on the other hand compares two dependent groups of categories generated from the same groups of participants each time (in this instance the outcome or effect calculated was how the engagement categories differed between the casual leisure occupations, and whether the difference was statistically significant) (Field, 2009). A Wilcoxon signed-rank test compared the repeated measurements data, to assess whether their population means differed. It is useful whether the data has a normal distribution or not, and so was used as an alternative to the paired Student's t-test because the population could not be necessarily assumed to be normally distributed. The Wilcoxon signed-rank test is a non-parametric statistical hypothesis test used when comparing two related samples, matched samples, or as in this case repeated measurements on a single sample to assess whether their population mean ranks differ, (i.e. it is a test of paired difference). To generate its results the Wilcoxon signed-rank test compares continuous data from a single variable (sensory level of casual leisure occupation) which has produced categorical data (from the ICER categories of engagement) when comparing data from a core group of participants (common to all occupations). This was possible because the ICER produced ranked (ordinal) categories in relation to the engagement categories and therefore the differences between them were visible. The Wilcoxon signed-rank test compared the differences between engagement categories in the occupations; it's use in this thesis to show where the difference between two occupations was greater than between two other occupations. In other words, a small P value means that the reader can be confident that the difference is significant rather than being due to chance, or other factors. If the P value is large, however, the difference is less likely to be significant and more likely to be due to chance. Arguably, statistical significance does not necessarily mean that the finding is clinically or practically significant. Table 11 uses asterisks to denote the degree of statistical significance (more asterisks =more significance).

The Friedman test analyses one-way repeated measures analysis of variance by ranks and so can go hand in hand with the Kruskal-Wallis one-way analysis of variance by ranks (Field, 2009). The Kruskal-Wallis test compares more than two independent groups of categories (Field, 2009). In this instance there were eight different casual leisure occupations or cases, the engagement categories generated by which were analysed using the Kruskal-Wallis test (Field, 2009). Because the observation data included multiple occupations or cases, the data were subjected to a one-way Kruskal-Wallis analysis of variance by ranks test (Gibbons & Chakraborti, 2003), and then compared across occupations with median categories being prepared for each leisure occupation to demonstrate the central piece of data (in terms of worth) across the range of data gathered. The Kruskal–Wallis one-way analysis of variance by ranks test compares several occupations when different participants take part in each case (which was not the case in this study) or when the resulting data do not show a normal distribution. It compares more than two samples that are independent, or not related. Since it is a non-parametric method, the Kruskal–Wallis test does not assume a normal distribution, unlike a one-way analysis of variance. However, the test does assume an identically shaped and proportioned distribution for each group, except for any difference in

medians. In this thesis, the null hypothesis was that the participants had the same median engagement category across several cases or casual leisure occupations; therefore, its use was appropriate. When the Kruskal-Wallis test leads to significant results, then engagement in at least one of the leisure occupations would be different from the other occupations. The test does not identify where or how many such differences occur, and not whether or not it occurs. Friedman's Test compares more than two dependent groups of categories (in this instance the effect was the engagement category generated by each casual leisure occupation) (Field, 2009). The Friedman test analyses of variance by ranks for one-way repeated measures such as time series data, and so can go hand in hand with the Kruskal-Wallis one-way analysis of variance by ranks (Field, 2009). The procedure involves ranking each row of data, then considering the values of ranks by columns. In this thesis, it identified whether (if the participants each demonstrate their engagement category in all the different leisure occupations observed), any leisure occupations ranked consistently higher or lower than the others were? It therefore assessed whether there was a significant difference between the engagingness of any of the leisure occupations observed.

Agreement between pilot raters

There might be a need to determine the extent to which the data collected by several different raters or on several different occasions agree (Sims & Wright, 2005). Inter-rater reliability means that the ratings made by two or more different raters agree, whereas intra-rater reliability is the agreement between ratings made by the same rater on several occasions (Sims & Wright, 2005). In response to the first research question, the pilot data pertains to assessment findings, i.e. opinions about whether a discrete behaviour occurs. In response to the second research question, the pilot data pertains to engagement categories, i.e. active or passive, engagement or non-engagement, when collected by several staff watching the same event. The Cohen's kappa coefficient assesses the level of agreement between the raters to determine whether the piloted tool or procedure captures the data required (Sims & Wright, 2005). This is necessary to decide, because if the raters were agreeing by chance, this is not true agreement (Sims & Wright, 2005). The Cohen's kappa coefficient indicates the achieved beyond-chance agreement as a proportion of the possible beyond-chance agreement (Sims & Wright, 2005).

Appendix vii The raw data from the discussion of the usual behaviour of the residents discussed.

	Resident 1	Resident 2	Resident 3	Resident 4	Resident 5	Resident 6	Resident 7	Resident 8	Resident 9
Eye gaze control	"normal"	"normal"	"normal"	"normal"	"normal"	"normal"	"normal"	"normal"	"normal"
Vocalisation	very expressive	very expressive	very expressive	laughs, quite expressive in a silent way	laughs if happy	laughs and makes noises	"normal"	"normal"	not coughing and relaxed
Level of awareness	Minimally Conscious State	aware of surroundings but not cooperative	Minimally Conscious State	very aware	Minimally Conscious State	"normal"	"normal"	"normal"	aware of surroundings
Concentration level	N/A	1:1 with familiar person - quite a while	N/A	"normal"	N/A	"normal"	"normal"	4-5- hours	3-4 hours
Coordination	N/A	"normal"	N/A	N/A	N/A	"normal"	clumsy	only moves head	poor

Eye blinking reflex							"normal"	"normal"	
Eye contact	N/A	"normal"	doesn't make eye contact but looks around	"normal"	"normal"	"normal"	"normal"	"normal"	"normal"
Self control	N/A	"normal"	"normal"	can communicate well so doesn't outburst	expresses self, but not outbursts	"normal"	"normal"	a bit uninhibited	"normal"
signs of anxiety	N/A	shrieking, making noise	quiet, crying		moving head, red in face	looking at staff to get their attention	more clumsy, calls for staff to get their attention	quiet	
Orientation and memory	N/A	needs constant reminders, volitional orientation level	N/A	aware of her routine, STM "normal", able to decide	N/A	"normal"	"normal"	"normal"	

Perseveration	N/A	"normal"	N/A		N/A	"normal"	"normal"		
Mood	flat	happy if not interrupted and left alone	happy	happy	mostly happy	jokes, good sense of humour	"normal"	happy	flat
Muscle tone (floppy/ rigid)	floppy	"normal"	"normal"		rigid	"normal"	"normal"	rigid	has head control/ "normal"
Perceptual ability	N/A	?	N/A		N/A	"normal"	"normal"	?	
Sense of time passing	N/A	?		"normal"	N/A	"normal"	"normal"	"normal"	
Sensitivity to light, sound	usually relaxed and less productive chest	doesn't like touch, very sensitive to light	Sensitive to sound but other senses "normal"	"normal"	"normal"	"normal"	"normal"	"normal"	"normal"
Speed of information processing	N/A	slow	N/A	"normal"	"normal"	"normal"	"normal"	slow	very slow

Tone of voice	N/A	expressive	loud	N/A	"normal"	expressive	very expressive	very expressive	"normal"
Word finding ability	N/A	"normal"	N/A	N/A	N/A	"normal" - uses gesture as well	with difficulty	doesn't speak	?
Understanding written words	N/A	?	N/A	"normal"	N/A	"normal"	"normal"	"normal"	?
Understanding spoken words	family think she can understand , she seems to focus in when people speak to her	"normal"	likes voices but doesn't understand them	"normal"	"normal"	"normal"	"normal"	"normal"	? Basic things

Appendix vii1 - Examples of how participants described the facets that contribute meaning to occupations and the meaning derived from leisure occupations include:

T he facets mentioned by the participants included belonging since humans are a social species and so a sense of being 'part of the group' (Participant 8) could be an important benefit of participating in leisure. Over two thirds of the participants noted an increase in 'team spirit' (Participant 9) and feeling a 'good atmosphere' (Participant 2) Resulting from collaborating in a group leisure project. Participant's who had been professional performers described being able to 'rejoined the performing community' (Participant 1), or reconnecting 'with others in the same profession' (Participant 10) when involved in a drama project. This sense of bond between participants led one to describe the loneliness that results from disability especially when communication or behaviour was affected. Therefore, 'simply being in the company of others', (Participant 11) was a huge step towards a sense of belonging. Social occupations could involve coordination around the lives of others. The rituals, shared language, and sense of humour that could be involved in being part of a group, contributed to shared values, and companionship, and could reflect the social status, beliefs and raison d'être of a group, indicating that leisure in a social context could bring with it an implicit sense of belonging (however short term). Altruism and social status beliefs could also influence feeling part of a group.

This was suggested because occupational-engagement could influence perceptions of health and well-being. Their occupational choices could enable individuals to adapt their performance to cope with altered health, viewing the resumption of meaningful occupations as proof that they were capable and healthy individuals with a sense of well-being. Several participants described their leisure as offering them the opportunity to escape from, and forget the present, thus helping them to feel freer and healthier. Similarly, social and achievement leisure was suggested to support mental health while uninvolving/ passive leisure could be significantly related to negative mental health outcomes, due to a lack of engagement.

Boredom was suggested to result from insufficient complexity or challenge, limited opportunities to engage in occupation, or a mismatch between the challenge of the occupation, and the individual's skill and motivations. So it was no surprise that the participants described leisure opportunities as a way of 'avoiding boredom' (Participant 14) and as offering a 'change from the boredom of everyday existence' (Participant 36). Boredom and being 'bored' (Participant 14, Participant 36) were words that participants used frequently. This

could be due in part, to their perceptions of what to do with their time, e.g. 'I don't do anything apart from listen to music' (Participant 25). This was relevant because Berlyne (1966) suggested that curiosity could result from insufficient stimulation, with learning, attitude change, and social interaction resulting from an optimal amount of novelty, unexpectedness, and complexity. Experience on the other hand, could have resulted from change and consistency, with reduced awareness underpinning boredom. Consequently, under stimulated individuals could seek any kind of stimulation to achieve a balance. On the other hand, stimulation overload or an inability to process the stimulation could lead to boredom, inability to deal with distractions and distress. This could demotivate the individual, diluting meaning and reducing well-being.

However, the ability to express creativity, and to reinforce self-awareness and self-esteem through self-expression, could be linked to concentration and exhilaration. Creativity could also refresh, invigorate, and offer an outlet for self-expression. Self-expression and 'being in touch with my creative side' (Participant 1) was suggested to result from occupations which are overtly creative, but also from those which require memory and association such as 'discussions, puzzle solving, or cultural celebrations' (Participant 1). One participant commented that creativity was 'another innate human need' (Participant 48). The participants appeared to value 'getting the creative juices flowing' (Participant 7), 'presenting a performance' (Participant 7) and 'dramatic expression' (Participant 1). A sense of freedom and enjoyment, leading to growth and legacy building could also have resulted, allowing others to see 'who we really are' (Participant 48). Self-expression, satisfaction, and well-being have been described as the potential rewards of occupational-engagement.

Furthermore, leisure could offer opportunities for experimentation, risk-taking, and challenge. Therefore, un/under occupied individuals could feel socially excluded and demoralised, and use leisure as a coping/ escaping strategy. Occupational-performance was suggested to influence self-identity and well-being through reflection, goal orientation and social approval. Likewise, internalisation of the perceptions of others could influence self-identity. Several of the participants interviewed reported 'feeling valued' (Participant 7), being 'treated like kings and queens for the day' (Participant 7) or made to 'feel important and involved' (Participant 29), because 'being treated as an individual with choices... promotes a sense of self worth' (participant 35). Moreover, restrictions to occupational participation could limit an individual's self and social identity. Additionally, the cultural, religious, or spiritual attributes of an occupation, and the feedback received influence self-esteem, social roles, approval, and values. When describing large seasonal events, several participants describe an opportunity for 'interaction with others' (Participant 41). However, others explained their regret at having 'no intimate relationships' (Participant 31). Fifty two percent of participants reported that the interactive drama project had increased social interaction amongst participants.

Several leisure opportunities were reported as being those which encouraged participants to 'be daring and take risks' (Participant 34) or 'to be daring when I wouldn't have been before' (Participant 1). Several

participants actively welcomed the opportunity to 'push the boat out' (Participant 24) or 'stretch myself' (Participant 18) whereas others 'wouldn't say no to a challenge' (Participant 24). One participant reported that 'I had to use my limbs and memory' (Participant 17), another finding it 'difficult having to learn the story, whilst having to act it' (Participant 2). A younger participant described how 'it was a challenge to remember a bit more about the play' (Participant 18). Berlyne (1966) suggested that boredom could have resulted from a lack of challenge, while Passmore (1998) suggested that it could be experienced significantly more when an individual is engaged in passive leisure or the challenge was perceived to be less than the skills brought to the occupation. Achievement was suggested to result from competition, personal challenge, widening experience, experimentation or risk-taking. Furthermore, occupational-engagement was suggested to result from motivation to participate resulting from challenge; while meaningfulness, challenge, and satisfaction could compensate for occupational imbalance. Challenge was reported to be one of the salient motivating qualities of many leisure experiences, especially those of a more intense nature.

Likewise, leisure could link the individual with a past life, offering a buffer between the impact of negative life events and the reconstruction of a life story that is continuous with the past, while generating optimism and sustaining an ability to cope with present circumstances. The occupation could have 'reminded me of school days' (Participant 4), 'and other links with my past life' (participant 6), enabling participants to remember things 'from the past', setting off 'tangential memories of the past' (Participant 1). Inevitably, memories which provoke links with the past bring up thoughts about how 'life before was happy' (Participant 5) when participating in similar occupations.

A few of the participants were taking piano lessons; however, informal learning also occurred, e.g., I 'learned about others, their sense of humour … their skills' (Participant 3) or 'to be proud of myself' (Participant's 6 & 11). In fact, over half of the participants reported discovering new things about themselves and others. Musical performances were described as 'providing something entertaining and educational' (Participant 1). Learning (embedded in social relations) was suggested to be central to occupational-engagement but not highly valued by others, with self-organisation and self-determination being required to enable participants to aim for self-actualisation.

Furthermore, everyday life waccording to Meyer (1977) to be made up of a rhythm of short and long-term reality check occupations which contributed to a social groups' values and beliefs about time use, influencing perceptions of time passing. This rhythm, whether internal, or social, if balanced around 'actual doing' could result in a sense of well-being. This sense of rhythm could also be derived from engagement in routines and occupations that follow themes and trends across the lifespan, e.g., a play focus in childhood leading to a work focus in adulthood. Seasonal events were suggested to remind participants of their position in relation to the 'passing weeks, months, seasons, or years' (Participant 7). This lets them 'mark the passing of time rather than life passing

us by' (participant 7). Volunteers, performers or facilitators from other communities and organisations could also provide residents 'with the passing of time in the present world outside' (Participant 16), as could the TV and newspapers. Furthermore, the coordination of social occupations could involve an interweaving of the actions, schedules, and goals of participants and could engender a sense of belonging at the same time.

Self selected occupations, could lead to pride in achievement and a sense of well-being. Therefore, a clear sense of individual purpose or goal orientation was suggested to influence occupational-performance and result from reflection about how to achieve or contribute to a goal. Goal achievement could facilitate a positive reflection on accomplishment, or lead to frustration or lack of confidence. Repeated lack of success could motivate persistence, leading to redoubled effort or to withdrawal, depending on whether the effort required was realistic, and on the individual's optimism, resilience, and self-efficacy beliefs. Several participants expressed having 'looked forward to' (Participant 17) being part of the group, or 'liked having something to aim for' (Participant 24). Participants' aspirations ranged from 'I'd like to do another degree' (Participant 25) to wishing to 'go out more' (Participant 26) or to participate in 'more of a range' (Participant 9) of leisure opportunities.

Control and choice of occupations could also influence perceptions of quality of life, act as an intrinsic motivator, and enhance the meaning of an occupation. Leisure, being self-determined and autonomous, could therefore promote curiosity, a sense of control, and adaptation to and coping with life. A synthesis of the meaning and context of an occupation could additionally influence choice making and acceptance of the rules or norms of an occupation. This could in turn influence interest, excitement, and confidence, leading to enhanced performance, persistence, self-esteem, well-being and engagement. In an home, there is a danger that participants experience little choice of location and timing for their occupations if they are organised on a group basis. Opportunities for self-determination could cushion the stress involved in disability. Nearly two thirds of participants felt that they had a choice about whether to attend an interactive drama project. However, another fifth were not sure; describing how 'there was no where else to go' (Participant 11), which limited their perception of the choices available or 'the room was too crowded to leave once we were there' (Participant 13). Others felt 'expected to join in' (Participant 21), or had someone, e.g. a spouse, making 'choices for him in the belief that he would have come anyway' (Participant 12).

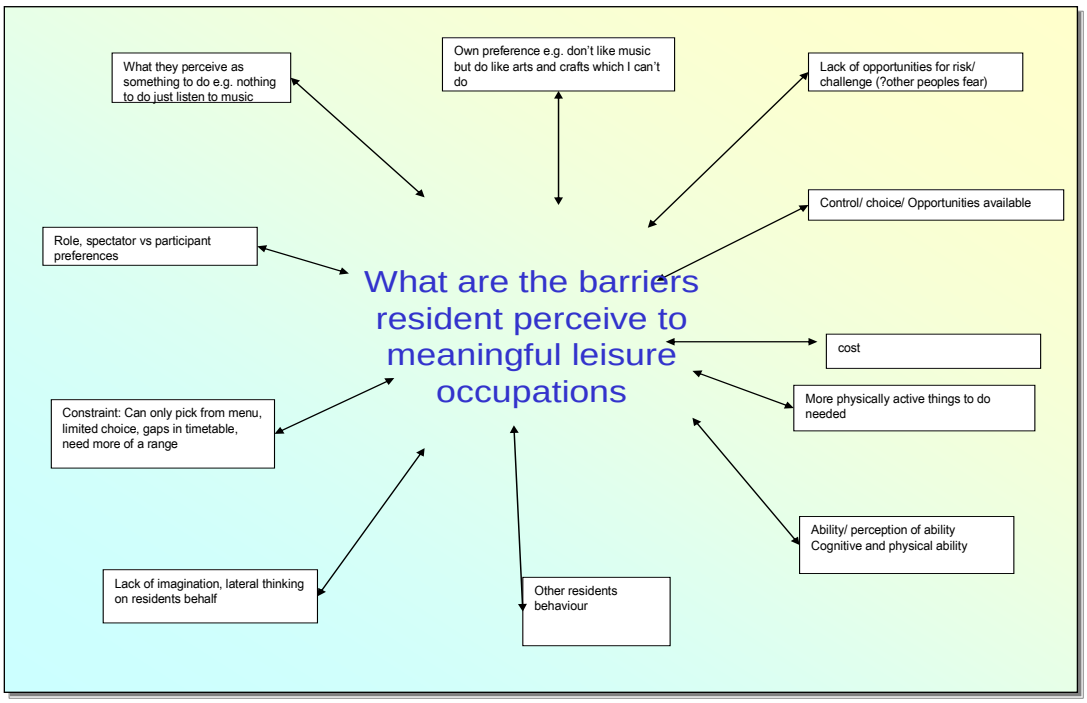
A sense of self-efficacy is an individual's belief in his or her ability to succeed, which could determine how they thought, behaved, and felt; contributing to a sense of self-worth, creativity and self-expression. Successful achievement, whether experienced or witnessed in others, could strengthen the individual's sense of self-efficacy; while a lack of success could undermine and weaken self-efficacy. Individuals were suggested to adapt their occupational participation to cope with altered health and reported the resumption of meaningful occupations to be taken as proof of capability and health. These findings equated doing with living, aiding adjustment to disability or as participants stated, 'It's not the end just because we are in wheel chairs' (Participant 1), and 'this is who I am

- a lady of leisure' (Participant 7). Two pleasantly surprised residents described how they 'hadn't realised that I could act' (Participant 7) and 'don't I look fine in my costume, I got my photo in the newspaper too' (Participant 9).

Furthermore, satisfaction with time use, especially productive and leisure was suggested have a significant influence on adjustment to disability and life satisfaction. This may be because having a satisfying leisure lifestyle could contribute to achieving and maintaining a sense of health and well-being; acknowledgment of social identity, and adjustment to disability. Leisure based social relationships with role models were suggested to influence adjustment to a disability. The reconstruction of a leisure lifestyle could serve as a link between the present and previous identity, and help the process of learning to live with a new self-identity, adjusting to a new self-image and renovating the individual's life story beyond disability. A lack of leisure engagement could have a dramatic effect on the individual's experience of illness, offering insufficient diversion or leaving them vulnerable to stress. Solitary leisure could offer opportunities for self-reflection, problem solving, and relaxation, which could influence identity development and transcend negative life events.

Appendix vii1a Barriers to leisure engagement?

Figure A showing the barriers to participation perceived by residents



Many environmental, physical and psychological barriers influence leisure participation such as transport issues, issues of accessibility, loss of energy and stamina, inadequate finances, physical disability, lack of interest, feelings of uncertainty, fear of falling and a fear of going out at night (Fenech 2008). However, the barriers to leisure participation mentioned by residents in the 3 data sets reviewed include:

Resident's own preference

No two individuals are the same and so individual preferences vary. However, an issue raised by several residents was that music (which can be perceived as almost the ultimate in accessible leisure) can become fairly tarnished. This is especially true when a resident has to listen to music which is not their own choice, or has to listen to "next doors" (Participant 30) music as well as their own, or the programme is felt to be "too music focussed" (Participant 24). Several residents reported a preference for art and craft rather than music but felt prevented from participating by their disability.

Lack of opportunities to take risks or experience challenge

Evidently several residents were frustrated at being “wrapped up in cotton wool” (Participant 30) and wanted to “push the boat out” (Participant 24) in terms of their leisure opportunities. One mentioned missing the “adrenaline rush” (Participant 31) of taking risks, whilst a “lack of challenging activities” (Participant 32) was mentioned by others. An example given by a paraplegic resident was that she would like to “walk beside water” (Participant 24) in her wheelchair, while another expressed a desire to learn Spanish.

What they perceive as something to do

One resident reported that there “is nothing to do, only listen to music” (Participant 25). This links to personal preferences and to the over use of easy to arrange or access leisure occupations e.g. karaoke or watching the television. Residents and family members reported music as being “over used”.

Ability/ perception of ability (*by themselves or others)*

The profound level of disability experienced by the residents limits what they can get involved in, if there is the lack of enablement of leisure occupations to make them accessible. The potential for enablement may be the reason that occupational deprivation is not felt to apply to disability, because in theory Assistive Technology means that any leisure occupation can be accessed by anybody. However, the residents have such a high dependency level that this is not always the case at present. Pain, physical or cognitive impairment, emotional lability and fatigue, or the care of decubitus ulcers can limit the length of time that a resident can tolerate an occupation and their capacity to participate in it leading to the necessity for adapted occupations, assistive technology, and supporter facilitation.

Role preference versus the role offered by the leisure occupation to hand

The residents reported a 41% preference for a spectator role, a 31% preference for a participant role and a 28% preference for whichever role was more appropriate for the occupation.

Table A Demonstrating the Role preference expressed by residents.

	Number of residents	%
Either	9	28
Participant	10	31
spectator	13	41
	32	100

Sense of constraint

Stroke survivors reported 80% deterioration in leisure domains (Bhogal et al 2003). Backman (1991) considered that the main reason for the decision to discontinue an occupation was a perception of constraint. Constraint may link to loss of interest, lack of facilities, unfitness, and physical disability, or lack of time. Discontinuing a previously enjoyed leisure occupation may occur when the skill or abilities required are greater than challenge or if the skill or abilities required is lesser than the challenge.

The mismatch of perceptions of the role to undertake, plus the lack of assistive technology to enable access mentioned earlier and the profound level of disability experienced by the residents may all contribute to the residents' sense of constraint. This may potentially explain a little why the Aquability sessions appear to be more engaging than the other leisure occupations observed; because the buoyancy and weightless ness involved in being in the pool offer residents a sense of freedom, which immediately cease when they return to dry land and a gravitational environment.

Lack of imagination

Different families use free time in different ways and some may be unused to using free time for leisure occupations. This will affect the family's support for the individual's leisure occupations as well as their choice of occupations (as will other family influences such as beliefs, ethnicity, religion etc). Attitudes and levels of commitment to leisure have a major influence prioritising leisure opportunity provision. McLean (2005) demonstrated a lack of interest by individuals in taking part in occupations with were unusual. Women and individuals with a high educational attainment level are least likely to engage in leisure occupations post stroke (Bhogal et al 2003).

The residents reported their own and their leisure supporter's "lack of variety and imagination" (Participant 33). This will have influence the choice of occupation, the range of leisure opportunities available, how the occupation is adapted to make it accessible and whether it is worth experimenting with and participating in.

"Other residents' behaviour"

Participant 9 pointed out that "other residents can be distracting". Challenging behaviour in individuals with cognitive deficits may be signs of unmet need and are particularly likely to occur in periods when the individual is unoccupied or bored (Kolanowski et al 2001). Leisure occupations may therefore reduce such behaviours. However, behavioural difficulties such as aggression, non-compliance, impulsiveness, or disinhibition may make social inclusion difficult because of the safety of others and difficulties with engaging in occupations with others. This behaviour can be "distracting to others" (Participant 34), offensive, "out of context" (Participant 35) or "unpredictable" (Participant 36), which is why the Huntington's disease unit send a staff member with each individual participating in large leisure events away from the residence. An individual's behaviour can sometimes be the most prominent symptom of a neurological disability to the lay observer. The reactions of others to this behaviour can in turn cause more problems than the behaviour itself. In a group of residents who may be at risk of sensory-overload and who are vulnerable adults it is not surprising that the behaviour of other residents affects them. This behaviour may result from the symptomatology of the residents and so requires a higher level of tolerance to modify or accept.

Wanting to do something more physically active

A lack of vestibular stimulation may influence the pleasure derived from a leisure occupation (King 1974), so the residents' intuitive requests for more active leisure pursuits appear to be appropriate. Sports such as Boccia are new to the organisation because until recently the opportunity to experience more physically active leisure has been quite limited.

Perception of value for money

The residents' have a restricted income, but they also have limited expenses since their living costs are covered by the commissions of their care. Outings and other leisure occupations appear to challenge their perceptions of value for money because of the specialist equipment and vehicles required, especially when added to the costs per mile of long distance outings.

Control and choice of opportunities

The resident's own preference, limitation to ability, role perception mismatch, sense of constraint, lack of imagination, lack of opportunity, value for money etc all appear to contribute to a reduced sense of control and choice. Especially when pressures of work mean that staff offer fewer choices than they think that they do (Fenech 2009).

Appendix vii1b Family data

Furthermore, Forty-six family members participated in the leisure satisfaction audit on behalf of individuals with neuropalliative conditions who lacked the mental or consistent communication capacity to participate in the study. The family members reported that leisure occupations took place alone (1 resident/ 2%), with a computer (1 resident/ 2%), with other residents (9 residents/ 20%), volunteers (9 residents/ 20%), staff (23 residents/ 50%), or family members/ family (26 residents/ 57%). Eighteen residents (37%) were reported as being unable therefore not applicable to participate in any way as far as the family knew and 1 resident (2%) who was reported as unable to participate with others, but who participated with their family.

The family members reported that in their opinion 2 (4%) of residents would have preferred to take a participant rather than a spectator role in a leisure occupation. Six (20%) were described as preferring to take a spectator role. One family member (2%) was uncertain as to which role their resident would prefer, while 17 (37%) were reported as preferring either role depending on the occupation. The remaining 17 (37%) did not respond to the question.

Table B showing with whom the residents (who were able to participate) participated in leisure occupations

Alone	Computer	Unable therefore not applicable	Residents	Volunteers	Staff	Family members/ Family	Total of Types of Supporters for Each Resident
Number of residents							
					3		1
						4	1
			1			1	2
		1				1	2
					5	5	2
					1	1	2
			2		2	2	3
1					1	1	3
			1		1	1	3
	1				1	1	3
				4	4	4	3
			5	5	5	5	4
1	1	1	9	9	23	26	Total for each group of facilitators

2%	2%	2%	20%	20%	50%	57%	% of (family reporting) residents

An example of a comment made to illustrate dissatisfaction attributed to free time use was that “she doesn’t access any leisure; her sitting tolerance is only 2-3 hrs”. Another family member reported that she was “not really doing a lot because of her sitting tolerance - leisure opportunities clash with ‘R’s routine as she goes to bed at 2pm” (Participant 37). The factors which contributed to the sense of exclusion reported include being limited by the dimensions or manoeuvrability of the wheelchair (e.g. “chair too large for boat trip” (Participant 47) or “chair not suitable to leave the ward” (Participant 43, Participant 41). Another issue mentioned was “sitting tolerance” (Participant 48, Participant 49, Participant 37), or by timing, because their “condition does not allow him to attend an evening leisure activity” (Participant 46). A repeated theme was that residents described were as being too “unable therefore not applicable to participate” (Participant 50). On the topic of outings, one family member expressed the view that “if she can’t participate then she can’t go” (Participant 51).

The themes, which came from the audit collection of data about relatives and visitor’s dissatisfaction with their relatives’ use of leisure time, were also enlightening. The themes that arose included family members not valuing leisure for their resident through comments such as “Leisure not applicable in this case” (Participant 50, Participant 58, and Participant 62), and “No activities undertaken, no point” (Participant 63).

Appendix vii1c Staff Data

Furthermore, seventy staff responded on behalf of residents who were unable to reliably and consistently express their opinions verbally to a series of questions about their leisure satisfaction, (and did not have a regular family visitor) as part of the leisure satisfaction audit.

When asked what role the resident would prefer to take in a leisure occupation 32 (40%) reported a preference for a spectator role and 6 (7.5%) a preference for a participant role, with 28 (35%) expressing a preference for either role depending on the circumstances.

Table C showing which would be the residents preferred role in a leisure occupation (Spectator or Participant)

Spectator		Participant	
either	28	either	28
spectator	32	Participant	6
uncertain	1	uncertain	1
no response/ doesn't	19	no response/ doesn't	45
total	80	total	80

Staff were also asked about the residents overall satisfaction with their use of free time. Fifteen percent (12) were uncertain, 35% (28) thought that their residents were satisfied sometimes, 26% (21) thought that their residents were dissatisfied, and 22% (18) thought that their residents were satisfied. The reasons given for dissatisfaction included health related factors such as an inability to participate as they would wish reinforcing their current situation, limited accessible leisure opportunities, being limited by their own or others behaviour, requiring a high level of care, and sleeping all the time. Twenty six percent (23) of residents reported that their residents could be feeling excluded from leisure occupations, with 25% (20) being reported as not feeling excluded. The largest group (30 or 37.5%) were those represented by staff that were uncertain whether they felt excluded. The reasons given for feeling excluded included comments such as "her strict xxx faith (her husband is strict about what she can and can't do therefore no shows)" (Participant 70). More frequent reasons included "behaviour" (Participant 72), "church won't allow her in because she swears" (Participant 91), or "can't communicate therefore gets agitated in crowds" (Participant 92), "likes to go to pub but can't because of sitting tolerance" (Participant 49). Unfortunately, one resident enjoyed outings, "but choreaform movements make eating dangerous" (Participant 86). While another experienced "limitations in communication" (Participant 81) or a "husband doesn't see the point" (Participant 90).

Table D shows that residents experience a range of different leisure partners. Several participate with volunteers, staff, family and other residents whereas others only have contact with staff or staff and family.

Table D showing with whom the residents who were able to participate in leisure occupations did so

not applicable	Residents	Volunteers	Staff	Family members/ Family	Total of Types of Supporters for Each Resident
Number of residents					
13					0
			24		1
				3	1
			27	27	2
	3		3		2
	1			1	2
	4		4	4	3
		4	4	4	3
	1	1	1	1	4
13	9	5	63	40	Total for each group of facilitators
16%	11%	6%	77%	50%	% of (family reporting) residents

The 27 staff that completed a self-reported questionnaire following the interactive drama project answered a mix of open-ended questions and closed questions with a Likert scale of responses e.g.

Yes Neutral No

2 1 0 -1 -2

The questions sought to reveal whether staff had learned anything about the resident's or were acting/ feeling differently because of the project. Additionally, staff members reflected upon changes that they had noticed in the residents, including social interaction levels, mood, and confidence. They were asked about the interactive drama project's influence staff resident relationships and the importance and meaning of such occupations being facilitated for residents. Staff comments about their learning included:

"Some of the residents really came out of themselves during the project" (Participant 29). "Terence and Grace (character visitors) adapted themselves amazingly to fit in with the tastes and characters of the individual residents" (Participant 29).

"I learned what a bit of stimulation can do - individual interaction can create some sort of response from them which was great" (participant 20).

Table E showing responses to the question "Did you learn anything new about residents?"

Number of staff who responded	% of total responses	Staff response
4	15%	-2
4	15%	0
3	11%	1
11	41%	2
5	19%	no response

This may influence staff – resident relationships in the future. However a week after the performances only 6.5% (2) of residents had noticed a positive change in how staff had been treating them following taking a role in the performances. Whereas 44% (15) of staff felt that the performances had improved staff – resident relationships. Sixty one percent (19) of residents reported staff acting just the same towards them, while 22% (6) of staff felt that relationships remained the same throughout the project.

Nineteen (70%) felt that their residents had enjoyed the performances very much, 3 (11%) felt that there residents had gained some enjoyment from them and 2 (7%) were unsure about this. One staff member reported, "I think the resident's thoroughly enjoyed the project. I know they were really sad that it was only 3 weeks and continue to comment on it, even now is over" Thirty three percent (9) of staff had not noticed any alteration in resident's self-esteem while 44% (12) of staff did, 18% (5) noticing reduced self-esteem and 26% (7) noticing increased self-esteem). Thirty percent (8) reported their residents being much less stressed during the project while 10 (37%) reported their residents to be less stressed. Nineteen percent (5) were unsure about this. Fifteen percent (4) felt that there was a definite change of atmosphere on the residence for the positive, 7 (26%) felt that the atmosphere had changed a little while 6 (22%) were unsure about this.

Twenty seven percent (7) had noticed residents displaying an altered self-esteem because of the project. Staff comments included:

"Residents smiling and enjoying actual sessions" (Participant 97)

"One of my residents was thrilled to be cast as Juliet for one session. She told all her relatives who came to visit, demonstrating definite improved self-esteem" (Participant 29)

"They all seemed to enjoy and express themselves appropriately" (Participant 98)

Forty four percent (12) of staff felt that the project had had a positive effect on staff resident relationship (with 33% (9) reporting a very strong impact). Twenty two percent (6) were unsure as to whether there had been

any impact while 11% (3) felt that it had had a negative effect on relationships (in 7% (2) of cases a very negative effect). This latter comment was from a residence where staff had struggled to get residents up and dressed for morning performances, which had been less than evenly shared out between the residences. Twenty nine percent (7) of staff reported no increase in social interaction amongst residents during the project, 30% (8) were unsure while 6 (22%) reported an increase and in 2 (7%) of cases a definite increase in social interaction. Fifty seven percent (15) of staff had offered the residents control over whether to attend the interactive drama project.

Appendix vii1d Recreation Link Nurse Data

The Recreation Link Nurses were asked to rank the facets that contributed to meaning, highlighted in the literature of occupational science. Data collection using questionnaires from individuals would allow participants to respond in their own right or represent a residence wide view and may be appropriate where time is limited (Robson 2002), was proposed. Whilst it could have been more appropriate to gather this information using qualitative interviews, the Director of Clinical Services had stipulated that a methodology be used which removed them from their caring duties as little as possible. Therefore, the Recreation Link Nurses from each of the five main long-term care residences and the Huntington's Disease Unit were asked to prioritise the meanings of leisure occupational participation, in isolation during their regular monthly meeting (thus removing them from their duties no more than usual). The 90 data points were gathered from staff who represented each residence. It was felt that supporters who could perceive what demands an activity has and who were conscious of their own facilitation abilities, may be more aware of how meaningful an occupation can be. Conversely, this consciousness could also have resulted in a resident being acutely aware of the lack of meaningfulness an occupation can have for them. Following a quantitative analysis of the data, this information was to form part of the introduction for a resource pack to guide facilitators about what to incorporate into a leisure occupation and encourage a balanced leisure lifestyle.

Table F Collated data collected from the Recreation Link Nurses about their perception of the relative priority of the facets which contribute to the meaning of occupations when attributed to resident own leisure in order of priority

	Very important	Moderately important	Necessary	Moderately Unimportant	Totally irrelevant
A sense of importance, purpose or meaning	6 (100%)	0	0	0	0
Being fully human	5 (83%)	1 (17%)	0	0	0
Belonging	4 (67%)	2 (33%)	0	0	0
Preventing boredom	4 (67%)	2 (33%)	0	0	0
Accomplishment /Achievement	4 (67%)	1 (17%)	0	0	0
Self-expression/ Creativity	3 (50%)	3 (50%)	0	0	0
A sense of health and capability	3 (50%)	3 (50%)	0	0	0
A clear sense of the rhythm of life	3 (50%)	2 (33%)	1 (17%)	0	0
Self-identity (individual/social)	2 (33%)	3 (50%)	1 (17%)	0	0
Engagement in the occupation	2 (33%)	3 (50%)	0	1 (17%)	0
Control and Choice of occupation	2 (33%)	2 (33%)	2 (33%)	0	0

Goal Orientation	1 (17%)	1 (17%)	4 (67%)	0	0
Individual growth and life satisfaction	1 (17%)	0	3 (50%)	2 (33%)	0
Age/ cultural/ historical/ gender identity	0	1 (17%)	2 (33%)	2 (33%)	0
Occupational environment which is conducive to engagement	0	0	3 (50%)	3 (50%)	0

The Recreation Link Nurses reported that a sense of importance, purpose, or meaning could have been very important by 6 participants (100%). Being fully human was also perceived to be very important by 5 participants (83%) and moderately important by 1 participant (17%). Belonging was perceived to be very important by 4 participants (67%), moderately important by 2 participants (33%). Preventing boredom was professed to be very important by 4 participants (67%), moderately important by 2 participants (33%). Accomplishment /achievement seemed to be very important to 4 participants (67%) and moderately important to 1 participant (17%). Self-expression/ Creativity were perceived to be very important by 3 participants (50%) and moderately important by 3 participants (50%). A sense of health and capability appeared to be very important to 3 participants (50%), and moderately important to 3 participants (50%). A clear sense of the rhythm of life was perceived to be very important by 3 participants (50%), moderately important by 2 participants (33%), and necessary by 1 participants (17%).

Self-identity (individual/social) appeared to be very important to 2 participants (33%), moderately important to 3 participants (50%), and necessary to 1 participants (17%). Engagement in the occupation was perceived to be very important by 2 participants (33%), moderately important by 3 participants (50%), and moderately unimportant by 1participant (17%). Control and choice of occupation/ self-determination was perceived to be very important by 2 participants (33%), moderately important by 2 participants (33%), and necessary by 2 participants (33%). Goal orientation appeared to be very important to 1 participant (17%), moderately important to 1 participant (17%), and necessary to 4 participants (67%). Individual growth and life satisfaction were perceived to be very important by 1 participant (17%), necessary by 3 participants (50%), and moderately unimportant by 2 participant (33%). Age/ cultural/ historical/ gender identity were perceived to be moderately important by 1 participant (17%), necessary by 2 participants (33%), and moderately unimportant by 3 participant (50%). Consideration of the occupational environment was perceived to be necessary by 3 participants (50%) and moderately unimportant by 2 participants (33%).

It was considered by the Recreation Link Nurse forum that facts such as, cultural (rules, customs, and traditions) / historical attributes, the environment in which the occupation may be carried out, social interaction, participant growth and life satisfaction and Goal orientation were the least important facets which make up a leisure occupation. This highlights a variance between the perceptions of staff members who deal with the day-to-day leisure decisions of the participants and the Occupational Scientists. This discrepancy could have been due to a lack of understanding of the social and holistic needs of residents. Alternatively, objectives and priorities, associated with basic healthcare, could have been a more prominent focus for the staff.

The Recreation Link Nurses prioritisation of the facets that make a leisure occupation meaningful was at variance with the literature of occupational science in the area of reinforcing the individual's cultural & historical background, the environment in which the occupation occurs, opportunities for social interaction, or resident growth, life satisfaction or goal orientation. However, they reported valuing the sense of health and capability, the sense of importance, purpose or meaning, the feeling of being fully human and the sense of belonging that comes about through leisure. They also valued preventing boredom, opportunities for self-expression, creativity, achievement, and control. Additionally they valued opportunities to gain a clear sense of the rhythm of life, of self-identity, choice of occupation and engagement in the occupation. These finding should however, be treated with caution because the study involved a small sample which was biased towards healthcare assistants, so that procedural rather than evidence based and critically reflective practice could have been evident. Consequently, it could be that qualified staff could have valued leisure more. This staff group could have been expected to be biased towards leisure since these staff all had a role, which involved a particular focus on leisure enablement. Furthermore, the study used the terminology of occupational science with a sample group who were not occupational scientists.

Appendix viii A copy of the Residence Manager consent form and participant information sheet

Service Evaluation Participant Consent Form

Tuesday, 12 February 2008

Royal Hospital for Neuro-disability

West Hill

London

SW15 3SW

Title of study:

Investigation of engagement in 6 different casual leisure occupations with varying levels of sensory content with individuals with neuropalliative conditions, in long term residential care

Investigator:

Anne Fenech **International Fellow in Recreation and Leisure Activities, Royal Hospital for Neuro-disability, West Hill, London SW15 3SW.**

Purpose of study:

This service evaluation aims identify the signs of sensory overload demonstrated by residents of the Royal Hospital for Neuro-disability, and to prioritise the meanings of leisure highlighted in the literature.

Methods:

I understand that I will be to interviewed to gain my opinions of what signs residents of the Royal Hospital for Neuro-Disability demonstrate when they are experiencing sensory overload and what priority staff place on the meanings of leisure occupations discussed in the peer reviewed literature.

Contact for queries: Anne Fenech

International Fellow in Recreational and Leisure Activities

Royal Hospital for Neuro-disability

West Hill London SW15 3SW

Telephone: 020 8780 4500 x 5140

Email: afenech@rhn.org.uk

THIS COPY IS FOR THE SERVICE EVALUATION PARTICIPANT TO KEEP

SERVICE EVALUATION PARTICIPANT'S CONSENT FORM

Tuesday, 12 February 2008

Royal Hospital for Neuro-disability, West Hill, Putney, London SW15 3SW

Study Title: Investigation of engagement in 6 different casual leisure occupations with varying levels of sensory content with individuals with neuropalliative conditions, in long term residential care

Investigators:

Anne Fenech International Fellow in Recreation and Leisure Activities, Royal Hospital for Neuro-disability, West Hill, London SW15 3SW.

Have you read the Information sheet about this service evaluation project??
Yes No

Have you had the opportunity to ask questions and discuss this service evaluation project?
Yes No

Do you know how long your part in the service evaluation project will take?
Yes No

Have you received enough information about the service evaluation project?
Yes No

Who have you spoken to? (write name)..... Anne Fenech

Do you understand that you are free to withdraw from the study: at any time; without having to give a reason?
Yes No

Do you understand that the information obtained will be kept confidentially?
Yes No

Do you agree to take part in this study?
Yes No

NAME OF SERVICE EVALUATION PARTICIPANT: .....
Signed [redacted] Date: ..... 14/2/08 .....

If service evaluation participant is unable to write, signed on their behalf by: .....
Signed:..... Date: .....

WITNESS: .....
Signed:..... Date: .....

Appendix ix The data collection format used to interview the Residence Manager

How do you identify when a resident is experiencing sensory-overload.

For each of your residents:

What is the resident's behaviour usual resting behaviour?

What is xxxxxxx normal ability to **control his eye movements**	
What is xxxxxxx normal ability to **vocalise or make noises**	
What is xxxxxxx normal level of **awareness**	
What is xxxxxxx normal level of **concentration**	
what is xxxxxxx normal **coordination** like	
What is xxxxxxx normal **eye blinking reflex** like	
What is xxxxxxx normal **eye contact** like	
What is xxxxxxx normal level of **self control**	
What is are the signs that xxxxxx is getting anxious	
What is xxxxxxx normal level of **orientation and memory** like	
What is xxxxxxx normal level of **repetition**	
What is xxxxxxx normal **mood**	
What is xxxxxxx normal **muscle tone** like (floppy/ rigid)	
What is xxxxxxx normal **perceptual ability**	
What is xxxxxxx normal **sense of time** like	
What is xxxxxxx normal **sensitivity to light, sound** like	
What is xxxxxxx normal **information processing** like	
What is xxxxxxx normal **tone of voice** like	
What is xxxxxxx normal **word finding ability** like	
What is xxxxxxx normal level of **understanding written words**	
What is xxxxxxx normal level of **understanding spoken words**	

How do you know when a resident is overloaded? Do they exhibit any signs of:

Altered ability to **direct gaze/ visual acuity** compared to usual	
Altered ability to **vocalise** compared to usual	
Altered **awareness** compared to usual	
Altered **concentration** compared to usual	
Altered **coordination** compared to usual	
Altered **eye blinking reflex** compared to usual	
Altered **eye contact** compared to usual	
Altered **self control** compared to usual	
Altered level of **anxiety** compared to usual	
Altered level of **orientation and memory** compared to usual	
Altered level of **repetition** compared to usual	
Altered **mood** compared to usual	
Altered **muscle tone** compared to usual	
Altered **perceptual ability** compared to usual	
Altered **sense of time** compared to usual	
Altered **sensitivity to light, sound** compared to usual	
Altered **information processing** compared to usual	
Altered **tone of voice** compared to usual e.g. Voice becomes monotone	
Altered **word finding ability** compared to usual	
Altered level of **understanding written words**	
Altered level of **understanding spoken words**	

How long does it take for him to recover?

Appendix x Ethical approval for the study was granted by the University of Roehampton School of Human and Life Sciences Ethics Committee

Roehampton University
London

SCHOOL OF HUMAN & LIFE SCIENCES
Roehampton University
Whitelands College
Holybourne Avenue
London SW15 4JD
Professor Claus Vögele
Tel: +44 (0)20-8392 3510
e-mail: c.vogele@roehampton.ac.uk

MEMORANDUM

TO: Anne Fenech
CC: Dr. John Rae

FROM: Prof. Claus Vögele

DATE: 12th February 2008

SUBJECT: Ethics Application (Ref: PSY 07/008)

I am pleased to advise you that the School Ethics Committee has made the following decision with regard to the Ethics Application for your project entitled:

" Investigation of engagement in 6 different casual leisure occupations with varying levels of sensory content with people with complex neurological disabilities, in long term residential care "

1: Approved ☐

2: Approved with Minor Conditions/ Revisions ☑

3: Approved with Major Conditions/ Revisions ☐

Please note that approval is given pending ratification by the University Ethics Board who will contact you directly by email regarding their decision.

4: Rejected ☐

Conditions/ Revisions:
1) Only participants who can give expressed consent (and not implied) will take part in the study.

The Chairs of the School Ethics Committee (Prof. Claus Vögele) or of your Subject Area Ethics Working Group (Dr. John Rae) will be happy to provide any further feedback to you.

Please could you confirm with the chair of your Subject Area Ethics Working Group once you have successfully met any conditions imposed either by the School Ethics Committee or the University Ethics Board.

With very best wishes for a successful project,

Appendix xi Approval to collect marginal-participant observations of engagement data from the Director of the Institute of Neuropalliative Rehabilitation

Memo

To: Anne Fenech International Fellow in Recreation and Leisure

From: Prof Keith Andrews Director of the Institute of Neuropalliative Rehabilitation

Date: 26th June 2007

Re: Marginal participant observations of engagement

I am happy to consent to gathering data via marginal participant observation. Data should be collected during leisure opportunities offered to residents of the Royal Hospital for Neuro-disability.

This data will be gathered for service evaluation purposes and for use in your PhD which proposes to continue this theme.

Appendix xi Approval for data collection, (provided that specific restrictions were in place to protect the vulnerable adults who were the participant population) from the Director of Clinical Services

In a message dated 03/12/2007 14:18:37 GMT Standard Time, ylewis@rhn.org.uk Re: Service Evaluation writes:

I am happy for you to proceed in principal with the observations, staff interviews and meta analysis on the basis that we discussed i.e. that it is a leisure satisfaction evaluation.

Thanks

Yvonne

Yvonne C Lewis
Director of Clinical Services
Royal Hospital for Neuro-disability
West Hill, Putney
London, SW15 3SW

Tel: 020 8780 4552
Email: ylewis@rhn.org.uk
www.rhn.org.uk

Appendix xii The raw data from the discussion of the signs of sensory-overload exhibited

	Resident 1	Resident 2	Resident 3	Resident 4	Resident 5	Resident 6	Resident 7	Resident 8	Resident 9
Altered yye gaze control	less	less	less	less	less	less	less	less	less
Altered vocalisation	less	less	less	less	less	less	less	same	less
Altered level of awareness	less	less	less	less	less	less	less	?	less
Altered concentration level	N/A			less		same	less	less	less
Altered coordination	N/A			N/A		less	less	less	
Altered eye blinking reflex	no eye blink								
Altered eye contact	less	same	less	less	less	less	less	same	less
Altered self control	N/A		less		same	same	less	same	

Altered signs of anxiety	N/A		more anxious	more anxious	more anxious	withdraws, more passive	withdraws, more passive	more anxious	
Altered orientation and memory	N/A		N/A	less	N/A	less	same	same	less
Altered perseveration	N/A	more	N/A		N/A	same	same	same	
Altered mood		less happy	withdraws	flat	same	withdraws	less happy	same	less happy
Altered muscle tone (floppy/ rigid)	lower tone	lower tone		lower tone	higher tone	lower tone	lower tone	lower tone	higher tone
Altered perceptual ability	N/A		N/A		N/A	less	same	less	
Altered sense of time passing	N/A			less	N/A	less	same	less	

Altered sensitivity to light, sound	more productive chest	more sensitive to light,, doesn't use Snoezelen , doesn't like it	more sensitive to light,, snoezelen too much after 15/20 minutes	more sensitive to light, likes dimness	same	more sensitive to light,, refuses snoezelen	more sensitive to light, likes dimness	more sensitive to light	more sensitive to light
Altered speed of information processing	N/A	less	N/A	less	same	less	less	less	less
Altered tone of voice	N/A	more monotone	more monotone	N/A	more monotone	more monotone	more monotone	more monotone	more monotone
Altered word finding ability	N/A			N/A	N/A		less	N/A	

Altered understanding written words	N/A			?	N/A	less	?	?	
Altered understanding spoken words	less able	less able	less able	less able	less able	less able	?	?	less
Recovery time	4-5 hours	3-4 hours	unpredictable 29 min - 1 hour	½ day - 3 hours	2 - 3 hours	1 - 2 hours	3 hours	at once	3 hours

Appendix xiii Activity analysis of each occupation based on the Hersch et al., (2005) format

Areas of occupational performance	
A. Analysis of the group's occupational capacity for ADL	ADL such as bathing, showering, bowel and bladder management, dressing, eating, personal hygiene and grooming, and sleep/rest all enable, prepare for and facilitate the resident's engagement in leisure occupations. They are occupations for which the residents required support from staff, because they were too complex to conduct unassisted.
B. Analysis of the group's occupational capacity for IADL	Care staff made every effort to support the residents in their maintenance of relationships and roles with friends, pets and family. However, the residents' high dependency levels meant that they did not usually engage in the physical care of others. However, non-disturbance of other residents could count as caring, and this was relevant in several of the occupations observed. Financial management, to afford any transport costs, materials, entry tickets or equipment, was usually the responsibility of the residents' carers. However, none of the occupations observed involved any financial commitment on behalf of the residents, other than acquiring a swimming costume. This was an important consideration, which could have skewed the sample towards those with fewer choices and less financial resources available. To have energy left for meaningful and purposeful leisure occupations, energy conservation, involved staff carrying out all health management and maintenance for the residents. The home provided necessary items such as food and furniture; therefore, the residents could perceive shopping and home management as leisure occupations. The home also encouraged residents to personalise and "own" their own room. However, meal preparation and tidying up enabled staff to prepare for and facilitate the residents' engagement in other occupations.
C. Analysis of the group's occupational capacity for undertaking Education	Educational participation and exploration of learning needs or interests could form part of an occupation, and lead to expanded knowledge and experience. This formal or informal process could involve learning about themselves and others, or about the topic and was reliant on communication and cognitive abilities.
D. Analysis of the group's occupational capacity for Work/Productivity	Overall, individuals with such high dependency needs tend to engage in productive occupations such as arts and crafts as leisure occupations, since paid employment opportunities are not available to them. Enjoyment, diversion, and the topic of the occupation could have contributed to their interest and performance, and subsequently to an improved adjustment to their disability.
E. Analysis of the group's occupational capacity for Play/Leisure	A leisure occupation of significance to the individual could engender the motivation to pursue the interest further, whilst it is also enjoyable in the short term.
F. Analysis of the group's occupational capacity for Social Participation	Most of the occupations observed (apart from the isolated listening and the Aquability session) were group events. They could offer topics for discussion with supporters during and after the event.

Control condition

Brief description of the occupation observed	Residents were seated in the dayroom awaiting the arrival of the live performer and the beginning of the performance. They were seated in a room with dimmed lighting and no TV or radio on. During these times residents are not engaged in any meaningful occupation, and in this context are waiting for the afternoons events to start.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	

smell	The control condition was provided in the day room of one of the upstairs wards. This was a modern room with four walls and windows on one side. Because lunch had been served in the dining room there was no all pervading smell of food in the day room. Because the day room was on a residence rather than a ward there were few clinical smells, and none, which were unusual on this occasion.
hearing	During the control condition, the nursing staff were engaged in their handover meeting between shifts and the non nursing staff were generally not present on the residence because they had joined the nursing handover, or were aware that this was generally the period immediately after a meal and therefore used for postprandial **nap**s. Consequently, there were no staff about, and visiting time had not yet commenced. Therefore, the atmosphere was a quiet one. However, for some residents with very good hearing the occasional accidental noise could have been heard e.g. something falling to the floor or traffic being very noisy on the street outside e.g. a fire engine.
taste	The participants had not been given any food or drink since leaving the dining room and so apart from regurgitation would not have been experiencing any tastes at this time.
touch	Each resident was sitting in their own chair and as part of the control condition had been placed father apart than usual so that they could not touch each other. They would have been able to feel their chair and their clothing however the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990)
seeing	The curtains were closed and so because it was a bright sunny day the ambient lighting was gloomy but not completely dark.
proprioceptive vestibular	Most residents remained passive and still during the control condition and therefore would not have experienced much if any proprioceptive or vestibular stimulation.
Critical commentary of sensory attributes	This case was offered in a large day room in the early afternoon and before a live performance was due to start. There were no staff passing along the corridor outside the room because the nursing handover was in process and so all staff even non nursing staff were attending that. The curtains were closed and the television had not been switched on. As many residents take a nap when not actively engaged there were no background sounds of music or radio's playing from other rooms. The dayroom was on the first floor and this was not the top floor so there were no sounds from birds in the garden or dogs in the street. The only person present other than the residents was the researcher who was purposefully moving very slowly and quietly so as not to disturb the residents. None of the residents were moving, many could not move or eat and drink without assistance and this was not available. Lunch had been cleared away and so there were no aromas which were novel or unusual to attract the resident attention. There was the potential for a hospital kind of smell that could include the aroma of air fresheners, incontinence and hibiscrub but this was not unusual and so was discounted because smell is a sense which quickly habituates or fades unless repeatedly stimulated. Due to the fear of aspiration no residents were left with food or drink when unsupervised so were not experiencing a sense of taste. Any sense of touch would come from the chair that they were sitting in and their clothes touching them however again touch is a sense which is screened out quite quickly unless it is irritating or has been recently renewed. Occasionally a resident would move their head to look around if they were able and this would offer some vestibular stimulation however most resident's chairs included head rests which they tended to allow to take the weight of their heads. Proprioceptive stimulation was limited by the resident's limited ability to move unaided. The room was not in total darkness and so residents with good eye sight could have been able to peer through the gloom, to look about them or to make out shapes.
minimum number of senses affected	**0**
maximum number of senses affected	**2**

Occupation Summary	
Performance attributes	None
Precautions and contraindications	None
Special Considerations	Even when doing nothing the residents are monitored for fitting, choking, or respiratory distress.
Occupational demands: Physical	None
Occupational demands: Communication	None
Occupational demands: Behavioural	None
Occupational demands: Social	None
Occupational demands: Cognitive	None
Resources required: Tools, materials, equipment	None
Space Demands (size, arrangement, surface, lighting, temperature, noise, humidity, ventilation)	The residents were seated in the day room of one of the residences.
Occupational (motor and processing) skills required	None
Occupational-performance patterns and contexts	This "waiting mode" is one which in the researcher's experience is experienced regularly by residents. It is a state of total occupational preclusion which occurs when other residents are being attended to.

Listening to audio books/radio/recorded music

Brief description of the occupation observed	Listening to an audio book or radio programme or recorded music of choice as the primary occupation (rather than one embedded in another occupation). This is perceived by many staff to be an accessible occupation for the most severely disabled residents; however it is one which several have reported to the researcher as being a victim of its own success and over used.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	The domestic staff placed great emphasis on reducing rather than masking smells. Some residents could have had pot pourri or odour neutralisers in their rooms but these had of necessity to be fairly mild because of the risk of fitting and choking, which is a constant risk with this clinical group.
hearing	The listening occupation happened behind the closed doors of each participants own room. These were designed to reduce noise interference from other residents' rooms. Furthermore, notices were hung from the door when the occupation was in progress, asking passers by, to do so quietly. However, for some residents with very good hearing the occasional accidental noise could have been heard e.g. something falling to the floor or traffic being very noisy on the street outside e.g. a fire engine. Consequently, the only noise was the recording being listened to. This was played at a comfortable level for the participants but with an understanding of not sharing the noise with others in adjacent rooms and corridors.
taste	The participants were not actively given any food or drink during the occupation and so apart from regurgitation would not have been experiencing any tastes at this time.

touch	Each resident was sitting in their own chair or lying on their own bed and as part of the listening occupation. They would have been able to feel their furniture and their clothing however the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990)
seeing	The film was shown in a large public room which had been laid out like a cinema, with a screen at one end and the residents sitting in a row facing the screen. This was a large Edwardian Assembly room with four walls and windows down one side. The blackout curtains were closedto reduce visual distractions therefore the room was really quite dark once the lights were turned out which drew attention to the film showing in the screen.
proprioceptive vestibular	Most residents remained passive and still during the listening case and therefore would not have experienced much if any proprioceptive or vestibular stimulation.
Critical commentary of sensory attributes	This case was offered in the residents own room with the curtains drawn, and doors closed to reduce the light and any background voices, sounds from birds in the garden or dogs in the street, or of music or radio's playing from other rooms or movement. There were no staff passing along the corridor outside the room because the nursing handover was in process and so all staff even non nursing staff were attending that. There was a do not disturb notice on the residents room door. The only person present other than the residents was the researcher who was purposefully moving very slowly and quietly so as not to disturb the residents. The resident was sitting or laying as they had chosen either in a chair or on their bed, depending upon their pressure care regime. The residents were encouraged to relax and be still to reduce the stimulation, many could not move or eat and drink without assistance. Any remaining food was cleared away quickly whenever it was no longer required to reduce the lingering aromas which could result, and so there were no aromas which were novel or unusual to attract the resident attention. There was the potential for a hospital kind of smell that could include the aroma of air fresheners, incontinence and hibiscrub but this was not unusual and so was discounted because smell is a sense which quickly habituates or fades unless repeatedly stimulated. Due to the fear of aspiration no residents were left with food or drink when unsupervised, and in this instance, were not offered a drink during the observation unless they specifically requested it and were allowed one, and so were not experiencing a sense of taste. Any sense of touch would come from the chair/ bed that they were sitting in and their clothes touching them however again touch is a sense which is screened out quite quickly unless it is irritating or has been recently renewed. Occasionally a resident would move their head to look around if they were able and this would offer some vestibular stimulation however most resident's chairs included head rests which they tended to allow to take the weight of their heads. Proprioceptive stimulation was limited by the resident's limited ability to move unaided. The room was not in total darkness and so residents with good eye sight could have been able to peer through the gloom, to look about them or to make out shapes. The only sound that could be heard once the observation had started was that of the recording. In some cases this was a reading from a holy text (1x bible, 1x Qu'ran), an audio book (3), music (6) or a radio programme (3).
minimum number of senses affected	**1**
maximum number of senses affected	**2**
Occupation Summary	
Performance attributes	• Turn on/ off and tune audio equipment • Place tape/ CD in machine • Check volume and clarity • Listen and concentrate to follow the programme
Precautions and contraindications	The volume should be loud enough to hear but not loud enough to interfere with other residents or be uncomfortable for the resident. Other residents' noise should not block out the sound of the programme to be listened to; however, their noise should not impede on the occupation being observed either.

	Listening material should be selected by the resident.
Special Considerations	Special Considerations include age appropriateness, cultural relevance, gender identification, personal interests and preferences as to listening material.
Occupational demands: Physical	Controlling / setting up the audio equipment (can be achieved by others on behalf of the resident in the context of complex disability.
Occupational demands: Communication	Agreement/ request to listen, selection of programme/ topic, communication with staff facilitating the occupation.
Occupational demands: Behavioural	Sitting or laying still, concentrating on the programme without disturbing others.
Occupational demands: Social	Discussing the programme with others during or after listening to audio books, recorded music or the radio, being somewhat isolated to facilitate concentration, can be listened to alone or in a group
Occupational demands: Cognitive	Concentration, attending to, understanding and following the programme, visualising the context of the programme
Resources required: Tools, materials, equipment	Facilitatory staff, audio equipment, tape/ CD etc
Space Demands (size, arrangement, surface, lighting, temperature, noise, humidity, ventilation)	Somewhere quiet, near enough to the audio equipment to hear it, dimmed lighting to reduce visual stimulation/ distractions comfortable temperature, seating to keep alert and able to concentrate

Occupational (motor and processing) skills required

A stable, aligned supported posture is required to maintain a sitting position. Self propelling or controlling an electric wheelchair requires coordination to avoid collisions as well as using the controls. It also requires strength, effort and stamina to move limbs or use the controls as well as the demands of listening to audio books, recorded music or the radio itself.
Listening to a recording could require the control of recording equipment or radio, however this can be provided by nearby staff if necessary.
Sufficient attention is needed to maintain concentration throughout listening to audio books, recorded music or the radio. The resident's knowledge could be enhanced through his choices, and how he uses tools and materials or discusses listening to audio books, recorded music or the radio with others.
Communication will be required if the resident needs assistance or wishes to discuss listening to audio books, recorded music or the radio. However it is usually required to comply with social norms and not interfere with listening to audio books, recorded music or the radio experience of other residents.

Occupational-performance patterns and contexts

The listening occupation could be conducted against a background of habits, routines and roles. The residents' role during the listening occupation will be that of a physically passive absorber of sound which is then processed to understand. During the listening occupation the resident could be attempting to link interests and roles e.g. understanding something said to them by a relative on an previous occasion, or continuing an interest in classical music which was enjoyed in the past.
The resident's could listen routinely to a radio programme each week or be continuing to listen to a further chapter of a book and so what they hear will continue from the past and be a stepping stone into the future.
Their listening habit could be to orientate themselves and link with the outside world by listening to current affaires of news programmes.
Each resident listening will vary in their personal, cultural, spiritual, clinical context. However the recording/

programme chosen should be as appropriate as possible to each individual. Some residents need to be reminded that the recording/ programme is fiction and not their own reality at times.

Watching a film show

Brief description of the occupation observed	On a Wednesday afternoon at the home the residents have the opportunity to watch a filmshow in the assembly room. The room is laid out rather like a theatre with a large screen at one end which show the film projected from behind it. Residents are given the choice to choose the film or make suggestions as to which film to watch the following month. The assembly room is very gloomy during the film show which adds to the atmosphere of being in a theatre but also enables residents to concentrate on the film and not be distracted by the movements of those about them. Each resident is accompanied by a staff member from their residence in case of emergency and to facilitate the resident's engagement with the film.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation.
hearing	The film watching occupation happened in a large public space but with the door closed to prevent distractions from other rooms and corridors. Furthermore, notices were hung from the door when the occupation was in progress, asking passers by, to do so quietly. However, for some residents with very good hearing the occasional accidental noise could have been heard e.g. something falling to the floor or traffic being very noisy on the street outside e.g. a fire engine. Consequently, the only noise was the film being watched and listened to. This was played at a comfortable level for the participants but with an understanding of not sharing the noise with others in adjacent rooms and corridors.
taste	The participants were not actively given any food or drink during the occupation and so apart from regurgitation would not have been experiencing any tastes at this time.
touch	Each resident was sitting in their own chair or lying on their own bed and as part of the film watching occupation. They would have been able to feel their furniture and their clothing however the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). On this occasion, they had been placed further apart than usual to avoid the likelihood of touching each other.
seeing	The film watching occupation was provided in the participants own room. This was a modern room with four walls and windows on one side. The curtains were closed to reduce visual distractions and all rooms had blackout curtains to assist residents to sleep and to experience appropriate circadian rhythms therefore the rooms were gloomy but not completely dark.
proprioceptive vestibular	Most residents remained passive and still during the listening case and therefore would not have experienced much if any proprioceptive or vestibular stimulation.
Critical commentary of sensory attributes	Domestic staff placed great importance on reducing rather than hiding smells. This occupation was carried out in a large public space, which did not have any motion sensing odour neutralisers in, as they were removed for the duration of the occupation. All remaining food has been cleared away quickly was no longer required to reduce persistent aromas, and therefore there is no smells that are new or unusual to attract the attention of the resident. There was the potential for a kind of hospital smell which could include the aroma of air fresheners, incontinence and hibiscrub but this was not unusual and therefore was discounted because the smell is a sense which habituates or fades rapidly. The film watching occupation happened in a large room but with the door closed to prevent distractions from other rooms and corridors. Furthermore, notices were attached to the door when the occupation is in progress, asking passers by, to do so quietly. However, for some residents with good hearing the occasional accidental noise could have been heard for example something falling on the floor or unusual traffic on the street outside. Therefore, the only noise was the film being watched and listened to. It was

	played at a comfortable level for participants, but with an understanding of not sharing the noise with other corridors and adjoining rooms. Fear of aspiration meant that residents were not left with food or beverages when unsupervised and in this case were not were offered during the observation unless they specifically requested, so apart from regurgitation would not have been experiencing any tastes at this time. Each resident was sitting in their own chair or lying on their own bed and as part of the film watching occupation. They could probably feel their furniture and clothes but the brain has a tendency to become accustomed to and therefore ignore touch, unless it is changed. On this occasion, they had been placed further apart than usual to avoid the likelihood of touching each other. The film watching occupation was provided in a large room with four walls and windows on one side. The blackout curtains were closed to reduce visual distractions. Most of the participants remained passive and still while watching the film show thus avoiding vestibular or proprioceptive stimulation.
minimum number of senses affected	**2**
maximum number of senses affected	**2**
Occupation Summary	
Performance attributes	• Tolerating/ maintaining sitting position • Watching & listening to the film • Understanding the film to follow the plot • Non disturbance of others
Precautions and contraindications	Films which include strobe lighting effects are contraindicated for residents who fit. Also some residents could confuse reality with the film at times, which needs to be managed.
Special Considerations	Special considerations include a gender, age and culturally appropriate choice of film. Many residents don't watch the filmshows because they cannot attend for long enough therefore the length of the film is an important consideration.
Occupational demands: Physical	Residents need to have sitting tolerance for the period of the film and getting to and from their residence.
Occupational demands: Communication	Residents generally try not to talk during the show so as not to disturb each other, but communication is required to express a preference for future film selections and to discuss the film with their attendant and visitors afterwards.
Occupational demands: Behavioural	Socially acceptable behaviour involves watching the film quietly to allow others to remain undisturbed and keeping relatively still. The atmosphere is very much that of a cinema.
Occupational demands: Cognitive	Residents require sufficient cognitive ability and concentration to understand the film and follow the plot.
Resources required: Tools, materials, equipment	Facilitatory staff, a projector, a screen and a DVD are required.
Space Demands (size, arrangement, surface, lighting, temperature, noise, humidity, ventilation)	The assembly room at the home is large enough to hold many residents with room to manoeuvre wheelchairs. It is kept at a comfortable temperature for non mobile residents and has lighting which can be faded up or down as appropriate.
Occupational (Motor and processing) skills required	
A stable, aligned supported posture is required to maintain a sitting position. The vast majority (96.2%) of the residents are permanent wheelchair users and so leisure activities are tailored to mobility from a wheelchair. Self propelling or controlling an electric wheelchair requires coordination to avoid collisions as well as using the controls. It also requires strength, effort and stamina to move limbs or use the controls as well as the demands of watching the filmshow itself. Sufficient attention is needed to maintain concentration throughout watching the filmshow. The resident's knowledge could be enhanced through his choices, and how he uses tools and materials and discusses watching the filmshow with others	

Communication will be required if the resident needs assistance or wishes to discuss watching the filmshow. However it is usually required to comply with social norms and not interfere with watching the filmshow by other residents.
Occupational-performance patterns and contexts
The filmshow viewing could be conducted against a background of habits, routines and roles. The residents' role during the filmshow will be that of a physically passive absorber of sound. During the filmshow the resident could be attempting to link interests and roles e.g. understanding something said to them by a visitor at some stage, or continuing an interest in classical music which was enjoyed in the past. The resident could attend the filmshow routinely each week or be continuing to watch a part of a series of films and so what they experience will continue from the past and link to the future. Their filmshow viewing habit could orientate or disorientate residents depending on the topic and whether they have difficulty distinguishing fact from fiction. Each resident watching the filmshow will vary in their personal, cultural, spiritual, clinical context. However the film chosen should be as appropriate as possible to the group and the individuals which make it up. Some residents need to be reminded that the recording/ programme is fiction and not their own reality at times.

Spectating at a live performance

Brief description of the occupation observed	The home regularly hosts live performances from musicians, dancers and actors etc. the occasion observed involved two actors portraying the role of a Doctor and a Nurse from the home during the late nineteenth century. The performances occurred in the day rooms of Hunter, Evitt and Glynn Wards. The rooms were laid out with a large space for the actors in the centre of the room for them to perform in the round. Residents had earlier in the week been given the choice of characters to have portrayed when they witnessed a board of admission from the same time period in the Maxwell Library with current day staff taking roles in the production e.g. the Chief Executive Officer. Residents' were accompanied by staff from their residence in case of emergency and to support the actors.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation.
hearing	The live performance happened in a large public space but with the door closed to prevent distractions from other rooms and corridors. Furthermore, notices were hung from the door when the occupation was in progress, asking passers by, to do so quietly. However, for some residents with very good hearing the occasional accidental noise could have been heard e.g. something falling to the floor or traffic being very noisy on the street outside e.g. a fire engine. Consequently, the only noise was made by the character visitors and the audience as they joined in. The participants were therefore offered the opportunity to hear the actors, and to follow the story being enacted.
taste	The participants were not actively given any food or drink during the occupation and so apart from regurgitation would not have been experiencing any tastes at this time.
touch	Each resident was sitting in their own chair; however, touch could have been experienced as the actors passed the participants. They would have been able to feel their furniture and their clothing however, the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). On this occasion, they had been placed further apart than usual to avoid the likelihood of touching each other. There was no expectation during the occupation that the participants would have to hold or touch any props as part of the performance.
seeing	The live performance occurred in a large public space; the assembly room. This was a large room with four walls and windows on one side. The curtains were open to allow in the sunshine. The assembly room was kept at a comfortable temperature for non-mobile residents and had lighting that could be faded up or down as appropriate. Consequently, the residents were offered the opportunity to watch the performance and could have been attracted to the actor's movements.
proprioceptive vestibular	Most residents remained passive and still during the live performance and therefore would not have experienced much if any proprioceptive or vestibular stimulation.
Critical commentary of	The domestic staff placed great emphasis on reducing rather than masking smells. This

sensory attributes	occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation. The show happened in a big public space but with the door closed to prevent distractions other rooms and corridors. Furthermore, notices were suspended from the door when the occupation is in progress; ask asking passers by, to do so quietly. However, for some residents with good hearing the occasional accidental noise could have been heard for example something falling on the floor or very noisy traffic on the street outside. Accordingly, the only noise was made by the character visitors and the audience as they joined in. The participants were therefore offered the opportunity to hear the actors and follow the story being presented. The participants were not actively given any food or drink during the occupation, and so apart from regurgitation would not have been experiencing any tastes at this time. Each resident was sitting in their own chair. However, touch could have been transmitted as the actors passed the participants. The participants would have been able to feel their furniture and their clothing however, the brain has a tendency to become habituated to touch unless it is changed. On this occasion, they were more spaced out than usual to avoid the risk of touching each other. There was no expectation during the occupation that the participants would hold or touch any props as part of the performance. The performance took place in the Assembly Room, a large room with four walls and windows on one side. The curtains were opened to admit the sunshine. The Assembly Room was maintained at a comfortable temperature for non-mobile residents and had lighting that could be faded up or down as required. Accordingly, the participants were given the opportunity to watch the performance and could have been attracted to the movements of the actor's. Most of the participants remained passive and still during the performance and would therefore not have experienced much if any proprioceptive or vestibular stimulation.
minimum number of senses affected	**2**
maximum number of senses affected	**3**
Occupation Summary	
Performance attributes	• Tolerating/ maintaining sitting position • Watching & listening to the performance • Understanding the performance to follow the plot
Precautions and contraindications	Some residents could confuse reality with the performance at times, which needs to be managed.
Special Considerations	Special considerations include a gender, age and culturally appropriate choice of performance. Many residents don't watch the performance because they cannot attend for long enough therefore the length of the performance is an important consideration.
Occupational demands: Physical	Residents need to have sitting tolerance for the period of the performance and getting to and from the performance.
Occupational demands: Communication	Residents were required to watch and listen to the performance and to follow the plot; no physically active participation was required.
Occupational demands: Behavioural	Socially acceptable behaviour involves watching the performance quietly to allow others to remain undisturbed and keeping relatively still.
Occupational demands: Cognitive	Residents require sufficient cognitive ability and concentration to understand the performance and follow the plot.
Resources required: Tools, materials, equipment	Facilitatory staff, stage space, actors and costumes. there were no props for residents use or stage sets involved.
Space Demands (size, arrangement, surface, lighting, temperature, noise, humidity, ventilation)	The day rooms are the largest rooms on the residences and due to the fact that not all residents were involved there was plenty of space to move residents around if they wished to be or needed to be. The assembly room at the home is large enough to hold many residents with room to manoeuvre wheelchairs. It is kept at a comfortable temperature for non mobile residents and has lighting which can be faded up or down as

	appropriate.

Occupational (Motor and processing) skills required
A stable, aligned supported posture is required to maintain a sitting position. Sufficient attention is needed to maintain concentration throughout the performance. Communication will be required if the resident needs assistance or wishes to discuss the performance.
Occupational-performance patterns and contexts
The performance spectating could be conducted against a background of habits, routines and roles. The residents' role during the performance will be that of a physically passive absorber of sound and sights. During the performance the resident could be attempting to link interests and roles e.g. understanding something said to them by a visitor at some stage, or continuing an interest in classical music which was enjoyed in the past. Each of the live performances presented at the home stand alone rather than being part of a series but could perhaps be selected by the residents based on their liking for a particular media of performing arts (e.g. a preference for drama over music). Their performance spectating could orientate or disorientate residents depending on the topic and whether they have difficulty distinguishing fact from fiction. Each resident watching the performance will vary in their personal, cultural, spiritual, clinical context. However the performance chosen should be as appropriate as possible to the group and the individuals which make it up. Some residents need to be reminded that the performance is fiction and not their own reality at times.

Interactive video installation

Brief description of the occupation observed	The Interactive Video can be used on floors walls to enable the resident to engage with the occupation and become part of the image. The Interactive Video incorporates Infrared detection with Digital Projection to detect movement, enabling residents to interact with the projection. They can do this because each projection has two layers. The lower layer being a single image and the upper layer being a directory of images that are revealed by the interaction. The 'templates' can each be customised in many ways and at the home took the form of a night scene of London which when movement was detected left a trail of firework sparks in the participants wake. Another was called "the scatter" which gave the effect of autumn leaves scattering when approached or stepped on. The last was called the "water ripple" which had the logo of the Royal Hospital for neuro - disability appearing under water, with rippling distortions. A movement across the screen caused waves. Crucial to the installation for the residents use was a wall projection which repeated the image projected onto the floor enabling residents who could not lean to see the floor to still see what was occurring. Once present in the interactive video installation, residents were wheeled onto the floor screen/ mat and made aware of the reaction of the projection to their presence/ movements
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing

	odour neutralisers in, as these had been removed for the length of the occupation.
hearing	The interactive video projection happened in a large public space but with the door closed to prevent distractions from other rooms and corridors. The participants were therefore offered the opportunity to hear the sounds and music that were generated by the video projection in response to their movements.
taste	The participants were not actively given any food or drink during the occupation and so apart from regurgitation would not have been experiencing any tastes at this time.
touch	Each resident was sitting in their own wheelchair and would have been able to feel their furniture and their clothing however, the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). As only one or two participants were using the projection floor/mat at a time, it is unlikely that they would have experienced touch other than this.
seeing	The interactive video projection occurred in a large public space; the assembly room. It was especially run in a totally blacked out environment, since the curtains were closed and it was late on a dark evening. The assembly room was kept at a comfortable temperature for non-mobile residents and had lighting that could be faded up or down as appropriate. Consequently, the residents were offered the opportunity to watch the projection and could have been attracted to the movements, special effects and patterns created by the projection.
proprioceptive	Some residents could propel their own chair or wave their arms if they are able. Those participants who could move their arms and legs would have experienced proprioceptive stimulation Consequently.
vestibular	The wheelchairs were actively moving around the floor/mat and so the participants would have experienced vestibular stimulation Consequently.
Critical commentary of sensory attributes	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation. The interactive video projection was presented in a big public space but with the door closed to prevent distractions other rooms and corridors. The participants were offered the opportunity to hear the sounds and music generated by the video projection in response to their movements. The participants were not given any food or drink during the occupation, and so apart from regurgitation would not have been experiencing any tastes at this time. Each resident was sitting in their own wheelchairs and could feel their furniture and clothes however; the brain has a tendency to become accustomed to touch unless it is changed and so they could have become used to these. Only one or two participants used floor/mat at a time, therefore it is unlikely that they have experienced touch other than this. The interactive video projection was presented in a large public space; the Assembly Room. It was especially run in a totally blacked out environment, since the curtains were closed and it was late on a dark evening. The Assembly Room was maintained at a comfortable temperature for non-mobile residents and had fade-able lighting. Accordingly, the inhabitants were given the opportunity to watch the projection and could have been attracted by the movements, special effects and patterns created on the wall or floor screens. Some residents could propel their own wheelchair or wave their arms. Those participants who could move their arms and legs could have experienced proprioceptive stimulation Consequently. The wheelchairs were actively moving around the floor/mat and so the participants would have experienced vestibular stimulation Consequently.
minimum number of senses affected	**3**
maximum number of senses affected	**4**
Occupation Summary .	
Performance attributes	Wheelchair being self or attendant propelled across the screen/ mat Resident watching floor or wall screen • Resident making suggestions as to what movements to make if attendant propelled

Precautions and contraindications	The projection used no strobe lighting effects and so was appropriate for all conditions represented at the Royal Hospital for Neuro – disability. The floor mat should be large enough to allow several residents a sufficient turning area to avoid collisions.
Special Considerations	The projection itself should be age, culture and gender appropriate or neutral
Occupational demands: Physical	Some residents could propel their own chair or wave their arms if they are able.
Occupational demands: Communication	Communication with attendant is required for attendant propelled wheelchairs.
Occupational demands: Behavioural	Socially appropriate behaviour is required to not impede the enjoyment of others.
Occupational demands: Cognitive	The understanding that their movements cause the alterations to the projection enhances engagement.
Resources required: Tools, materials, equipment	Facilitatory staff, projection equipment and software, screen/mats and an audio system are required.
Space Demands	A room large enough for several wheelchair users to use the projection at once, with lowered lighting to enhance the projection. An audio system to portray the auditory reactions of the software to movement.

Occupational (motor and processing) skills required

A stable, aligned supported posture is required to maintain a sitting position. Self propelling or controlling an electric wheelchair requires coordination to avoid collisions as well as using the controls. It also requires strength, effort and stamina to move limbs or use the controls as well as the demands of the occupation itself e.g. arm waving>
Attendant propelled residents can impact on the reaction just as much as self propelling ones.
Sufficient attention is needed to maintain concentration throughout the occupation. The resident's knowledge could be enhanced through his choices, and how he uses tools and materials and discusses the occupation with others.
Coordination is required to avoid collisions. Executive skills assist residents to realise that reactions to movements are caused and that altering their movements will alter the projection.
Communication will be required if the resident needs assistance or wishes to discuss the occupation. However it is usually required to comply with social norms and not interfere with the occupational experience of other residents. Communication is also required to direct the attendant.

Occupational-performance patterns and contexts

This experience was a complete change from previous large celebratory events at the Royal Hospital for Neuro - disability, which in the past had involved fireworks and so had resulted in residents exhibiting startle reflexes cause by the noise and getting cold through being outside etc..
This occupation was completely new to the visitors, staff and residents who participated in it. The residents' role when participating in the interactive video installation was to stimulate the projection to react to them. For some the installation was an opportunity to link their interest in or experience of large celebratory events at the Royal Hospital for Neuro-disability, computers, fireworks, autumn leaves, London, and or water with the this new experience.
Each resident participating in the occupation will vary in their personal, cultural, spiritual, clinical context. However the recording/ programme chosen should be as appropriate as possible to the group and the individuals which make it up.

Making Music group

Brief description of the occupation observed	The making music group happens each Tuesday afternoon in the assembly room at the Royal Hospital for Neuro-disability. It is facilitated by a volunteer who brings a record deck and some simple musical instruments (which residents can shake or bang), and plays well known music which participants can sing along to or accompany. Residents also participate by wheelchair dancing with their attendant.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation.
Hearing	The Making Music Group happened in a large public space but with the door closed to prevent distractions from other rooms and corridors. The participants were therefore offered the opportunity to hear the music and singing and musical instruments being played. This was a noisy activity, whose musical contribution to the atmosphere of the home reverberated throughout the building. Conversations between supporters and participants were generally shouted thus adding to the noise.
taste	The participants were not actively given any food or drink during the occupation and so apart from regurgitation would not have been experiencing any tastes at this time.
touch	Each resident was sitting in their own wheelchair and would have been able to feel their furniture and their clothing however, the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). Furthermore, the participants were offered musical instruments to bang or play and these would have generated tactile stimulation if held, and when banged against another surface.
seeing	The Making Music Group occurred in a large public space; the assembly room. The curtains were opened to let in the afternoon sunshine, in addition to the lighting that could be faded up or down as appropriate. The room was kept at a comfortable temperature for non-mobile residents. The residents were offered the opportunity to see the Disk Jockey, the equipment, each other, their supporters and the musical instruments. Furthermore, they would have been able to watch each other dancing if the wished.
proprioceptive	Banging and playing the musical instruments could have led to the participants experiencing proprioceptive stimulation. Furthermore, other participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing proprioceptive stimulation.
vestibular	The wheelchairs of those participants who were dancing were actively moving around the floor and so these participants would have experienced vestibular stimulation Consequently. Furthermore, other participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing vestibular stimulation.
Critical commentary of sensory attributes	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation. The making music group happened in a big public space but with the door closed to prevent distractions from other rooms and corridors and to contain the noise emanating from the room. Participants were therefore offered the opportunity to hear the music, singing and play some musical instruments. The conversations between supporters and participants were generally shouted and so added to the noise. The participants were not actively given any food or drink during the occupation and so apart from regurgitation would not have been experiencing any tastes at this time. Each resident was sitting in their own wheelchairs and could have been able to feel their furniture and clothes however, the brain has a tendency to become accustomed to the sensation and so ignore it. Furthermore, participants were able to sing, or to bang musical instruments, wheelchair dance which could have generated tactile stimulation if and when struck against another surface. The music group which was held in the Assembly Room with the curtains opened to let the afternoon sun, in addition to the lighting which could be faded up or down as appropriate. The room was maintained at a comfortable temperature for non-mobile residents. The inhabitants had the opportunity to see the disk Jockey, equipment, the other participants, their supporters and the musical instruments. Furthermore, they could watch each other dance if the desired. Banging the musical instruments could have led to

	the participants experiencing proprioceptive stimulation. Furthermore, other participants could have been nodding, or swaying to the rhythm of music and thus proprioceptive stimulation could have been experienced. Wheelchairs of participants who danced moved around the floor and therefore these participants could have experienced vestibular stimulation as well.
minimum number of senses affected	**4**
maximum number of senses affected	**5**
Occupation Summary	
Performance attributes	• Singing • Shaking or banging instruments • Being wheeled around the dance floor by their attendant/ self propelled dancing • Chatting to other residents, visitors or their attendants
Precautions and contraindications	Music with sudden loud bangs is generally avoided e.g. 1812 overture. Music should be familiar enough to hum along to or to stimulate recognition.
Special Considerations	The music played is in response to requests from residents either at the current session or if the music was not to hand fn response to a request from a pervious session. It is therefore a mix of current popular music and older music; although the choice of music is generally age appropriate occasionally there are adhoc requests for music from a stage show or a television show including children's television such as “Pinkey and Perky". or “The Wombles”.
Occupational demands: Physical	Some residents could propel their own chair or wave their arms if they are able, the majority dance with the assistance of their attendant. A few bang of shake musical instruments. Most remain physically passive due to their physical limitations and yet appear to enjoy being part of the group.
Occupational demands: Communication	Those who can vocalise and wish to sing do so, others chat with their visitors or attendants using assistive technology.
Occupational demands: Behavioural	Communication with attendant is required for attendant propelled wheelchairs. Socially acceptable behaviour is required to reduce disturbance to other participants.
Occupational demands: Cognitive	Singing along to music requires recognition and memory of the words or tune, while using the simple musical instruments requires an understanding of how to make a sound with it.
Resources required: Tools, materials, equipment	Facilitatory staff, record deck, simple musical instruments, selection of CD’s and the host Disk Jockey.
Space Demands	The assembly room is used for this activity because it is big enough to accommodate a large group which involves wheelchair dancing.
Occupational (motor and processing) skills required	
A stable aligned supported posture is required to maintain a sitting position and to maximise upper limb function. Self propelling or controlling an electric wheelchair requires coordination to avoid collisions as well as using the controls. It also requires strength, effort and stamina to move limbs or use the controls. Some residents are able to add to the cacophony of sound by manipulating the musical instruments to make a noise or by singing. Sufficient attention is needed to maintain concentration throughout the occupation. Communication will be required if the resident needs assistance or wishes to discuss their experience and to sing along.	
Occupational-performance patterns and contexts	
The music requested does not on the whole reflect the cultural background of the residents who described themselves as being from an African, Asian, Chinese, Hindu, Jewish, Muslim, or Sikh background during the audit (Royal Hospital For Neuro-disability 2006). This group appears to be used by visitors as an opportunity for intergenerational leisure (Downs, 2008) with grandparents singing along with their grandchildren for example to a children's song. The music often appears to evoke memories and conversation about past events recalled. Residents with a strong musical past could relish the opportunity to join in or could shun current ability in comparison to their previous musical skill.	

The residents seem to attend regularly and so can request favourites and chat with the DJ or each other about the music and their preferences.

Interactive Drama

Occupation	**Interactive Drama Performance**
Brief description of the occupation observed	The interactive drama project was based on three residences which had not hosted the project described by Fenech (2009). It involved residency by a theatre group who specialise in bringing 'character visitors' into healthcare environments. Interactive Drama is a form of theatre in which audiences participate as 'Spect-Actors', with their interventions being part of the performance. The characters treat everybody the same - engaging residents, staff and visitors in their world listening and responding in character to whatever they say in return. The characters everyone's input is valuable and so accept everything they're told and use it to develop their story, activities and interactions.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation.
hearing	The Interactive drama performance happened in the day room of the residence. The participants were offered the opportunity to hear the speaking, music and singing which the performance entailed.
taste	Those participants who were allowed to have them could have been offered "wine" to drink during the ballroom scene and so could have experienced its taste.
touch	Each resident was sitting in their own wheelchair and would have been able to feel their furniture and their clothing however, the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). Furthermore, the participants were offered props to hold or use and these would have generated tactile stimulation if held, and when banged against another surface.
seeing	The Interactive drama performance occurred in the day room of the residence. The curtains were opened to let in the afternoon sunshine and the room was kept at a comfortable temperature for non-mobile residents. The residents were offered the opportunity to see the actors, each other, their supporters, the costumes and the props.
proprioceptive	Using the props and costumes could have led to the participants experiencing proprioceptive stimulation. Furthermore, other participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing proprioceptive stimulation.
vestibular	The wheelchairs of those participants who were acting were actively moving around the floor and so these participants would have experienced vestibular stimulation Consequently. Furthermore, other participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing vestibular stimulation.
Critical commentary of sensory attributes	The domestic staff placed great emphasis on reducing rather than masking smells. This occupation was conducted in a large public space, which did not have any motion sensing odour neutralisers in, as these had been removed for the length of the occupation. The Interactive drama performance happened in day room of the residence. The participants had the opportunity to hear speaking, music and singing involved. Participants who were allowed to have them could have been offered "wine" to drink during the ballroom scene and so could have experienced its taste. Each resident was sitting in their own wheelchair and could feel their furniture and clothes however; the brain tends to become accustomed to the sensation, unless it is changed and so they could not have noticed this. Furthermore, participants were offered props to hold or use and these could have generated tactile stimulation if held and when struck against another surface. The Interactive drama performance took place in day room of the residence. The curtains were opened to let the afternoon sunshine and the room has been maintained at a

	comfortable temperature for non-mobile residents. The participants were offered the opportunity to see the actors, their supporters, each other, the costumes and the props. Using the props and costumes could have led to the participants experiencing proprioceptive stimulation. Furthermore, the participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing proprioceptive stimulation. The wheelchairs of those participants who were acting were actively moving around the floor and so these participants would have experienced vestibular stimulation Consequently. Furthermore, other participants could have been moving to the rhythm of the music, nodding their heads, and thus experiencing vestibular stimulation.
minimum number of senses affected	**3**
maximum number of senses affected	**6**
Occupation Summary	
Performance attributes	• Accepting, holding or using props • Responding to the character visitors appropriately • Self or attendant propelled movement about the stage area
Precautions and contraindications	This occupation can involve the use of liquids as props e.g. as wine during the ball scene in Romeo and Juliet. Care should be taken to avoid its use with residents with dysphagia who will choke Consequently. Residents with challenging behaviour should also be highlighted to the actors to handle with care. Actors should be shown how to put the brakes on a wheelchair if they are going to move one.
Special Considerations	The actors were very careful to behave appropriately to and acknowledge the residents age, culture, experience and gender.
Occupational demands: Physical	Holding or using props involved manipulation or stabilising of the props such as hats and cloaks, goblets, swords, trumpets and flowers. Self or attendant propelled movement about the stage area was also required.
Occupational demands: Communication	Communication with the characters, visitors, other residents and staff was both verbal and assisted by technology.
Occupational demands: Behavioural	Accepting the props involved remaining still so that they did not fall to the floor, and not actively rejecting them. In order not to detract from other resident's enjoyment socially acceptable behaviour was expected. Responding to the character visitors appropriately involved repeating lines as prompted or responding when addressed by the characters.
Occupational demands: Cognitive	The cognitive demands of interactive drama include remembering lines and understanding what is said, as well as remembering that the project was going on and turning up for performances.
Resources required:	Facilitatory staff, props, scenery and actors
Space Demands	The space used was the day rooms of the residences involved. These were arranged so that the stage and props were in the middle and away from the entrance. The lighting was adjusted to demonstrate the difference between the formal (performance) and less formal parts of the performance.
Occupational (motor and processing) skills required	

A stable, aligned supported posture is required to maintain a sitting position. Controlling an electric wheelchair requires coordination to avoid collisions as well as using the controls. Holding or using props requires limb mobility, strength, effort and stamina. Maintaining engagement, attention and concentration throughout a performance appeared quite tiring for several residents. Making choices using props and discussing the project with visitors, other residents and staff required memory and understanding of what was going on. Communication will be required if the resident needs assistance or wishes to discuss the occupation and to direct the attendant propelling a wheelchair.
Occupational-performance patterns and contexts
This experience involved a change in routine for residents and staff. The residents' role when participating in the interactive drama was to stimulate the characters and influence the performance. For some the project was an opportunity to link their interest in or experience of theatre, performing, Shakespeare or the 1950's. with their current situation. Each resident participating in the occupation will vary in their personal, cultural, spiritual, clinical context. However the theme for the performances was chosen to be as appropriate as possible to the group and the individuals which make it up.

Aquability session

Brief description of the occupation observed	Aquability sessions give residents the opportunity to use the pool for fun. Before attending Aquability, a resident must be assessed in a hydrotherapy session. Each Aquability session is tailored according to the requests of the resident. These sessions often include movement to the residents own music. Aquability allows residents to control their own water based activities and determine their own environment. Being in the water enables them to move and use their bodies in ways that they would not normally be able to, sometimes allowing residents to stand or walk. By relaxing their muscles in these sessions some patients have reported being free from pain after a session. Being in the water frequently leads to a greater level of interaction between staff and residents, whilst enabling them to gain self confidence by determining the nature of the sessions themselves.
Sensory stimulation (key 1=definitely/ for all, ?=possibly/ for some)	
smell	Smell could have been experienced by those participants who were aware of the aroma of the chlorine in the pool.
hearing	The residents were offered the opportunity to play their own music selection, Furthermore, the pool atmosphere appeared to amplify the noise of voices when the participants and the supporters spoke, sang, laughed or shouted .
taste	Those residents who accidentally took a mouthful of the water could have tasted it but this was not to be encouraged due to the risk of aspiration.
touch	Each resident was hoisted into the pool, which would have led to the participants feeling the sling, their swimming costume however; the brain has a tendency to become habituated to this sensation unless it is changed (Parent, 1978, Hutchinson, 1990). They would also have felt the sensation of the water and the tides and ripples that were generated. Furthermore, the participants were offered balls, water pistols and games to hold or use and these would have generated tactile stimulation if held, and when banged against the side or a supporter. The pool also offered quite a hard atmosphere since the floor; walls and pool sides were all tiled and a little chilly.
seeing	The pool was a very light and airy hexagonal room. The curtains were opened to let in the afternoon sunshine and the room was kept at a warm temperature for non-mobile and less than normally dressed residents. The residents could see their supporters, the stained glass in the ceiling and the patterns that this made in the water and the toys that they were offered to play with.

proprioceptive	Using the games and the movement of the water could have led to the participants experiencing proprioceptive stimulation. Furthermore, the participants could have been moving to the rhythm of the music, nodding their heads, feet and arms, and thus experiencing proprioceptive stimulation.
vestibular	The participants could have been moving to the rhythm of the music, or moving, rocking or nodding their heads, feet and arms, and thus experiencing vestibular stimulation.
Critical commentary of sensory attributes	Smell could have been experienced by those participants who were aware of the aroma of the chlorine in the pool. The residents were offered the opportunity to play their own music selection, Furthermore, the pool atmosphere appeared to amplify the noise of voices when the participants and the supporters spoke, sang, laughed or shouted . Those residents who accidentally took a mouthful of the water could have tasted it but this was not to be encouraged due to the risk of aspiration. Each resident was hoisted into the pool, which would have led to the participants feeling the sling, their swimming costume however; the brain has a tendency to become habituated to this sensation unless it is changed. They would also have felt the sensation of the water and the tides and ripples that were generated. Furthermore, the participants were offered balls, water pistols and games to hold or use and these would have generated tactile stimulation if held, and when banged against the side or a supporter. The pool also offered quite a hard atmosphere since the floor; walls and pool sides were all tiled and a little chilly. The pool was a very light and airy hexagonal room. The curtains were opened to let in the afternoon sunshine and the room was kept at a warm temperature for non-mobile and less than normally dressed residents. The residents could see their supporters, the stained glass in the ceiling and the patterns that this made in the water and the toys that they were offered to play with. Using the games and the movement of the water could have led to the participants experiencing proprioceptive stimulation. Furthermore, the participants could have been moving to the rhythm of the music, nodding their heads, feet and arms, and thus experiencing proprioceptive stimulation. The participants could have been moving to the rhythm of the music, or moving, rocking or nodding their heads, feet and arms, and thus experiencing vestibular stimulation.
minimum number of senses affected	**6**
maximum number of senses affected	**7**
Occupation Summary	
Performance attributes	Resident's enter the pool using a hoist, and can then float, relax, exercise, play games etc as they choose.
Precautions and contraindications	All residents who use the pool for fun have been initially assessed by the hydrotherapy staff. Contraindications should be considered on each occasion such as mood or health related conditions such as heart related symptoms, vomiting and diarrhoea, chlorine sensitivity, fear of water, recent thrombosis or CVA weight in excess of 17 stones, uncontrolled epilepsy, pyrexia etc.
Special Considerations	Special considerations include a gender and age awareness. Residents sometimes appear to become playful when in the pool or their behaviour can become sexually inappropriate.
Occupational demands: Physical	Hydrostatic pressure makes being in the water tiring but also because it is equal all over the bodies surface (below the water) it is relaxing on muscle tone and could even reduce the choreaform movements of individuals with Huntington's Disease. A human body is usually about 95% of the density of water and so will normally float with about 5% of it above the surface. The support offered by water can sometimes mean that residents ability to move increases in the water. With the support of floats they can often experience floating without staff support which could be a very rare experience for them not to be limited by gravity or the weight of their own bodies.
Occupational demands: Communication	Residents on the whole seem to be more interactive in the pool and to have a greater sense of playfulness so that residents communication attempts increase despite the fact that they do not have access to their usual assistive technology.

Occupational demands: Behavioural	Responding to the staff and volunteer can be confusing for some residents who are unused to being unencumbered by clothes (other than a swimming costume) assistive technology and wheelchairs or seeing others with only a swimming costume on.
Occupational demands: Cognitive	The cognitive demands of interactive drama include remembering lines and understanding what is said, as well as remembering that the project was going on and turning up for performances.
Resources required: Tools, materials, equipment	Facilitatory staff, balls, floats, pool, hoists.
Space Demands (size, arrangement, surface, lighting, temperature, noise, humidity, ventilation)	A hydrotherapy pool, a pool side hoist, support staff and session leader.

Occupational (motor and processing) skills required

The residents' limitations on dry land which are caused by gravity could be removed or reduced so that they can kick with their legs or move their arms a little. If this is the case they could choose to exercise to try to maintain this improvement, through actively attempting to move or play games with floats or balls. They could prefer to relax and simply float and enjoy the sense of being unencumbered.

Occupational-performance patterns and contexts

Each resident participating in the occupation will vary in their personal, cultural, spiritual, clinical context. An Aquability session offers a change of environment and experience of their own body for residents. This can be a regular occurrence if enjoyed (every 2 – 3 weeks).
The residents' role in the pool is to focus on their own wishes and instruct the staff about what they would like to do. This can involve selecting music and bringing the CD along to the session.

Examples of session content

Resident 1	Theme: exercise and playfulness	Swimming on back, standing, walking supported by 2, ducking down and blowing bubbles, kicking legs and making swimming motions with left arm, kicking, hitting and head butting ball back to staff, swimming, standing, walking, bubble blowing
Resident 2	Theme: Deep relaxation	Eyes shut, not speaking except when spoken too (opposite of her usual), passive opening of hands. Weaving about in water - pulled by staff and experiencing current and having water movement exaggerated by 2nd staff member.
Resident 3	Theme: floating and relaxing muscles	Experiencing water movement around her, passive opening of hands. Eyes shut, not speaking except when spoken too (opposite of her usual). Weaving about in water - pulled by staff and experiencing current and having water movement exaggerated by 2nd staff member. Responding to questions and conversation. floating with legs and ankles being held in an reflex inhibiting position (only possible when tone is reduced)
Resident 4	Theme: playful	Trying to push staff into pool from chair, splashing staff when in pool, swimming using arms and legs, floating with head support only, throwing ball at poolside staff and into floating goal, racing staff across pool, water pistol squirting poolside observer, swimming away from staff in pool

Resident 5	Theme: Playful active movement	Chatting with staff about music. Swimming motion with one arm. Splashing staff in pool/ water fight. Waving at staff on pool side. Squirting water, blowing bubbles and singing with the music. Pushing/ throwing ball at staff or goal.
Resident 6	Theme: relaxation	Floating but keeping ears and hands dry, discussing alcoholic preferences, squirting water at staff on the pool side, singing with radio, standing and kicking legs
Resident 7	Theme: Feeling of movement	Love songs from 1950's. Kicking feet as she is floated round the pool. Smiling and responding to staff, and making eye contact. Kicking feet, sitting up on knees of both staff and laughing. Kicking feet. Eye contact with staff. Waving at people on the poolside as she passes, raising arms as requested. Being rocked to rhythm of music. Walking supported by 2.
Resident 8	Theme: active movement	Staff making waves and discussing wind music selected, reduced muscle spasm in upper limbs, pushing with feet from wall of pool, standing and crouching to blow bubbles.
Resident 9	Theme: Movement and enjoying the freedom of buoyancy	Floating round the pool being splashed by the pool side staff who made waves and currents to move him about and enable him to enjoy the sense of floating freely and movement. Using head and hip floats and kicking self around the pool - entirely unaided/ floats only.
Resident 10	Theme: laughter & fun	Elvis CD. Punches ball when thrown from poolside. Smiling when floated round the pool. Punching ball into goal. Feeling the current, while being floated about.
Resident 11	Theme: exciting at times and at others calming	Classical/ jazz violin music. Kicking her feet, standing and bouncing at pool side. Pushing off from wall and floating across the pool moving both arms. Staff bouncing her in the water in lieu of a wave machine and rocking her from side to side, while floating round pool. Standing and holding bar and walking sideways. Holding and throwing frisbees.
Resident 12	Theme: challenge. Movement and freedom	Laughing and kicking self round the pool. Water pistol fight with staff on pool side. Floating round the pool being splashed by the pool side staff and firing water jets back. Using head and hip floats and kicking himself around the pool - entirely unaided/ floats only. Standing on bottom and shooting or throwing frisbees. Staff making waves. Head butting beach ball into goal or to staff.
Resident 13	Theme: freedom and control of the environment	Swimming on front, floating amidst balls which touched body when passing, relaxing. Shouting and laughing occasionally to listen to the echoes.
Resident 14	Theme: freedom, current and light	Floating totally free because supported by floats (head, trunk, legs, arms, feet. Rocking in the current made by poolside staff. Watching light play on ceiling of pool and in coloured glass in windows.

Appendix xiv A copy of a resident and participant information sheet, and a guardian consent form

Service Evaluation Participant Consent Form

Tuesday, 12 February 2008

[redacted]

Investigation of engagement in **7** different casual leisure occupations with varying levels of sensory content with individuals with neuropalliative conditions, in long term residential care

Investigator:

Anne Fenech [redacted]

Purpose of study:

This service evaluation aims identify the signs of sensory overload demonstrated by residents of the [redacted] and to prioritise the meanings of leisure highlighted in the literature.

Methods:

I understand that I will be to interviewed to gain my opinions of what signs residents of the [redacted] demonstrate when they are experiencing sensory overload and what priority staff place on the meanings of leisure occupations discussed in the peer reviewed literature.

Contact for queries: Anne Fenech

International Fellow in Recreational and Leisure Activities

[redacted]

THIS COPY IS FOR THE SERVICE EVALUATION PARTICIPANT TO KEEP

Service evaluation Information Sheet

Service evaluation title

Investigation of engagement in 7 different casual leisure occupations with varying levels of sensory attributes with people with neurological disabilities, in long term residential care

Investigators:
Anne Fenech International Fellow in Recreation and Leisure Activities, Royal Hospital for Neuro-disability, West Hill, London SW15 3SW.

1. Invitation paragraph

You are being invited to take part in a service evaluation project. Before you decide it is important for you to understand why the service evaluation is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Please ask me if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

INVOLVE (a national advisory Group, which aims to promote and support active public involvement in health and social care service evaluation) publish a public information pack (Booklet 1 – "so what is it all about") attached. This booklet gives more information about health and social care research and looks at some questions you could want to ask. A copy of this booklet is attached to this information sheet. The contact details for involve are: INVOLVE, Wessex House, Upper Market street, Eastleigh, Hampshire, SO50 9FD.

2. Background

People with neuropalliative conditions find it harder to sift information received via their senses than before their case began. This means that they can be overloaded by sensory stimuli more easily than other people.

3. Aims

This service evaluation aims to establish whether leisure activities are more enjoyable and less overloading if they contain more or fewer sensory stimulation than normal.

4. Duration

The actual service evaluation will take about nine months from observing the leisure activities to sharing the results with you in a leaflet for carers and residents. The leisure activities, which will be observed, will last for 45 minutes each. Each person will be observed during 8 leisure activities.

5. Why have I been chosen?

I am inviting all residents who take part in leisure activities and who are willing to be involved to be part of this service evaluation.

6. Do I have to take part?

It is up to you to decide. I will describe the service evaluation and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

7. What will happen to me if I take part?

An observer will be sitting in the room with you watching how you take part in the leisure activity. They will note down whether you seem to be enjoying the activity and are able to take part or whether you are not enjoying it.

8. Expenses

Because the leisure activities that you will be participating are available to you whether you participate in the service evaluation or not you will not incur any additional expenses.

9. What do I have to do?

You will not have to do anything new. I will simply be observing you taking part in the activity in the same way that you normally would.

10. What is the procedure that is being tested?

The leisure activities that you will be participating in are already available to you at the Royal Hospital for Neuro-disability; they are not new or specially arranged for the service evaluation project.

11. What are the possible disadvantages and risks of taking part?

Taking part in this service evaluation will not affect your right to take part in any future sensory-based leisure activities because your name will not be on the notes. If you make any suggestions Social and Recreation Service will be encouraged to take them into account in the future.

12. What are the possible benefits of taking part?

I hope that the service evaluation will help you to have your 'voice' heard because your views and opinion count. The information I get from this service evaluation could help me to create a better way of offering leisure opportunities and could benefit future people affected by brain damage.

13. **What happens when the service evaluation stops?**

You will continue to have access to the leisure activities that you wish to participate in.

14. **What if there is a problem?**

If you find it disconcerting being watched, the observer will stop, or move depending on your preference.

If you have a concern about any aspect of this service evaluation, you can speak to me in the first instance and I will do my best to answer your questions. I can be contacted on 07980 919545. If you feel that the issue remains unresolved please speak to my supervisor Yvonne Lewis (Director of Clinical Services) 0208 780 4552

If you wish to make a formal complaint you can do this through the hospitals' complaints procedure by contacting Helen Mills, Head of Risk Management on Tel: 0208 780 4520 or email hrmills@rhn.org.uk.

15. Will my taking part in this service evaluation be kept confidential?

All information that is collected about you during the course of the service evaluation will be kept strictly confidential, and any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised.

16. What will happen if I don't want to carry on with the service evaluation?

You can stop participating in the service evaluation at any time. This will not affect your right to participate in any leisure activities, neither will it affect you care.

17. What will happen to any samples I give?

You will not be asked to give any samples as part of this service evaluation project

18. Will any physiological or genetic tests be done?

No physiological or genetic tests will be conducted as part of this service evaluation project

19. What will happen to the results of the service evaluation?

You will not be identified in any report/publication. The results of the service evaluation will be discussed in a seminar for staff, will be published in a peer reviewed journal and will be presented to participants and visitors to the Royal Hospital for Neuro-disability in a leaflet and at the Royal Hospital for Neuro-disability "meet the service researcher's" which is held annually. They will contribute to the PhD thesis of the International Fellow in Recreation and Leisure Activities.

20. Who has reviewed this service evaluation?

The Research Committee of the Royal Hospital for Neuro-disability (Prof Keith Andrews [Director of Institute], Dr Elaine Pierce [Head of Research & Development Support Unit], Dr Wendy Magee [International Fellow in Music Therapy], Dr Ceri Bowen [International Fellow in Working with Families], Mark Baker [International Fellow in Nursing in Neuropalliative conditions], Dr Sophie Duport [Research Governance Manager], Jose Spring [Research Co-ordinator]) and Yvonne Lewis (Director of Clinical Services), have reviewed this service evaluation.

Further information and contact
For further information, please contact:

Anne Fenech
International Fellow in Recreational and Leisure Activities
The Institute of Neuropalliative Rehabilitation
Royal Hospital for Neuro-disability
West Hill London SW15 3SW
Telephone: 020 8780 4500 xii 5140
Email: aFenech@rhn.org.uk

Thank you for considering taking part in this service evaluation.
The participant will be given a copy of the information sheet and a signed consent form to keep and a copy will be placed in their care plan notes.

ATTACH PUBLIC INFOResidence ManagerATION PACK HERE

LEISURE SATISFACTION EVALUATION PARTICIPANT'S CONSENT FORM

(The leisure satisfaction evaluation participant should complete the whole of this sheet himself/herself. If they are unable to, a member of staff should complete the form under instruction from the leisure satisfaction evaluation participant and in the presence of a witness.)

15th February 2008

Study Title: Investigation of engagement in 6 different casual leisure occupations with varying levels of sensory content with individuals with neuropalliative conditions, in long term residential care

Investigator:
Anne Fenech [redacted]

Have you read the Information sheet about this service evaluation project??

Yes

No

Have you had the opportunity to ask questions and discuss this service evaluation project?

Yes

No

Do you know how long your part in the service evaluation project will take?

Yes

No

Have you received enough information about the service evaluation project?

Yes

No

Who have you spoken to? (write name).....

Do you understand that you are free to withdraw from the study: at any time; without having to give a reason?

Yes

No

Do you understand that the information obtained will be kept confidentially?

Yes

No

Do you agree to take part in this study?

Yes

No

NAME OF SERVICE EVALUATION PARTICIPANT: [redacted]

Signed Date:

If service evaluation participant is unable to write, signed on their behalf by:

[redacted]

Signed date:

WITNESS

[redacted]

Signed: Date:

NAME OF INVESTIGATOR: Anne Fenech

Signed [redacted] Date: 15th February 2008

THIS COPY IS TO BE RETURNED TO ANNE FENECH

A copy of the guardian consent form

LEISURE SATISFACTION EVALUATION PARTICIPANT'S CONSENT FOR

(The leisure satisfaction evaluation participant should complete the whole of this sheet himself/ are unable to, a member of staff should complete the form under instruction from the leis evaluation participant and in the presence of a witness.)

15th February 2008

Recreation and Leisure Services

11 February 2008 Ref: Ladder to the Moon 2008

Dear [redacted]

The theatre project Ladder to the Moon will be in residence on Evitt, Glyn and Hunter ward from the 25th-29th February. This project will enable individuals to have the opportunity to get involved in interactive with the opportunity to help direct a new storyline!

I would be grateful if you could express your consent for your family member's participation in the project by completing the attached slip at the end of this letter. As this project develops, with new ideas and storylines during the week, there will be some photographic recording to enable us to show how much enjoyment has been achieved from the project. Please complete the attached consent form and do outline if you do not wish your family member to be involved with photography, this will not affect his/her ability to participate.

My colleague Anne Fenech *International Fellow in Recreational and Leisure Activities* is undertaking a service evaluation investigating engagement in 6 different casual leisure occupations with different sensory content, one of which will be this project. All information relating to this is enclosed and I would be grateful if you could sign the consent form if you are happy for your relative's inclusion in the evaluation. Anne will be taking observations in the project and the participant will not be required to contribute in anyway and a decision to not be involved will not affect his/her participation or enjoyment of the project in any way. Please return all information directly using the stamped addressed envelope by the week ending **22nd February.**

I would like to take this opportunity to invite you to come and join in with the project and to see what the project is all about. I hope that your relative enjoys the project, and I look forward to any feedback that you may have regarding this new opportunity. If you have any questions about the information requested or about the theatre project, please do not hesitate to contact me directly,

Yours Sincerely,

I agree to my father taking part only on the condition that should he become distressed at any point then he is withdra from the study immediately

[redacted]

Name of Participant: [redacted] Ward [redacted]

I do~~not~~ wish my family member to be involved with the interactive theatre project Ladder to the Moon which is taking place on my ward in the week commencing 25th February 2008.

Signed: [redacted] .....

Signed by on behalf of (please outline your relationship): [redacted]

Print Name [redacted] Date [redacted]

Appendix xv Publications contributed to by the researcher

Fenech, A. Shaw-Fisher, K. (2012) Lifelong Leisure And Therapeutic Recreation In Zasler, Katz, & Zafonte, Brain Injury Medicine: Principles And Practice (2nd Ed) New York: Demos Medical Publishing

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Fenech, A. Sadlo, G. (2008) Being, belonging but not doing: a special case of occupational deprivation? Public Journal of Occupational Therapy available from http://www.ot.public-journal.com/Downloads/details/id=28.html accessed 09/08/2012

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Appendix xvi The influence of the researcher's publications on papers published by other authors

Following the examiners advise and to illustrate the unique contribution of this programme of research and its clinical implications, this appendix will demonstrate the influence of the researcher's publications on papers published by other authors.

An example of a publication by another author which drew upon the researcher's work will shortly be published in hard copy by Martelli *et al.* (2013) (but was available as an early online version in July 2012). Martelli *et al's.* (2013) literature review addressed some of the issues around adapting to disability for individuals with NPC. Consequently, it was suggested that a primary goal of community-based rehabilitation is community participation and integration (Martelli *et al.,* 2013). As part of this, Martelli *et al.* (2013) drew upon Fenech & Shaw-Fisher (2012) when they recommend a thorough assessment of environmental influences on participation. Furthermore, they also drew upon Fenech & Shaw-Fisher (2012) when they suggest that leisure is an important attribute of identity and life satisfaction. Martelli *et al.* (2013) took their argument further to suggested that, employment-focused views of productivity neglect the roles which are meaningful for the individual and which could be linked to non-vocational, leisure, family roles and productive relationships, community service and learning and education. Martelli *et al.* (2013) drew heavily on the researcher's work and in particular, on Fenech & Shaw-Fisher (2012) when discussing the benefits of leisure, the meaning derived from leisure and the participant's sense of occupational balance in relation to quality of life, adjustment to disability and well-being. Further, they suggested that an inability to maintain previous leisure occupations could reinforce uncertainty about the future, proposing yet again, that leisure satisfaction could be a predictor of quality of life.

Likewise, Wensley & Slade (2012) drew upon Fenech (2008) in their interpretative phenomenological approach study to suggest that both the leisure occupation and the individual's occupational preference and capacity should be assessed, to adapt it appropriately to his or her abilities. This reflects the occupational analysis of the participants as a group and the individual occupations observed/ cases presented in chapter five.

Heung & Yuen Loke (2012) drew upon Fenech (2008) when they suggested that barriers to leisure participation could include past experiences, lifestyle, educational level, social constraints, low income, and lack of support from others. They further drew upon Fenech (2008) when they suggested that life satisfaction could be derived from choosing their leisure activities freely, because this contributed to a sense of personal identity, social well-being and coping with negative life events.

Baker (2012) suggested that individuals with NPC experience environmental barriers, issues of lack of choice, and issues of decision-making capacity; being highly dependent across the lifespan, and cited Fenech (2008) to reinforce his argument. He suggested that the complexity of care required for adults with these conditions was beginning to be reflected in the literature across a range of disciplines such as music therapy; psychology, family therapy, occupational therapy, leisure and recreation, and more interdisciplinary care. However, all this research was conducted at the home studied in this thesis, at about the same time and so used the same resident population for his studies. The home has a

reputation for caring for the most disabled individuals receiving residential care in the UK, which is why it created its institute (to share and investigate good practice); but it could be argued, that the evidence base behind neuropalliative rehabilitation is skewed towards it's practice at present.

Cook *et al.* (2012) conducted a systematic literature review upon which they based their 'Guidelines for Occupational Therapists working with people with Huntington's disease' with a view to describing the occupational-performance problems experienced by individual's with Huntington's disease, and the associated role of the occupational therapist. These clinical guidelines drew on Fenech & Baker (2008) (describing it as an expert opinion) to recommend the use of the sensory profile to draw up a leisure based sensory diet as a way to engage residents with severe cognitive dysfunction amongst their symptoms, in occupations. This recommendation mirrors the researcher's advice to the home, which was not taken up by its management (as it was regarded as an unnecessary intrusion on residents' privacy). Despite this, the researcher had a sense of preaching to the converted when discussing this issue with Occupational Therapists working there. However perhaps these guidelines will reinforce the researcher's message, and by depersonalising it and escalating it to a European level, could make it more palatable to the home directly, as well as influencing the wider domain of Huntington's Disease management.

In another article, which cited Fenech (2008), Li-Tang Chiang (2011) described leisure time agriculture or "occasional farming" as having the potential to grow as an industry, as more city dwellers and retirees wish to experience a more natural way of life. This win-win situation is where city dwellers could experience an authentic farm experience as a form of holiday, while farmers get some much-needed labour e.g. working in the fields, planting, irrigating, and harvesting crops. Li-Tang Chiang (2011) used a convenience sample of 515 Taiwanese temporary occasional farmers, to explore leisure preferences, expectations, constraints and benefits (social, educational, and physiological). Li-Tang Chiang (2011) concluded that gender, age, marital status, education level, employment type, and income had a significant impact on leisure preferences, constraints, and benefits.

In another article, which cited Fenech (2008), Soriano & Batson (2011) suggested that while spontaneous joy and other positive emotions of the moment were difficult to quantify and capture (drawing on Fenech, 2010), positive emotions such as enjoyment or satisfaction could be demonstrated in part by attendance (as opposed to absence) and by verbal participation, which would appear similar to Kishida and Kemp's (2006) definition of active engagement.

Mackenzie & O'Toole's (2011) book about occupational analysis in practice drew upon Fenech (2008) to suggest that supporting engagement in leisure occupations involves adapting the occupation, using assistive technology, changing the environment or experimenting with new leisure occupations which satisfy the needs of the individual. This book upheld a point made in this thesis that leisure gains in importance for individuals with a disability (even acting as an alternative), when employment is not available. Despite this, they suggest that there is a persistent undervaluing of leisure roles, which could influence the self-image of an individual with a leisure lifestyle through no choice of their own. This is something that the researcher experienced, particularly when gathering data for a study of the priority placed on the meanings derived from leisure. This study collected data from biomedical model orientated staff who appeared to place meaning and personal identity low on their list of considerations when determining interventions with residents. At about the time that Mackenzie & O'Toole's (2011) book was being published, this study of priorities was removed from this thesis because of advice from the thesis supervisors.

Baker (2011) drew upon his work with the researcher (Fenech and Baker, 2008) to suggest that for relatives of individuals with NPC, spending time together could help in strengthening their sense of partnership, positive use of leisure time, and social contacts. This would appear to link to the outcomes of the service evaluation about Aquability, which the researcher had conducted in 2008. One of the recommendations of Fenech (2011) was to facilitate family members desire to join their relatives in the pool sometimes. Another example of residents and families learning and playing together was both the interactive video installation mentioned in chapter five and the making music group, both of which seemed to bring out the child in all participants, thus levelling them so that intergenerational leisure was enjoyable.

Spring et al (2011) cited Fenech's work when they focused on gardening to increase sensory stimulation through the visual, tactile and olfactory stimulation of individuals with NPC. This article did not describe its literature search or data collection methodology. Consequently, its conclusions that gardening could be a diversionary occupation, offering 'important' sensory fulfilment, and thus was suited to residential settings, should be treated with caution in the light of the suggestion made Resulting from the preliminary study that individuals with NPC could experience sensory-overload. Furthermore, Spring (2011) stressed that like the occupations observed in chapter five, gardening offered a range of sensory experiences to support participation, group cohesiveness, well-being and motivation. Whilst welcomed, this recommendation should also be treated with caution given the lack of sensory profile assessment undertaken at the home, the apparent risk of sensory-overload (which will therefore not be made explicit) and the homes precedent of using inundating multi sensory suites with all the stimulation switched on, as opposed to tailored to their sensory preferences.

Baker & Shears (2010) work-based, professional education workshops, and the subsequent article which they published focusing on issues of sex and sexuality training for care professionals, suggested that individuals living with NPC may have significant cognitive, behavioural, physical and communication needs, presenting environmental barriers, limited choice, and issues of capacity and decision-making. To support this argument they drew upon Fenech & Baker (2008) and suggested that these needs resulted in challenges for staff working with this client group.

In 2009; Fenech and Baker's (2008) definition of NPC's was replicated in several papers. These included, Baker *et al.* (2009) who described them as 'rare' and more 'common' conditions with significant cognitive, behavioural, communication and physical needs which are specific and diverse. Similarly, Baker & Kakora-Shiner (2009) acknowledged Fenech & Baker's (2008) description of NPC as being either rare or more common conditions in their advanced stages. They suggested that these could influence emotional wellbeing and relationships, making such individuals prone to social isolation and a sense of exclusion from the day-to-day activities, which could further complicate the achievement of a good quality of life due to having limited opportunities to engage in self-determined occupations and enjoyable use of their free time. Further they drew upon Fenech and Baker (2008) to suggest that such individuals may find that free time activities were enforced because they have nothing else to do. They also drew upon Fenech and Baker (2008) to suggest that being socially or achievement-orientated leisure may contribute to self-identity and creativity. Additionally they drew upon Fenech and Baker (2008) by suggesting that for leisure occupations to be meaningful, they should include a sense of importance, purpose and meaning for the person, along with opportunities for achievement and expression of creativity. Following Fenech and Baker's (2008) example they also endorsed the importance of leisure supporters identifying and

enabling casual leisure activities, through personalising and adapting the individual's environment and creating a sense of privacy. Another article, by Baker and Blumlein (2009), drew upon Fenech and Baker's (2008) description of NPC by saying that they are made up of common and rare neurological conditions, which affect the brain. When discussing Huntington's Disease, Baker and Blumlein (2009) suggested that significant cognitive, behavioural, communication and physical needs may result and therefore may have a wide-ranging influence on occupational performance.

Stonier's (2008) case study presented a multi-sensory approach to creative event planning. This article drew upon Fenech 2008, Fenech & Baker 2008 and Fenech 2009 (in press at the time) to argue that although care-giving in a home should focus on holistic "person centred" care, with leisure and recreation being an essential part of maintaining quality of life; there was still a need for large, social leisure events and creative projects. This type of large seasonal event could be considered to contribute to the range of (or balance of) leisure opportunities experienced.

Broadhurst et al's. (2008) case study based article (also part of the special edition and contributed by staff at the home) drew upon a literature review on the home's website (Royal Hospital for Neuro-disability, 2005) to suggest that the role of the leisure supporter is to ensure that the occupation is adapted to fit the person and not the other way around. They suggested that there was a need for analysis of the individual and the occupation to enable a fit between the two (Royal Hospital for Neuro-disability, 2006), and that without suitable adaptation, an individual could not be able to access a leisure occupation (Royal Hospital for Neuro-disability, 2007). This was a predictable message given that the authors were Occupational Therapists. This article used case studies to demonstrate this, and how leisure could be accessed as part of lifelong leisure as well as during the rehabilitation phase of an individual's recovery. Their approach was different to that used by Shaw-Fisher in Fenech & Shaw-Fisher (2012) which appeared to be less individual focussed, and more procedural once the recreational activity had been selected. This could not be surprising given the definitions of recreation and of leisure given in 1.2. Here recreation was described as the revitalisation resulting from the pursuit of leisure occupations, but those which were prescribed (and whose regimen was quite concrete) rather than being freely chosen and made ever more meaningful through their participation (Buettner *et al.,* 2010). It is interesting therefore to reflect on the difference in philosophy between the professions of Shaw-Fisher (a Recreational Therapist) and Fenech (an Occupational Therapist). Having worked together on their book chapter Shaw-Fisher was considering retraining as an Occupational Therapist, but the researcher wonders whether the close but quite different philosophies would be very difficult to transcend.

In 2007, Gage wrote about the Interactive Drama Project that 'People's reactions have been just amazing, from not interacting at all to interacting astonishingly well', thus directly quoting the researcher, (whom he had interviewed). Additionally in his 2006 article, Gage described how actors from professional theatre company, performed an interactive version of Shakespeare's Romeo and Juliet as part of a nine-month project. This was available to six hospitals across South West London and was designed to engage residents by bringing them a stimulus outside of the everyday. He then again directly quoted the researcher who said that "The residents have really enjoyed having xxxxxx in the hospital,". "The performances engaged residents entirely. To begin with most just watched what was happening, but by halfway through the placement, they were playing musical instruments or acting as characters in the play."

Summary

This section will discuss what the researcher has learned from other authors who cited her work and from her own critique of her publications. One of the frustrations of the fellowship was the repeated message from peer reviewers that "no one is that disabled". However using the commonly used assessments (at the home) also left her readers baffled as to the message that they gave and so perhaps they are not as widely used in the context of rehabilitation as she had thought. However, Baker (2012) suggested that individuals with NPC experience environmental barriers, issues of lack of choice, high levels of dependence, and issues of decision-making capacity. This divergence of perception about levels of disability is interesting in the light of the periodic "right to life" cases heard at the high court. These could give the impression that such cases are very rare but professional who work with individuals with profound levels of disability could regard this level of disability as more mainstream since this is their main experience when practicing.

It is interesting to note the influence of the researcher on practice, some of it positive and some of it perplexing. For example the article by Cunningham et al (2012), discusses Aquability, the use of the ICER and the sport of Boccia at the home four years after the end of the fellowship. Furthermore, Cook *et al.* (2012) recommended the use of the sensory profile to draw up leisure based sensory diets as a way to engage residents with severe cognitive dysfunction amongst their symptoms, in occupations. While Baker (2011) suggested that for relatives of people living with NPC, spending time with the individual could help in strengthening their sense of partnership, positive use of leisure time, and social contacts. Stonier (2008) argued that although individualised leisure was important; there was also a need for social leisure events. So some of the researcher's work is still in use; for example Aquability, the use of the ICER, relatives engaging in leisure with their resident and the sport of Boccia at the home. It is hoped that Cook *et al's.* (2012) recommendation about the use of the sensory profile to draw up leisure based sensory diets could be taken on board at some point too.

Spring et al (2011) suggested the need to increase sensory stimulation for individuals with NPC. This should be treated with caution, (in the light of the preliminary study) given the lack of sensory profile assessment undertaken at the home. Therefore, it appears that the message about sensory-overload could not have been fully appreciated, despite the wealth of medical research that is emerging about sensory gating deficits in individuals with NPC.

Wensley & Slade (2012), Mackenzie & O'Toole (2011) and Broadhurst *et al.* (2008) all suggested that the role of the leisure supporter is to ensure that an activity is adapted (based on an occupational analysis) to fit the person and not the other way around and that without suitable adaptation (to the occupation and the occupational environment), an individual could not be able to access a leisure occupation.

The most exciting thing though is that Martelli *et al.* (2013) recommended an assessment of the occupational environment since the authors are Doctors and Psychologists. Furthermore, they suggested that leisure is an important attribute of identity, self and life satisfaction, meaning and occupational balance, which was very gratifying, since occupational science, is a fairly new academic discipline and only by breaking into new domains like leisure science and medical texts books will it get widely known.

The point of sections 6.1, 6.2 and 6.3 was to enable the researcher to improve her work outputs, as well as developing skills in receiving feedback. In a way, these sections have also helped her to further understand quality

standards and assessment criteria when related to her own work as opposed to her own struggle to critically appraise the work of other writers. This could help to rebuild her confidence to present her ideas and answer questions about them, becoming an expert in her own learning. Despite being a compatriot of Robert the Bruce, she has a lot to learn about persistence and resilience. Hard lessons have been learned during the critiquing process, for example, Fenech (2010) did not provide a clear rationale for the chosen methodology and also failed to provide a substantive literature review, additionally a lack of experimental rigour reduces the reliability and validity of the findings. Fenech (2005) also fell short of the requirements for a literature review, but was valuable as an overview of the importance of leisure in the lives of the general population and of the costs of losing meaningful occupations on the unemployed and disabled. The article highlighted the need for meaningful leisure occupations for individuals with NPC and for more research to be conducted in this area. Fenech & Baker (2008) provided useful insight into leisure occupation and sensory diets, but lacked detail about the results of assessments and linkage to sensory stimulation theory as understood by an Occupational Therapist. Furthermore, the article could have been greatly improved by detailed consideration of the influence of factors such as age, severity of condition, cognitive abilities, environment, and the use of technology. Indeed, this would have enhanced the external validity of the valuable information contained within the article. Fenech (2008) could have been improved by providing a more structured argument, and more examples. Fenech (2009) presented survey results in the text and in tables in the appendices. However, the findings need to be interpreted with caution and further similar studies should be conducted in a variety of long-term care facilities, perhaps using a variety of methodologies. Fenech (2011) again provided the results of observations in tables to allow for replication, whilst emphasising the need for further research in this area. Resulting from policies within the home experimental conditions were not ideal and so the findings should be interpreted with caution; with an awareness that Aquability could be accountable for some but not all of the positive outcomes experienced by participants. Further research, with more rigorous experimental conditions could shed further light on the true impact of Aquability, especially if conducted using a longitudinal design or a different control group.

When critiquing her publications and this thesis it became clear that the researcher's writing style lacked rigour because of flaws such as not describing literature sampling methods, difficulties with structuring arguments and backing these up with specific examples. Addressing these issues and conducting further research in a variety of long-term care facilities, using a variety of rigorous experimental research methodologies, could therefore improve the quality of further publications, but this requires support from research supervisors.

Appendix vii3 The raw data from the time sampled observations of engagement excluding field notes

KEY to Raw Observation of engagement data using the ICER

	Code allocated during data collection	
Active non-engagement	1	- interacts with the environment in an inappropriate manner by manipulation/movement and/or vocalisation
Passive non-engagement	2	- does not interact with the environment and does not do what is expected during the activity.
Undifferentiated engagement	3	- interacts with the environment automatically/ repetitively
Passive engagement	4	- interacts with the environment without manipulation or vocalisation.
Active engagement	5	- participation with the environment appropriately/ manipulating materials or vocalising.

Raw Observation of engagement data from the control group using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45- 46	median	average for each resident
Resident 1	2	2	2	2	2	2	2	2	2	2	2	2
Resident 2	2	2	2	2	2	2	2	2	2	2	2	2
Resident 3	2	2	2	2	2	2	2	2	2	2	2	2
Resident 4	2	2	2	2	2	2	2	2	2	2	2	2
Resident 5	2	2	2	2	2	2	2	2	2	2	2	2
Resident 6	2	2	2	2	2	2	2	2	2	2	2	2
Resident 7	2	2	2	2	2	2	2	2	2	2	2	2
Resident 8	2	2	2	2	2	2	2	2	2	2	2	2
Resident 9	2	2	2	2	2	2	2	2	2	2	2	2
Resident 10	2	2	2	2	2	2	2	2	2	2	2	2
Resident 11	2	2	1	2	2	2	1	2	2	2	2	1.8
Resident 12	2	2	2	2	2	2	2	2	2	2	2	2
Resident 13	2	2	1	2	2	2	2	1	2	2	2	1.8
Resident 14	2	2	2	2	2	2	2	2	2	2	2	2
average for each time sample	2	2	1.9	2	2	2	1.9	1.9	2	2		

Raw Observation of engagement data from the listening occupation using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45- 46	median	average for each resident
Resident 1	4	4	4	4	2	2	2	2	2	2	2	2.8
Resident 2	4	2	2	2	2	2	2	2	2	2	2	2.2
Resident 3	4	2	2	2	2	2	2	2	2	2	2	2.2
Resident 4	4	4	4	2	2	2	2	2	2	2	2	2.6
Resident 5	4	4	2	2	2	2	2	2	2	2	2	2.4
Resident 6	4	4	1	1	1	1	1	1	1	1	1	1.6
Resident 7	4	4	4	2	2	2	2	2	2	4	2	2.8
Resident 8	4	4	4	4	4	2	2	2	2	2	3	3
Resident 9	4	4	4	4	4	2	2	2	2	2	3	3
Resident 10	4	4	4	4	2	2	2	2	2	2	2	2.8
Resident 11	4	4	4	4	4	4	4	4	4	1	4	3.7
Resident 12	4	4	1	1	1	1	1	1	1	1	1	1.6
Resident 13	4	4	4	4	4	4	4	1	1	1	4	3.1
Resident 14	4	1	4	4	1	4	2	2	2	2	2	2.6
average for each time sample	4	4	3	3	2	2	2	2	2	2		

Raw Observation of engagement data from the Watching a Film show occupation using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	median	average for each resident
Resident 1	4	4	4	4	4	4	4	3	3	3	4	3.7
Resident 2	4	4	4	4	4	4	4	4	4	4	4	4
Resident 3	4	4	4	4	4	4	4	4	4	4	4	4
Resident 4	4	4	4	4	4	4	4	4	4	4	4	4
Resident 5	4	4	4	4	4	4	4	4	4	4	4	4
Resident 6	4	4	4	4	4	4	4	4	4	4	4	4
Resident 7	4	4	4	4	4	4	4	4	4	4	4	4
Resident 8	4	4	4	4	4	4	4	4	4	4	4	4
Resident 9	4	4	4	4	4	4	4	4	4	4	4	4
Resident 10	4	4	4	4	4	4	4	4	4	4	4	4
Resident 11	4	4	4	4	4	4	4	4	4	4	4	4
Resident 12	4	4	4	4	4	4	3	3	3	4	4	3.7
Resident 13	4	4	4	4	4	4	4	4	3	3	4	3.8
Resident 14	4	4	4	4	4	4	4	4	4	3	4	3.9
average for each time sample	4	4	4	4	4	4	4	4	4	4		

Raw Observation of engagement data from the Spectating at a live performance occupation using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	median	average for each resident
Resident 1	4	4	4	4	4	5	5	4	4	4	4	4.2
Resident 2	5	4	5	4	5	4	4	5	4	4	4	4.4
Resident 3	4	4	4	5	5	5	4	4	4	5	4	4.4
Resident 4	5	5	5	5	5	4	4	5	4	5	5	4.7
Resident 5	2	2	2	4	4	5	5	2	2	4	3	3.2
Resident 6	5	5	5	4	4	5	5	4	5	4	5	4.7
Resident 7	4	4	5	5	5	5	5	5	5	5	5	4.8
Resident 8	5	4	5	5	5	5	5	4	5	5	5	4.8
Resident 9	4	4	4	5	4	5	5	4	2	2	4	4.3
Resident 10	2	2	2	2	5	5	5	4	5	5	4.5	3.6
Resident 11	5	5	5	5	5	5	5	5	5	5	5	5
Resident 12	2	2	2	2	2	2	2	2	2	2	2	2
Resident 13	5	5	5	5	4	4	4	5	5	5	5	4.7
Resident 14	5	5	5	5	5	3	3	3	4	5	5	4.3
average for each time sample	4	4	4	4	4	4	4	4	4	4		

Raw Observation of engagement data from the interactive video installation occupation using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	median	average for each resident
Resident 1	4	5	5	5	5	5	5	5	5	5	5	4.9
Resident 2	4	5	5	4	5	5	5	5	5	5	5	4.8
Resident 3	4	4	4	4	4	4	4	5	5	5	4	4.3
Resident 4	4	4	4	4	4	4	4	5	5	5	4	4.3
Resident 5	5	5	5	5	4	5	5	5	5	5	5	4.9
Resident 6	5	5	5	4	4	5	4	4	5	5	5	4.6
Resident 7	5	4	5	4	4	4	4	4	4	4	4	4.2
Resident 8	5	5	5	5	4	4	5	5	5	5	5	4.8
Resident 9	4	4	5	5	5	5	5	5	4	4	5	4.6
Resident 10	5	5	5	5	5	5	5	5	5	5	5	5
Resident 11	4	5	5	4	5	5	5	5	5	4	5	4.7
Resident 12	5	5	5	5	5	5	5	5	5	5	5	5
Resident 13	4	5	4	4	4	4	4	4	4	4	4	4.1
Resident 14	4	4	4	4	4	4	4	4	4	4	4	4
average for each time sample	4	5	5	4	4	5	5	5	5	5		

Raw Observation of engagement data from the making music group occupation using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	median	average for each resident
Resident 1	5	5	4	5	5	5	5	5	5	5	5	4.9
Resident 2	5	5	5	5	5	5	5	5	5	5	5	5
Resident 3	5	5	5	5	5	5	4	5	5	5	5	4.9
Resident 4	4	5	5	5	5	5	5	5	4	5	5	4.8
Resident 5	4	5	5	5	5	5	5	5	5	5	5	4.9
Resident 6	4	4	4	5	5	5	4	5	5	5	5	4.6
Resident 7	5	5	5	5	5	5	5	5	5	5	5	5
Resident 8	4	4	2	2	4	4	4	4	5	5	4	3.8
Resident 9	5	5	5	4	5	5	5	4	5	5	5	4.8
Resident 10	4	4	4	5	5	5	4	4	5	5	4.5	4.5
Resident 11	4	4	5	5	4	5	5	5	5	5	5	4.7
Resident 12	4	5	4	5	4	5	5	5	5	5	5	4.7
Resident 13	5	5	5	5	5	5	5	5	5	5	5	5
Resident 14	5	4	5	4	4	4	5	5	5	5	5	4.6
average for each time sample	5	5	5	5	5	5	5	5	5	5		

Raw Observation of engagement data from the Interactive drama occupation using the ICER

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20 -21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	median	average for each resident
Resident 1	4	4	5	5	5	5	5	5	5	5	5	4.8
Resident 2	4	4	5	5	5	5	2	2	4	4	4	4
Resident 3	4	4	5	5	5	5	4	4	1	1	4	3.8
Resident 4	4	4	5	5	5	5	5	5	4	4	5	4.6
Resident 5	5	4	5	5	5	5	5	4	5	5	5	4.8
Resident 6	5	5	4	4	4	4	4	4	4	4	4	4.2
Resident 7	5	5	4	4	5	5	5	5	4	4	5	4.6
Resident 8	5	5	5	4	4	5	5	4	5	4	5	4.6
Resident 9	5	5	5	5	5	1	1	1	1	1	3	3
Resident 10	5	5	5	5	5	3	3	3	4	5	5	4.3
Resident 11	5	5	5	5	5	4	4	5	4	5	5	4.7
Resident 12	5	5	5	5	5	4	5	5	5	5	5	4.9
Resident 13	5	5	5	5	5	5	5	5	5	5	5	5
Resident 14	5	5	5	5	5	5	5	5	4	4	5	4.8
average for each time sample	5	5	5	5	5	4	4	4	4	4		

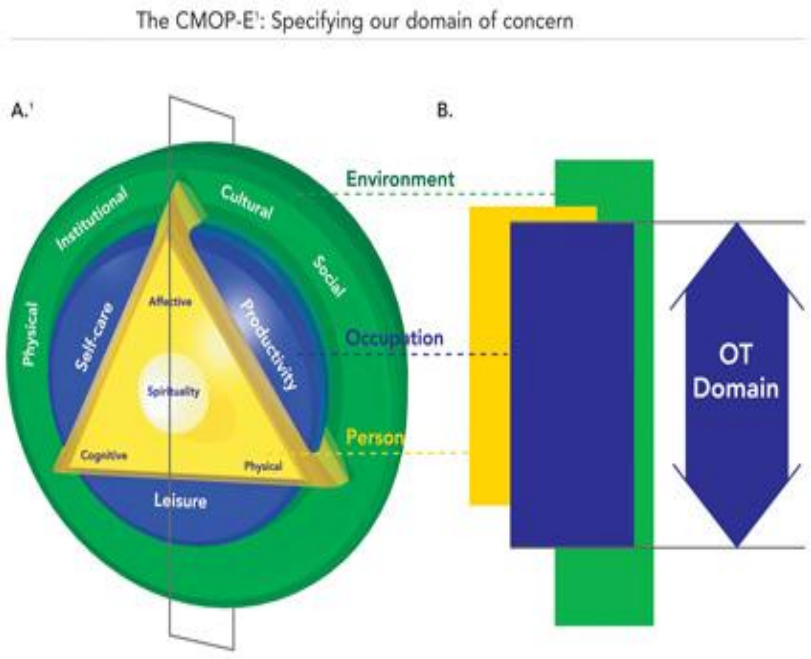
Raw Observation of engagement data from the Aquability occupation using the ICER

	Minute 1 - 2	**Minute 5-6**	**Minute 10 - 11**	**Minute 15 - 16**	**Minute 20 -21**	**Minute 25 - 26**	**Minute 30 - 31**	**Minute 35 - 36**	**Minute 40 - 41**	**Minute 45-46**	**median**	**average for each resident**
Resident 1	5	4	5	4	4	4	5	4	4	5	4	4.4
Resident 2	5	5	5	5	5	5	5	5	5	5	5	5
Resident 3	5	5	5	5	5	5	5	5	5	5	5	5
Resident 4	5	5	5	5	5	5	5	5	5	5	5	5
Resident 5	5	5	5	5	5	5	5	5	5	5	5	5
Resident 6	5	5	5	5	5	5	5	5	5	5	5	5
Resident 7	5	5	5	5	5	5	5	5	5	5	5	5
Resident 8	5	5	5	5	5	5	5	5	5	5	5	5
Resident 9	5	5	5	5	5	5	5	5	5	5	5	5
Resident 10	5	5	5	5	5	5	5	5	5	5	5	5
Resident 11	5	5	5	5	5	5	5	5	5	5	5	5
Resident 12	5	5	5	5	5	5	5	5	5	5	5	5
Resident 13	5	4	5	5	5	5	5	5	5	4	5	4.8
Resident 14	5	5	5	5	5	5	5	5	5	5	5	5
average for each time sample	5	5	5	5	5	5	5	5	5	5		

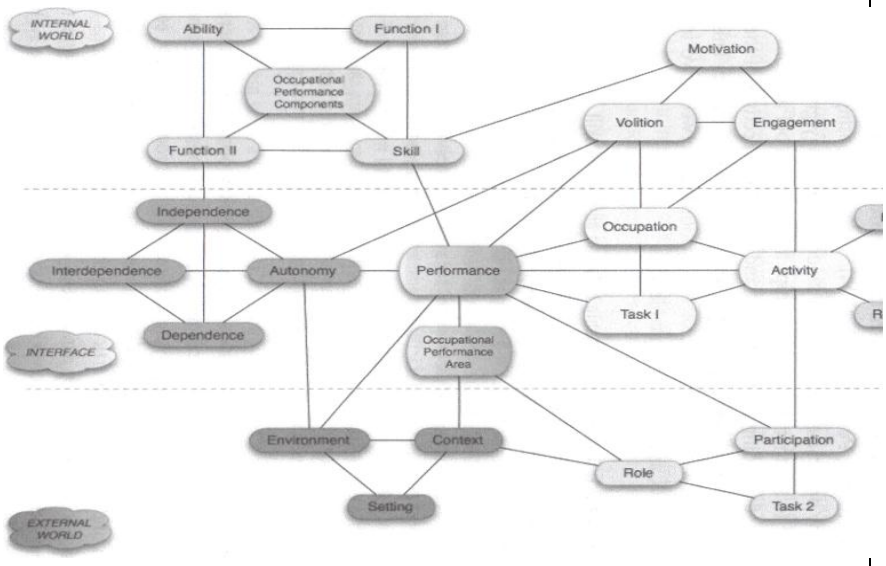
Glossary

Before reading the current study, please be aware of the glossary, which defines terms, which have a specific meaning to an Occupational Therapist, which is different from its use as a lay term e.g. human occupation. It also defines terms, which the researcher had to differentiate during the research process. Apart from serious and casual leisure it does not differentiate between the very specific and different meanings to a leisure scientist e.g. leisure and recreation, since in the domain of occupational therapy they are relatively indivisible.

Ability	A personal characteristic that supports occupational-performance (ENOTHE, 2006)
Active Leisure	Active leisure involves the expenditure of energy (physical or mental). Low-impact physical activities include walking and yoga, which make low energy, socialisation and competitiveness demands. High-impact activities such as dancing, kickboxing, aerobics and football are more energetic and competitive. Other active leisure involves almost no physical activity, but requires considerable mental effort, such as playing chess or painting a picture.
Active Participation	Humans viewed as active agents in their own development i.e. taking an active role (either physically or mentally).
Activity	A sequence of the actions recognisable and observable that, taken together in a particular context.
Activity	An activity is an observable unit of behaviour which has observable or determinable temporal beginning & end points (Suto 1998) A set of tasks with a specific end point or outcome that is greater than that of any constituent task (Townsend & Polatajko (2007) p19
Activity	A structured series of actions or tasks that contribute to occupations (ENOTHE, 2006).
Activity analysis:	A process of dissecting an activity into its component parts and task sequence to identify its inherent properties and the skills required for its performance, thus allowing the therapist to evaluate its therapeutic potential (Creek, 2003).
Activity grading:	Manipulating the component parts of an activity, or the factors required for the performance of a task or activity, to meet therapeutic goals (Creek, 2003).
Activity synthesis:	Combining activity components and features of the environment to produce a new activity that will enable performance to be assessed or achieve a desired therapeutic outcome (Creek, 2003)
Activity	A series of linked episodes of task performance by an individual which takes place on a specific occasion during a finite period for a particular reason. Activity is characteristic of and essential to human existence. (Creek, 2003)

Adaptation	Adaptation is the process of change in behaviour in response to new or different circumstances.
Agnosia	Agnosia is a loss of ability to recognise objects, persons, sonds, shapes, or smells while the sensory receptor organs remain fully functioning.
Alexia	Alexia is the inability to recognise text.
Anomia	Anomia is a word-finding problem leading to an inability to name objects or recognise the name of objects. This involves perception not comprehension or the capacity to repeat the words, since the individual could describe the objects function accurately without being able to recall its name.
Apraxia	Apraxia inability to carry out learned purposeful movements, despite having the desire and the physical ability to do so, it is not caused by in-coordination, sensory loss, or failure to comprehend simple commands (which can be tested by asking the person to recognise the correct movement from a series).
Aquability	This is a participant-controlled leisure occupation during which a resident which uses the pool for fun. The participant can decide what to do, choose the music, the lighting and other environmental options
Bipedal	Ability to walk on two feet
Body functions	(a client factor, including physical, cognitive, psychosocial aspects) - "the physiological function of body systems (including psychological functions)" (WHO, 2001, p. 10)
Body structures -	"anatomical parts of the body such as organs, limbs, and their components [that support body function]" (WHO, 2001, p. 10)
Canadian Model of Occupational-performance (CMOP-E)	

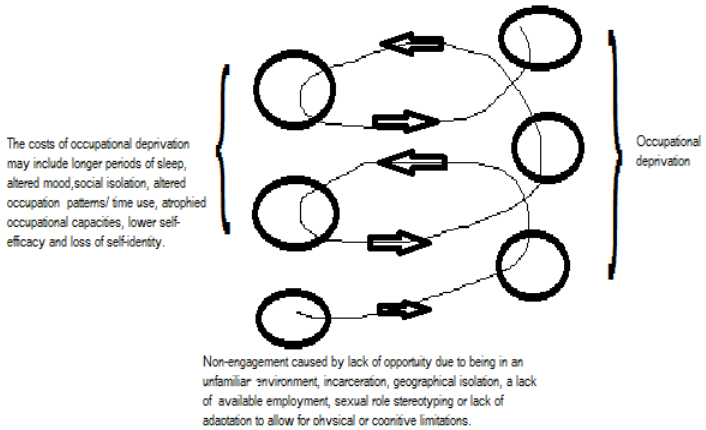
Casual Leisure	An immediately pleasant activity which is intrinsically rewarding and relatively of short duration which demands little or no special training to enjoy. It can be subdivided into play (including dabbling), relaxation (sitting, napping, strolling), passive entertainment (some TV, books, recorded music), active entertainment (games of chance, party games), sociable conversation, and sensory stimulation (sex, eating, drinking).
Choreaform Movements	Choreaform movements are jerking or writhing movements, progressing to random, uncontrollable, and perpetual twitching which impair coordination; which absent during sleep.
Client Factors:	Those factors that reside within the client and that may affect performance in areas of occupation. Client factors include body functions and body structures. Body functions and structures are considered when determining which functions and structures are needed to carry out an occupation/activity and how the body functions and structures may be changed as a result of engaging in an occupation/activity.
Code of Ethics:	"Ethical standards that apply to occupational therapy personnel at all levels" (Penny & Slater, 2006). See Occupational Therapy Code of Ethics and Ethics Standards (American Occupational Therapy Association, 2010).
Collaboration:	To work together with a mutual sharing of thoughts and ideas (ACOTE glossary).
Committed Occupations	Have a work or productivity character but not usually renumerated – non market production
Competency:	Performance, knowledge, and skill abilities requisite for fulfilling the responsibilities of the given practitioner's generic position (Wilson, 1977, p. 574)
Context:	Refers to a variety of interrelated conditions within and surrounding the client that influence performance. Contexts include cultural, physical, social, personal, spiritual, temporal, and virtual (AOTA, 2008).
Contracted Occupations	Involve paid productivity or formal education
Cultural Awareness	Understanding of the similarities & differences in attitudes, values, beliefs & customs between themselves & people from other countries or other backgrounds (i.e. People with a different worldview)
Cultural Competency	An awareness of, sensitivity to and knowledge of the meaning of culture.
Cultural Safety	Is about positive attitudinal change towards those who are culturally different from ourselves and
Culture	"Culture is the shared knowledge and schemes created by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them" (Lederach,p. 9,1995). "Culture has been defined in a number of ways, but most simply, as the learned and shared behavior of a community of interacting human beings" (Useem & Useem,p. 169, 1963).
Domain of concern:	The scope of occupational therapy practice, including the people with whom

	occupational therapists work, the issues with which they are concerned, the purpose of occupational therapy intervention and the roles taken by occupational therapists (Creek, 2003)
Dysgraphia	Difficulty writing due to reduced fine motor skills and could experience mixed hand dominance, or hand-to-hand incoordination. It could not affect all fine motor skills, but can result in writing skills, which are below average, despite reading ability being intact.
Dysphagia	Dysphagia is a difficulty, or partial inability to swallow because of injury to the brain or the nerves that control swallowing or the muscles involved in swallowing.
Dyspraxia	Dyspraxia is a difficulty carrying out learned purposeful movements, despite having the desire and the physical ability to perform the movements. It is not caused by in-coordination, sensory loss, or failure to comprehend simple commands.
Efficacy:	Having the desired influence or outcome (Neistadt & Crepeau, 2003).
Embedded occupation	An occupation implanted within or surrounded by another such as doing one thing at the same time as doing another (e.g. using laptop computer whilst commuting on a train).
Empowerment	Empowerment is the process of increasing ability by offering choices to enhance actions and outcomes.
Enablement	Enablement is the catalyst, means or opportunity to make someone able, or of instituting that change.
European Conceptual Framework for Occupational Therapy	 Creek (2010)
Evidence-based Practice:	"Conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based [health care] means integrating individual clinical expertise with the best available external clinical evidence from systematic research" (Sackett, 2000, p.2)

Flow	The mental condition in which the individual is completely engrossed in what they are doing, feeling excited by, focussed on and fully involved in an occupation. Familiar terms for this or similar mental states include being on the ball, in the zone, or in the groove.
Free Time Occupations	Time left over after other 3 types of occupations are completed. Does not necessarily entirely consist ofleisure. Can include occupations we feel obligated to undertake such as weddings or family functions, work functions.
Frequently experienced	Experienced regularly, totally familiar i.e. Occurring or appearing quite often or at close interval, habitual or regular
Function1	The underlying physical and psychological components that support occupational-performance (ENOTHE, 2006)
Function2	The capacity to use occupational-performance components to carry out a task, activity or occupation (ENOTHE, 2006)
Habits	Relatively automatic, repetitive patterns of human behaviour
Health	Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.(WHO, 1946).
Hemianopia	Hemianopia is an inability to perceive light, colour, and object from half of the visual field
Hyperlexia	Hyperlexia involves an average or above average ability to recognise text or numbers. Hyperlexic individuals could have an exceptional ability to decode language and thus could become very early readers. Hyperlexia is the opposite of a/ dyslexia.
Interactive Drama	Interactive Drama is a form of theatre in which the audience's interventions become part of the performance.
Justice	"the establishment or determination of rights according to the rules of law or equity" http://www.merriam-webster.com/dictionary
Lifestyle Balance	A pattern of occupations resulting in reduced stress & improved well-being
Lifestyle Imbalance	Imbalance that occurs when there is difficulty meeting physical social and psychological needs, there are too many or too few role demands or there is inadequate time (perceived or actual) to meet daily demands
Live Performance	A performance performed before an audience, in real time.
Low Sensory Registration	Low Sensory Registration results from a high neurological threshold to be reached before sensory stimulation is noticed and a passive self-adjustment strategy.

Macroflow	Deep flow occupation where challenges and skills are balanced leading to a full range and depth of experience
Making Music Group	Playing of well-known music for participants to sing along to, dance to or accompany.
Meaning:	Significance, importance. Meaning is highly personal and predominantly Contextual (Creek, 2003).
Meaningful:	Full of meaning, significant. An activity is meaningful if it is intentional andif it has some significance for the person carrying it out (Creek, 2003).
Microflow	Embedded inconsequential occupations that will bring enjoyment to otherwise low-skill and low-challenge activities e.g. doodling, chewing gum or humming
Multi Sensory Environment (MSE)	A non-directive multi or uni sensory experience, which adapts the lighting, atmosphere, sounds, and textures to the specific needs of the individual at the time of use.
Multisensory	Multisensory involving many senses
Necessary Occupations	Necessary occupations are human occupations that meet basic physiological and self-maintenance needs and therefore amount to necessary time usage.
Necessary Occupations	Necessary occupations are human occupations that meet basic physiological and self-maintenance needs and therefore amount to necessary time usage.
Necessary Occupations	Occupations that meet basic physiological and self maintenance needs including eating, sleeping/ rest, sex, personal care (Bathing, toileting, grooming)
Neurological Thresholds	The quantity of stimulation required so that the nervous system notices it. Humans need a balance between low and high thresholds to maintain attention and consciousness.
Neuro-Occupation	Neuro-Occupation involves a combination of the concepts of neuroscience and human occupations. Human occupations and their embedded routines emerge because of dynamic neurological processes whereby the brain is in a state of expectation and thus sensitive to internal and external events.
Neuropalliative	Neuropalliative services offer palliative care to individuals with progressive neurological disorders that are incurable but not unmanageable. Rehabilitation involves the interaction of specialist neurology, rehabilitation and palliative care services.
Neuroplasticity	Neuroplasticity enables the reorganisation of neural pathways and functions in response to adding, re-routing or removing connections.
Neurorehabilitation	Neurorehabilitation is the restoration of autonomy and of meaningful and necessary roles and abilities following neurological illness or because of neurological disability.

Neurotypical	Typical neurological ability to process sensory information, language and social cues which enables neurological development and function, within the normal range of neurodiversity.
Nominal Data	Nominal data includes values, which can be assigned a numerical labels, i.e. they can be counted but not ordered e.g. eye colour could produce categorical data such as, Blue=1, green=2, brown=3.
Novel	Not experienced before i.e. new, unusual, or different
Occupation	'our occupations are all the active processes of looking after ourselves and others, enjoying life, and being socially and economically productive over the lifespan and in various contexts' (Townsend, 1997,p19) 'the activities people engage in throughout their daily lives to fulfil their time give their life meaning' (American OT Association, 1997,p864) An activity or set of activities that is performed with some consistency & regularity that brings structure & is given value & meaning by individuals & a culture (Townsend & Polatajko (2007) p19
Occupation	A group of activities that has personal and sociocultural meaning, is named within a culture and supports participation in society. Occupations can be categorised as self-care, productivity and/or leisure (ENOTHE, 2006)
Occupation(S)	Occupations are the things that individual's do to occupy life and move towards planned outcomes such as paid work, unpaid work, self-care, care of others, leisure, recreation, or subsistence. They are organised, and given meaning by individuals and their context.
Occupation:	The highest level of complexity of human function which provide longitudinal organisation of time and effort in a person's life. Occupation defines and organises a sphere of action over a period of time and is perceived by the individual as part of her/his personal and social identity (Creek, 2003).
Occupation:	Ordinary and extraordinary things people do in their day-to-day lives that occupy time, modify the environment, ensure survival, maintain well-being, nurture others, contribute to society, and pass on cultural meanings and through which people develop skills, knowledge, and capacity for doing and fulfilling their potential (Hocking, 2008).
Occupational Alienation	The sense of insignificance, purposelessness, frustration, and loss of control that results from occupational-engagement that are not satisfying.
Occupational Alienation	Is the outcome when people experience daily life as meaningless or purposeless.Eg. People who live in aged care facilities who are required to participate in occupations that they find meaningless
Occupational alienation:	A sense that one's occupations are meaningless and unfulfilling, typically

	associated with feelings of powerlessness to alter the situation (Creek, 2003).
Occupational Apartheid	The separation between those who can engage in meaningful and necessary occupations and those who are occupationally deprived
Occupational Balance	The extent to which we are able to organise and participate in occupations in a manner congruent with our aspirations and values is referred to as occupational balance.It is a perceived state of satisfactory participation in valued, obligatory and discretionary activities; and occurs when the impact of occupations on one another is harmonious, cohesive and under control.
Occupational behaviour:	Active engagement in occupation; the developmental continuum of work and play (Creek, 2003)
Occupational Capacity	
Occupational Competence	Changes in occupational behaviour over time are as a result of the development of*occupational competence.*Competency is developed along a continuum from *novice to mastery*. Trial & error and practice are needed for developing competence.
Occupational Deprivation	A state of long-standing exclusion from engagement in necessary or meaningful occupations, which the individual cannot control. O'Sullivan and Hocking (2006) and Hearle *et al.* (2005), described the insidious effects of occupational deprivation. They suggested that as individuals do less, they lose capacity. When doing gets harder, occupations become less rewarding and individuals are less motivated to try, so they do less. 
Occupational Deprivation	Engagement in occupations of necessity and/or meaning are limited due to external factors that are generally outside their control. Eg. Children who are deprived of opportunities and resources to play because of poverty or childhood disability.
Occupational	Having few occupations and/or being deprived ofopportunities to participate

deprivation:	in a repertoire of occupations which would normally be expected at a certain age within a particular culture (Creek, 2003).
Occupational Development	A repertoire or collection of occupations and occupational patterns, beginning at birth and continuing across the lifespan, resulting from an interaction of the genetic makeup of the individual and the environment in which they live.
Occupational Development	The systematic process of change in *occupational behaviours* across time
Occupational Disruption	A temporary limitation to participation in meaningful occupations.
Occupational Disruption	"When a person's normal pattern of occupational-engagement is disrupted due to significant life events, environmental changes, becoming ill or sustaining an injury from which full recovery is expected" (Whiteford, p. 201, 2000)
Occupational-engagement	An individual's participation (performance, thoughts and emotions) under certain environmental conditions, which involve choice, motivation and meaning.
Occupational-engagement :	Attention or commitment to an undertaking; fascination or involvement with an activity or interest so that the attention is held fast. (Creek, 2003)
Occupational form:	The sociocultural and physical characteristics of an occupation that exist independent of the person engaging in the occupation and that influence the occupational-performance of the individual (Creek, 2003).
Occupational Habits	Recurring and mainly automatic patterns of time use within the context of daily occupations.
Occupational Imbalance	A state whereby health and life satisfaction are compromised due to the lack of occupational diversity.
Occupational Imbalance	When there is a lack of congruence across occupations or between occupations & one's core values.Occupational imbalance can be due to over or under occupation.
Occupational imbalance:	A lack of variety in occupation; an undue focus on one occupation or category of occupation to the exclusion of others (Creek, 2003).
Occupational Injustice	Occurs where structural & contextual factors impede the occupational rights of individuals, groups or communities.The outcomes of occupational injustice are occupational imbalance, marginalisation, deprivation & alienation.
Occupational Justice	The part of social justice that is applicable to human occupation or a lack of opportunity.

Occupational Justice	Recognises humans as occupational beings who need and want to participate in occupations to develop and thrive.Access to occupations of personal meaning and societal value is seen as a right. Outcomes of occupational justice are conceptualised as having one's occupational rights met
Occupational Marginalization	Occurs when people are not afforded the opportunity to participate in occupations to exert choices and decision making related to occupational participation. Eg. People with disabilities are excluded from employment opportunities and have few expectations that employment is possible
Occupational Participation	The engagement of the individual in goal-directed pursuits.
Occupational-performance	The act of undertaking an occupation. The physical, mental and emotional part of completion or doing of occupations, could involve observable movement or attributes.
Occupational Performance	Occupational-performance is the ability to choose, organise and satisfactorily perform meaningful occupations that are culturally defined, age appropriate for looking after oneself, enjoying life and contributing to the social & economic fabric of the community (CAOT, 1997) Performance of all the activities that make up the individual's lifestyle. influenced by a person's physical, cognitive psychosocial and environmental factors. Changes across the lifespan The interaction between a person the occupations they perform and the environment in which they act is bi-directional. People respond to the change in the environment and people adapt the environment to suit their needs. Occupations result from the intentional & particular behaviour of a particular person in interaction with particular aspects of the environment.
Occupational-performance Areas (ENOTHE)	Categories of tasks, activities and occupations that are typically part of daily life. They are usually called self-care, productivity and leisure.
Occupational-performance Components (ENOTHE)	Abilities and skills that enable and affect engagement in tasks, activities and occupations. These can be categorised, for example, as physical, cognitive, psychosocial and affective.
Occupational-performance Environment (ENOTHE)	External factors that demand and shape occupational performance. These factors are physical, sociocultural and temporal.
Occupational performance:	The actions of the individual elicited and guided by the occupational form (Creek, 2003).
Occupational Performance:	The ability to carry out activities of daily life. Includes activities in the areas of occupation: ADL (also called BADL and PADL), IADL, education, work, play, leisure, and social participation. Occupational-performance is the accomplishment of the selected

	activity or occupation resulting from the dynamic transaction among the client, the context, and the activity. Improving or enabling skills and patterns in occupational-performance leads to engagement in occupations or activities (AOTA, 2008).
Occupational Perspective	'The exclusive contribution that occupational therapy brings to a multi-discipline health environment is a profound understanding of enabling occupation.' (Wilding, C. 2010)
Occupational Possibilities	The set of occupations that exist at any given place and time across the evolution of the human species that provide opportunities for engagement and participation.
Occupational Potential	Potential for occupational capacity due to holding the prerequisite skills, knowledge and abilities to undertake an occupation. This develops over time to encompass and reflect the characteristics of the individual and the environment.
Occupational Profile:	A profile that describes the client's occupational history, pattern of daily living, interests, values and needs (AOTA, 2008).
Occupational Repertoire	The array of occupations that an individual has at a specific point in time is their *occupational repertoire.*
Occupational Rights	The right to: Experience occupation as meaningful and enriching. Develop through participation in occupations for health and social inclusion. Exert individual or population autonomy through choice in occupations. Benefit from fair privileges for diverse participation in occupations (balance).
Occupational Role	Social and cultural norms and expectations of occupational-performance that are associated with the individual's social and personal identity
Occupational Roles	A culturally defined pattern of occupation that reflects particular routines and habits.Patterns of behaviours that involve certain rights & duties that an individual is expected, trained and often encouraged to perform in a particular social situation.
Occupational Routines	Recurring sequences of time use, such as the regimen repeated upon waking.
Occupational Science	A field of study concerned with understanding human occupations, humans as occupational beings and the connection between health and occupation(s).
Occupational Science Perspective	Occupation encompasses everything that people do that has purpose, meaning and / or value. Occupation is a fundamental aspect of being human and shapes our identity as individuals, groups and societies. Occupation and its meaning, relevance and importance is defined culturally, economically, socially, politically and geographically. Occupation is dynamic changing over time and across the lifespan.

Occupational Transition	A point in time where there is a shift away from a particular set of occupations toward an alternative occupation or set of occupations.
Occupational/Activity/Task performance (ENOTHE)	Is choosing, organising and carrying out occupations/activities/tasks in interaction with the environment.
Occupationally Just World	A utopian vision of a world that enables individuals to flourish by doing what they decide is most meaningful and useful to themselves and to their communities.
Ordinal Data	Ordinal data could be counted and put in a natural order or ranked. The difference between data points is not necessarily the same.
Participant	Someone who takes part (physically, mentally or emotionally) in an activity or who consented to take part in the studies discussed in this thesis.
Passive Leisure	Involves little or no physical or mental energy, such as watching a film, or arcade games. They could not provide the benefits offered by active leisure activities but could be relaxing nevertheless.
Passive Participation	Concept that views humans as passive agents, taking a non-involved role or making a passive contribution.
Perseverating	Perseverating is the repetition or perseverance of a particular word, phrase, activity or gesture, despite the absence or cessation of a stimulus.
Physically Active Occupation	Requiring movement or action to join i.e. Involving or requiring physical exertion and energ(ENOTHE, 2006)y
Physically Passive occupation	Happening around the participant without any action from the individual. i.e. Receiving or subjected to an action without responding or initiating an action in return
Prosopagnosia	Prosopagnosia results in difficulty recognising and perceiving faces, while perception of other objects could be intact. Individuals could use 'piecemeal' or 'feature by feature' recognition strategies based on information such as clothing, hair colour, body shape, and voice to recognise people.
Protection of Vulnerable Adults Policy or POVA	Some adults are less able to protect themselves than others and some have difficulty making their wishes and feelings known. This may make them vulnerable to abuse. Consequently the home has an organisational policy which is updated every 3 years and which sets out how the organisation will enable its patients and residents to live free from fear or harm and have their rights and choices respected.
Residents	The entire population of individuals who live in the home.
Routines	Habitual, repeatable & predictable ways of acting
Sensation Avoiding	Avoidance behaviour because of a combination of low neurological thresholds and a proactive self-monitoring of sensory stimulation.

Sensation Seeking	Seeking sensation because of high neurological thresholds and a proactive self-monitoring of sensory stimulation.
Sensorimotor	Integrating both sensory and motor aspects of the body.
Sensory Adaptation	A change in the responsiveness of the sensory system to a constant stimulus, so that it is no longer recognised.
Sensory Attribute	A characteristic, aspect, trait, feature or element which could generate sensory stimulation if it is detected by a sensory receptor organ.
Sensory Gating	The process, by which the brain gate keeps, excludes or ignores unnecessary or unwanted stimuli to prevent over-stimulation. It helps the brain focus on a stimulus. It involves feed-forward and feedback inhibition of the stimulus perceived.
Sensory Habituation	A decline in response following repeated stimulation, caused by impeded vigilance by sensory organs (eye, skin, ear and so forth) especially when the stimuli will be presented quickly, which results in a decrease in behavioural responses.
Sensory Hypersensitivity	Over detection of stimulation resulting from low neurological thresholds that enable all stimulation to be noticed and a passive self-monitoring of sensory stimulation.
Sensory Integration	The process that organises sensory stimulation to enable occupational performance. This is the result of sensory attributess all feeding in to the RAS to give a comprehensive understanding of the internal and external environment.
Sensory Modulation	The ability to regulate behavioural responses proportionally to sensory stimuli. Individuals with increased levels of arousal could appear over responsive to sensory attributes (sensory defensive or sensitive). Individuals with a decreased level of arousal could appear under responsive to sensory input (sensory dormancy or low registration). Both extremes of modulation could be seen in one individual, but generally, one tends to dominate. Both interfere with sensory processing.
Sensory Processing	The process used by the nervous system uses to receive, organise and understand sensory input, thus making the individual aware of what is going on both around (e.g., from auditory and visual input) and within their body (e.g., from touch, joint receptors).
Sensory Regulation	A sensory environment, which neither over arouses nor habituates the patient, introducing limited stimulation interspersed with periods of rest.
Sensory Sensitisation	Enhancing the detect-ability of sensory stimuli.
Sensory Stimulation	To contribute energy because of invigoration or rousing of the senses - vision, audition, tactile, olfactory, gustatory, vestibular or proprioceptive.
Sensory Threshold	Threshold which sensory stimulation needs to exceed to be noticed.

Sensory-deprivation	The reduction or removal of sensory stimulation.
Sensory-overload	A condition where one or more of the senses are bombarded by stimuli to the point that it becomes difficult to focus on an occupation.
Serious Leisure	The structured pursuit through time, effort and perseverance, of a volunteer, amateur, hobby activity, leading to benefits such as special skills, knowledge, experience, social-identity and ethos.
Skill	An ability developed through practice which enables effective occupational-performance (ENOTHE, 2006)
Somatosensory	The perception and processing of sensory stimuli received via sensory detection organs.
Spect-Actors	Someone who is both a spectator and a participant in a performance
Spectator	Watcher, letting the activity happen around them, maintaining a passive role not actively participating
Spiritual:	"A deep experience of meaning by engaging in occupations that involves the enacting of personal ideologies, reflection, and intention within a supportive contextual environment" (Billock, 2008, p.91).
Supporter	This could be a staff member, a family member, a friend, or a volunteer. They act as someone upon whom to rely as a structural attribute or who promotes the interests of, facilitates the ability of or advocates for another.
Supporter To Participant Ratio	Amount of staff to each participant
Symptomatology	Symptomatology includes symptoms and how they combine to present patterns of diseases
Task	A series of structured steps (actions and/or thoughts) intended to accomplish a specific goal. This goal could either be: 1. The performance of an activity. or 2. A piece of work the individual is expected to do. (Enothe, 2006)
Tasks	A set of actions having an end point or a specific outcome (Townsend & Polatajko (2007) p19
Theory:	"An organized way of thinking about given phenomena. In occupational therapy, the phenomenon of concern is occupational endeavor. Theory attempts to (1) define and explain the relationships between concepts or ideas related to the phenomenon of interest, (2) explain how these relationships can predict behavior or events, and (3) suggest ways that the phenomenon can be changed or controlled. Occupation therapy theory is concerned with four major concepts related to occupational endeavor: person, environment, health, and occupation." (Neistadt & Crepeau, 2003).

Unisensory	Unisensory involving one sense
Work-Life Balance	The ability of individuals to manage the demands of both their paid employment & the rest of their lives.
Work-Life Conflict	A lack of 'fit' between goals of the employees & their responsibilities outside work and the goals of the organisation. Refers to the impact work has on individual stress, relationships & family well-being

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