UNIVERSITY OF SOUTHAMPTON

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

School of Psychology

Volume 1 of 1

An exploration into the challenges faced by parents of children with physical and/or psychological difficulties, and how an improved understanding of these challenges can help to inform the design and delivery of interventions, especially those involving co-therapy.

by

James Southwood

Thesis for the degree of Doctor of Clinical Psychology

May 2016

Word Count: 24,212 (excluding quotes)

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

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AN EXPLORATION INTO THE CHALLENGES FACED BY PARENTS OF CHILDREN WITH PHYSICAL AND/OR PSYCHOLOGICAL DIFFICULTIES, AND HOW AN IMPROVED UNDERSTANDING OF THESE CHALLENGES CAN HELP TO INFORM THE DESIGN AND DELIVERY OF INTERVENTIONS, ESPECIALLY THOSE INVOLVING CO-THERAPY.

James Southwood

The ability for parents to be directly involved and engaged in the implementation of clinical interventions for their child, can be both efficacious and key to improving the quality and usefulness of care for families and young people (Ingoldsby, 2010; Nock & Ferriter, 2005; Haine-Schlagel & Walsh, 2015). Chapter one is a systematic review examining the evidence for this position, with particular attention paid to the parental experiences of involvement during therapeutic interventions. The review identified fourteen studies with a variety of interventions, both physical and psychological in nature, from eight countries. The results suggested that five key themes were pertinent to parental experiences. These were: *the change in family life*, *the need to become expert in delivering interventions*, *the challenges that families faced*, *distress and uncertainty of the parent* and *the relationships parents had with health staff*. Each of these themes were explored, in depth, within the review and implications for practice and further research areas are identified.

Chapter two of this thesis is an empirical paper describing a study that used qualitative methodology to explore the lived experiences of eight parents of a child with a learning disability. The aim of the study was to learn more about parental experiences of implementing a psychological intervention for their child. Interpretative Phenomenological Analysis (IPA) was used to capture the subjective meanings that parents described about their experiences and four superordinate themes were identified, which were: *Adapting and changing, Developing confidence, Working with services* and *Building support*. These findings were consistent with previous literature suggesting that changes need to be made to services to better enable parents to access support. Clinical implications and suggestions for future research are provided.

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DECLARATION OF AUTHORSHIP

I, James Southwood, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

An exploration into the challenges faced by parents of children with physical and/or psychological difficulties and how an improved understanding of these challenges can help to inform the design and delivery of interventions, especially those involving co-therapy.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. 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 stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. 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;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed: ....

Date: ....

Acknowledgements

I would like to thank everybody who made this project possible. I am especially thankful to the parents who participated in the research interviews, for providing such honest and generous accounts of their experiences. I am also particularly grateful to Dr Helen Fairchild, Lorraine Bleakley and Erica Goddard, for their support in promoting the research and helping to facilitate interviews. Thank you to Dr George Johnson and Dr Emma Hines for their supervision throughout the project. I would especially like to acknowledge my sister, Dr Katherine Southwood, for her contribution and guidance, and my parents for providing unending encouragement and championing the merits of education and learning. A further thank you is owed to my Doctoral cohort for providing the emotional support needed when embarking on a project of this scale.

Chapter 1: Systematic Literature Review: Parental experiences of implementing therapeutic interventions for their child.

1.1 Introduction

The ability to engage both the child and their family within therapeutic treatment programmes has critically important clinical, implementation and policy implications for clinicians and commissioners striving to improve the quality and effectiveness of the care they are able to provide (Haine-Schlagel & Walsh, 2015). The current political climate both within the United Kingdom and abroad, has impacted upon and looks likely to further influence the evolution of health services, including the National Health Service (NHS) and the provision they are able to offer patients and their families (Karanikolos, Mladovsky, Cylus, Thomson, Basu et al, 2013). As a consequence of this, there has been increased interest in the ability of practitioners to attain and maintain engagement of young people and their families, as attrition rates and frequent cancellations dilute interventions, affect outcomes, and are costly to service providers (Spoth & Redmond, 2000; Gallucci, Swartz & Hackerman, 2014).

A high proportion of the National Institute for Health and Care Excellence (NICE) recommended treatments for children and young people are instructive, skills-based approaches that entail active child and parental participation both in and out of sessions and over the course of the treatment (Nock & Ferriter, 2005). While most research has focused on the effectiveness of the therapeutic content, basic level responsibility for attendance and adherence, which is pivotal to facilitating the child's engagement, mainly lie with the parent and is commonly overlooked.

In terms of the parental engagement literature, there has been quantitative attention paid to the demographics of patients and families that typically drop out of treatments. Such studies have highlighted risk factors such as low income, urban settings, and more severe mental health conditions, as well as client related factors such as low motivation or lack of rapport with the therapist (Snell-Johns, Mendez & Smith, 2004; Bados, Balaguer & Saldana, 2007). Even for families who are motivated to participate and do not fall into typically higher risk categories, gaining parental engagement within interventions remains challenging. Navigating a complex health system, overcoming service barriers as well as negotiating and understanding co-therapeutic roles, on top of the plethora of occurrences that can interfere with the treatment process, can mean that good day-to-day practice is not always enough on the part of clinicians to ensure engagement (Ingoldsby, 2010).

Further literature has questioned what constitutes parental engagement as a construct. Staudt (2007) proposes that parental engagement exists within two levels: *attitudinal* and *behavioural*. Attitudinal elements relate to the cognitive appraisal of treatments such as how helpful the treatment will be and motivational components such as willingness and cost-benefit analysis. The behavioural elements of engagement, Staudt suggests, have three stages which include initiation and help seeking, attendance, and active participation by both the parent and the child i.e. within sessions and at home. Research within this area has stressed that both attitudinal and behavioural engagement are necessary to produce meaningful parental engagement, highlighting that the attendance of a parent alone, does not represent the complex nature of participation (Nock & Ferriter, 2005; Israel, Thomsen, Langeveld & Stormark, 2007).

Most of the therapeutic modalities concerned with working with children acknowledge the significance of the family environment and the potential role of the parent as a facilitator or co-therapist (Goodall & Vorhaus, 2011). More specifically, within therapy a parent is able to provide a supporting role to both the child and the clinician, while also acting as intermediary for any potential miscommunications between the adult world of the therapist and the expert knowledge they have of their child. Furthermore, the parent is able to help implement homework plans and deliver interventions beyond that of the clinic or hospital boundaries. However, despite the cornerstone nature of the parental role, there is limited research into the parental experiences of implementing therapeutic interventions for their child, in particular qualitative research.

In order to address this gap in knowledge, this review explores the empirical evidence in a systematic fashion to address the question: *what are parental experiences of implementing therapeutic interventions for their child*? The objectives of the review are:

1. To review and appraise the quality of the evidence presented in the empirical papers.

2. To provide a narrative synthesis of the evidence.

3. To consider the clinical implications of the evidence in terms of working with parents to deliver psychological interventions.

4. To propose areas of future research.

By highlighting the foremost themes that occur when examining parental experiences, the review hopes to provide an insight into the degree of concordance between parents who have engaged with the interventions outlined in the reviewed studies. Gathering a better understanding of what parents are saying about engagement, the review hopes to present findings about what helped to accommodate full engagement as well as the barriers parents experienced when implementing therapeutic interventions for their child.

1.2 Methodological Approach

This review uses a systematic approach and a narrative synthesis in order to fully answer the research question concerning parental engagement within therapeutic interventions for their child. The aim of a review of this nature is to provide a structured critique of the research papers which claim to examine this particular phenomenon. In order to achieve this, there is an elevated degree of transparency within the research method to provide an accountable, replicable and updatable process (Furlan, Pennick, Bombardier & van Tulder, 2009).

The search for relevant research papers was conducted using the databases *PsychInfo* and *Web of Knowledge*. The search in both databases was conducted on 02nd November 2015. Both databases were searched using the same keywords in various combinations. The keywords used were: Father OR Mother OR Parent, Attitudes OR Expectations OR Experiences OR Involvement OR Role OR Training, and Treatment OR Therapy OR Intervention. The research terms were directly derived from the research question.

Articles were screened via the search engines to be available in English and published post the year 2000. This produced 249 articles which were further screened by inclusion criteria which included being published in a peer reviewed journal and excluding theses or dissertations, reported quantitative or qualitative data, and used parents as the research participants based on titles. From the screening this provided 79 eligible papers. Papers were omitted if they did not meet the inclusion criteria based on detailed reading of abstracts and some articles. Papers which did not meet the inclusion criteria were disregarded and 48 papers were read in order to review suitability. Further papers were excluded owing to being a case study, reporting on medical interventions, not being directly related to parental experiences, not being related to therapeutic interventions, not related to the parents' work with their own child, parents not implementing any intervention, a placebo study and review studies. This generated 14 relevant articles which were included in the review. Reference lists of the 14 studies were also considered for relevant papers which could be included in the review, but no further papers were added to the review. However, many papers were reviewed beyond the search strategy, most notably from before the year 2000, which were cited in the review to provide a contextual and theoretical explanation for the studies presented (See Figure 1: Flow chart: Study selection process).

The year 2000 was chosen as a cut off because the review wished to target parental experiences within a recent time frame i.e. the past 15 years, as opposed to more historical experiences which might reflect older forms of service provision. Papers were not screened for country of origin as the review hoped to consider modern parental experiences across a range of cultural healthcare systems under the hypothesis that there might be a ubiquitous or common nature in how parents experience implementing interventions, despite culture.

The final inclusion criterion for the fourteen published articles therefore were that the paper contained information relating to the experiences of mothers and/or fathers who had been involved in or were reporting on interventions or treatments for their child's physical or psychological health, that they were directly involved in assisting or helping to deliver. All of the papers were published in English, post the year 2000 and used either a qualitative or quantitative design and had a sample above one participant.

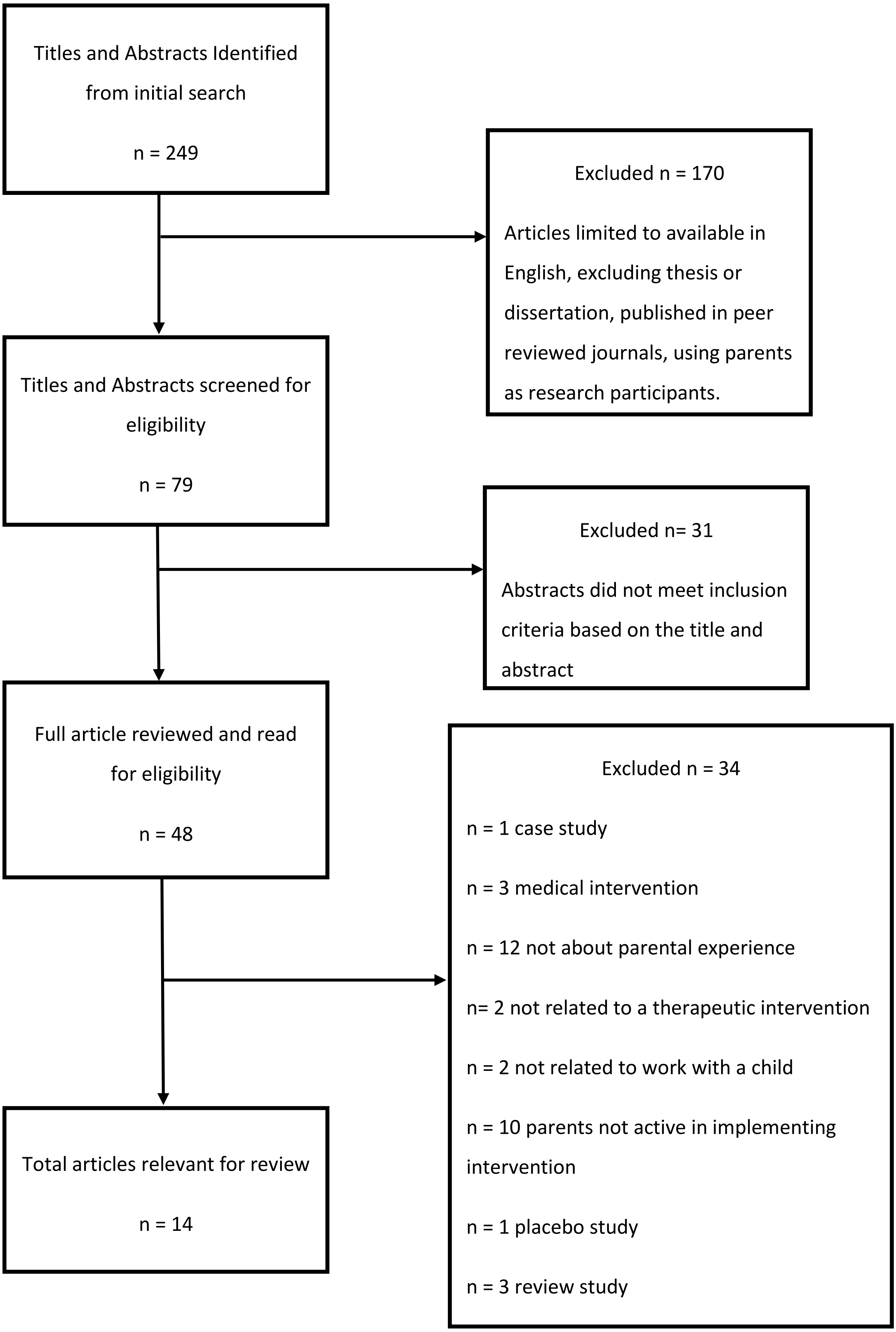
Each of the papers reviewed is outlined in the Descriptive Summary of Review Studies table (Appendix A). The review table outlines the research design that the study used, references the sample population who were included in the study, outlines the main research aim or objective, reports the main findings and evaluates the strengths and limitations of each of the studies.

While the advance in the accessibility of scientific evidence is helpful to researchers and clinicians, finding and evaluating the required evidence can be a difficult task. The reasons for this are likely to be multifactorial, however, it is vital that those looking to apply research evidence in practice are able to identify and appraise the relevant evidence. Consequently, it is vital that researchers use a good methodological approach, alongside the right tools, in order to assist in this process. Critical appraisal skills can support this practise, as they help to make sense of research methodologies, ensure reliability and help to certify that the right research will be selected as part of the evidence gathering procedure. The critical appraisal skills programme (CASP) allows for a systematic process by which the strengths and weaknesses of a research study can be categorised. The programme was first developed by Dr Amanda Burls in 1993 in order to aid clinicians and researchers in making sense of research methodologies, ensure reliability and draw the right conclusions from the research evidence. The programme has a virtual platform (www.casp-uk.net) which focuses on searching through various types of sources, which highlight the quality of the research by placing emphasis on rating reliability, methodological rigour, validity, the importance of the results and their application to the research needs. The website hosts several checklists to help lend direction for the researcher towards finding and reviewing particular types of research e.g. randomised-controlled trials, systematic reviews, case studies etc. This allows researchers and clinicians to screen for evidence that might be rated as low quality.

The programme is an established, valid, and reliable checklist for the assessment of the methodological quality of studies and was designed in order to assist clinicians on making decisions about the quality of the papers they are using to inform an evidence based approach. Adherence to this process enables the researcher to gather information on the usefulness of a study and its findings in an economical manner.

Therefore, each study was awarded a quality rating (see Quality Rating Chart, Appendix C). The quality rating was assessed using the CASP (Downs & Black, 1998). The researcher produced a quality rating chart (Appendix C) and rated each of the papers within the study with the criteria set out by the framework. The information, which was collated within the CASP, was not checked by any further researchers, but was discussed and read by the project supervisors.

Figure 1: Flow chart: Study selection process



1.3 Review Synopsis

This review details five core themes that were present within most of the 14 papers of the systematic search. The first to be discussed is that of the *changes to family life* that occur when parents have to undergo the diagnosis and treatment journey. Further categories of *Friends* and *Positive* are also explored as sub-themes as they were not present in a significant number of the studies but there was noteworthy mention in many of the studies. The sub-category of *Friends* looks at the social changes that many parents have to adjust to while *Positive* considers the secondary benefits of caring for a child during difficult circumstances. The second theme to be explored is the *expert role* that parents take on. The theme explores the transition many parents make from lay understandings to the detailed knowledge that they attain in order to implement interventions for their child. The third theme considered the *challenges* that were highlighted within the papers that parents often face. Further to this is a sub-category of *Money* which reflects on the issues around finance that parents within some of the studies commented on. The fourth theme is around *distress and uncertainty* which is about the personal and psychological challenges that parents were affected by throughout the therapeutic process. The final theme relates to parents' experiences of working with health *staff*. A table has been produced to demonstrate which themes appeared in which papers (Appendix B).

This review has considered parental involvement in both implementing psychological and physical health interventions. The physical health interventions involved cancer treatments, epilepsy, using sensory integration techniques, helping their child come to terms with and use tracheostomies and obesity interventions. Psychological interventions involved parents using services for children with a learning disability, psychosis, autism, ADHD and eating disorders. While the disorders the child had varied greatly, and the specifics of the parental involvement were to some degree disparate, the studies reported on both physical and psychological adjustment for the parents, perhaps reflecting the psychological effect of the physical health interventions e.g. weight management programmes, having a tracheostomy fitted and the experience of being diagnosed with cancer. Similarly, there often appeared to be physical consequences to psychological conditions such as anorexia and learning disability. In line with most current literature, it may be helpful to be aware that, where the primary target for an intervention the parent provided was either physically or psychologically orientated, there were also psychological consequences for physical health interventions or physical consequences for psychological interventions. Figure 2 outlines the core themes of the review whereby the themes were common to parents implementing both physically orientated and psychologically orientated interventions.

Figure 2: Core Themes of the Systematic Review

1.4 Results

1.4.1 The change in family life

Research within health literature has highlighted the adjustments families need to undertake when looking after a child with a medium to long term health condition (Patterson, Holm & Gurney, 2004; Tak & McCubbin, 2002). One of the initial changes that a family typically has to adjust to is the journey towards receiving a diagnosis for their child. Case (2001) highlights this theme in his research into parents of a child with a learning disability. Often the family are required to make an emotional change, that previous researchers such as Maxwell (1993) have called the parental bereavement process, for the loss of the “dream child” or healthy child. Research suggests that, in line with grief literature, parents will pass through familiar stages of grief, such as denial, anger, and shock (Manthorpe, 1995; Kubler-Ross, 2009). Despite this, as reported in Redmond and Richardson (2003), there is evidence of a commitment of parents to undertake their caring role as best they can, where few looked for care to be provided outside of the home environment. Case (2001) points out that, as in grief, most parents do not travel through such models with a linear trajectory and that health clinicians can help to empower parents by sensitively tailoring the information and support they offer (through increased awareness of how parents have understood and come to terms with the diagnosis and its process). Clarke and Fletcher (2004) highlight how overall the psychological scores for parents, in their study on children with cancer, around depression, anxiety, and stress were typically not much different to parents in "normal circumstances". However, during critical times such as diagnosis and relapse, scores would increase, suggesting that clinicians should be vigilant to the additional support that parents would require at critical stages in order to make a positive adjustment to change (Grootenhuis & Last, 1997).

Changes experienced by the families appeared to happen on a number of levels. The Benedetti, Garanhani and Sales (2014) study into parental experiences of delivering care for their child's cancer treatment, discussed the anxiety parents experience, as well as the practical changes to the home environment they had to make. They found that parents talked about the unexpected nature of taking up a caring role, which was not part of the plan that they had for their or their child's life. As part of adapting to this change they discussed remembering past strengths that they used to have and the difficulties they had encountered when remembering how their child used to be. In the study one parent is quoted as saying: "I do not like looking at photos of her… she was such a pretty child … and it is even bad to say it, but she became an ugly child, she got very swollen" (Benedetti, Garanhani & Sales, 2014 p,428). The parents described how their own lives in some cases had become unrecognisable, as they incorporated new and different habits into their routines in order to overcome some of the obstacles that having a child with a health condition posed. For example, the study quotes one parent who had to give up her pets and removed all of the carpets from her house owing to the decreased immunity that cancer brings. While these were necessary changes, the variety ranging from the emotional to the physical impact was described as a "striking and significant experience" (Benedetti, Garanhani & Sales, 2014 p428) on the lives of the parents within the study. The study by Benedetti, Garanhani and Sales (2014) does have limitations around generalisability however, meaning that the findings can only be considered tentatively.

One of the reasons the family make so many changes within the home are so that "normal life" is able to continue outside of it. Jones, Rodger, Broderick and De Monte (2009) interviewed families implementing treatment regimens for children with idiopathic arthritis. Parents within the study commented on the level of organisation needed to enable life to run smoothly, with one parent commenting: "It dominates our life… it means that almost every minute at home we're looking after her arthritis, so when she goes out the door she can do stuff her peers do" (Jones, Rodger, Broderick & De Monte, 2009, p253). Within the study parents commented that, to help facilitate the child's participation in prescribed exercises, the whole family took up the intervention and participated, incorporating it into their everyday tasks. Families commented that as well as ensuring participation, pairing treatment with everyday tasks meant not having to find additional time to complete interventions within their already busy schedules. Nonetheless, the study had a limited sample size and interviewed few fathers about their experiences, limiting the conclusions. The conclusions were also based upon prolonged engagement between the interviewer and participant which might also have biased the results. The study highlighted these concerns within its section of reflexivity.

Jones, Rodger, Broderick and De Monte (2009) explained that the increased responsibility parents took on for their child such as taking medications, completing exercises, teaching, and transporting their child to appointments, left many parents with a sense of conflicting roles, being both Mum or Dad, and carer. One parent is quoted: “I’m mum, nurse, doctor, psychiatrist trying to deal with her emotions, physically and emotionally” (Jones, Rodger, Broderick & De Monte, 2009, p254). Parents within the study noted the extra time spent with their child had been a side benefit, but described conflict in whether they felt this had brought them closer to their child. Some parents commented that they felt the parental bond had been lost as they were no longer just a parent.

Stewart, Chapple, Hughes, Poustie and Reilly (2008) in their study on parents’ management of obese children, found that how interventions were set up could also change the parenting style e.g. encouraging to controlling, leading to additional changes in the parent-child relationship. Furthermore, Jones, Rodger, Broderick and De Monte (2009) considered the impact on siblings, noting several parents’ concerns, that siblings had thought the other child now received “special treatment”, and parents worried that siblings had felt neglected. Tierney (2005) also found that siblings were described as coping well, or would distance themselves from the situation, which would lead to further parental concern around siblings “bottling things up” or becoming resentful. The study also found that most parents felt that health professionals overlooked the needs of siblings as the family environment changed. It is important to highlight that the study conducted by Tierney (2005) was a qualitative study using a conservative sample size. Therefore, the conclusions cannot be generalised beyond the research population in the study sample.

McNamara, Dickinson and Byrnes (2009) found that learning to manage their child’s treatment was a core theme among mothers in their study on parental input for children with tracheostomies. For the mothers in the study they had to learn not only to manage the condition, but also the technologies that assisted their child. As a consequence, the parents noted how getting up in the night involved managing both their child’s health needs as well as equipment. The additional sleep disruption led to exhaustion and being “in a fog” when carrying out day-to-day activities. Parents described management of care extending beyond health and safety and clinic appointments, extending into managing the ordering and delivery of medical supplies. For children with particularly complex health needs, there was also a requirement to run a “hospital at home” whereby professional caregivers frequent the home environment. Some parents reported this change as a negative impact, although most did not see this as changing the way they felt about their home, especially compared to the disruption caused by hospital admission (Wilson, Morse & Penrod, 1998). The paper also notes the division of labour between family members, with mothers being the main caregiver and other family members pulling together to offer the mothers respite when they could. The qualitative investigation in this paper used grounded theory to explore the experiences outlined. By the papers own admission, data saturation levels were not reached, therefore suggesting that further investigation needed to be completed in this area to achieve the “full story” of the parents’ experiences.

Singh (2003) further explored the role of fathers within treatments for boys with ADHD. The findings suggested that the mothers were typically responsible for decisions within the family relating to their child. Consequently, fathers reported knowing little about their son’s diagnosis or medication and became increasingly silent within the home, often not sharing their perspective with staff, family or friends. Within the study, fathers explained that when they did offer explanations as to what they felt might be the cause of some of the ADHD behaviours, this often led to disagreements and problems within the marriage. Interestingly, very few studies highlighted the theme around changes within the marriage or the missing paternal perspective.

1.4.1.1 Friendships

In order to manage the transformation that was reported in a number of the papers, there are reports from parents that how their family is able to cope often depends on the people that they share the experiences with. Benedetti, Garanhani and Sales (2014) discovered that parents found the words, attitudes and actions of the people around the family either provided them with help or made things worse. Case (2001) found that levels of social support were both boosted and maintained after children were diagnosed with a learning disability, which gave parents emotional and social support. As a consequence, the study reported reduced stress and more successful adjustment for these parents. Despite this, parents still felt that they were the ones who could offer the best standard of care for their child. The study concludes that professionals should therefore help to foster social contact in order to reduce isolation and to help improve confidence for parents. This sentiment was echoed in Redmond and Richardson (2003) with parents reporting having “no one to talk to” (Redmond & Richardson, 2003, p215) and a lack of external social contact.

Green (2007) found that parents who linked with other parents of children with Autism would share information about treatments with positive reports having a ripple effect. This was also found in Redmond and Richardson (2003) for parents of children with severe and life-threatening learning disability. However, the author notes that the degree of research evidence that supported a treatment, was not necessarily a deciding factor which led to an intervention uptake, but rather the source of the information could persuade parents' duration and perceived outcomes for certain interventions.

Jones, Rodger, Broderick and De Monte (2009) found that parents' fatigue when implementing interventions for their child had an impact on their ability to work and maintain positive relationships with their family and friends. Families who reported more support also reported increased compliance with the treatment regime. McNamara, Dickinson and Byrnes (2009) found that when parents were attending to their child in hospital, this increased isolation from both friends and family. Some mothers reported increased isolation because they lost trust in care staff and therefore felt that they had to stay. When treatment became complicated and the parents felt unable to trust caregivers outside of immediate family.

1.4.1.2 Finding the positive

Typically, most of the literature around child illness and parental involvement considers some of the negative impacts. However, within the literature there were also examples of how the family coping with illness brought about positive changes. Hastings, Allen, McDermott and Still (2002) note that qualitative approaches were particularly effective in highlighting positive dimensions relating to parental experiences. The study also highlighted that parents of disabled children found a sense of happiness and fulfilment that came from their familial resilience and a better understanding and awareness of their own coping strategies and strengths.

Case (2001) found that parents reported a positive change in the attitudes of friends and family which brought relationships closer than they previous had been. Parents also reported how therapeutic intervention and their relationship with staff had a positive impact on them. Cohn (2001) found that therapists were able to validate their experiences while also enabling them to shift their expectations and advocate for their child. Cohn (2001) found that as parents were involved in the therapy, they began to better understand their child which fostered greater acceptance of their child, furthermore building the sense of self-worth for the child. The study concluded that parents who attributed positive outcome to therapists perceived changes in their child's ability, activity levels, and self-efficacy. Stewart, Chapple, Hughes, Poustie and Reilly (2008) also noted the positive changes made by the children in terms of an increased undertaking of their own management programme which in turn, granted positive outcomes for parents.

McNamara, Dickinson and Byrnes (2009) found that some parents took on new skills such as measuring and assessing, setting goals, acquiring new knowledge, mobilising and pacing supply of resources, and employing others. Within the study, parents were also found to feel positive about having a role and taking responsibility for the care of their child. This finding was also found in Redmond and Richardson (2003) where a theme around the rewarding aspects of care was highlighted.

1.4.2 The need to become expert in delivering interventions

For children and young people, parents and relatives usually have a vital role in initiating diagnosis and treatment (Lincoln, Harrigan & McGorry, 1998; Helgason, 1990). However, for most parents this is just the start of the journey with an expectation from health care professionals that they will work in collaboration and ultimately pick up and continue with interventions and management programmes (Stewart, Chapple, Hughes, Poustie & Reilly, 2008; April, Feldman, Platt & Duffy, 2006). As parents can affect outcomes of treatment, it is imperative that therapists understand the ability of the parent to adapt to and undertake this role alongside any differences between the child and parental goals and perceptions of adherence. In order for parents to succeed in their role as co-therapist, the literature suggests that they are often compelled by circumstance to become lay experts in their child's care (Beresford, 1995). While some practitioners may welcome a more collaborative approach to seeing parents as expert in their own right, this is not always the case.

Ryan, Speechley, Levin and Stewart (2003) examined the difference between physicians' and parents' ratings of the child's seizure activity as part of their investigation into the former's perceptions of epilepsy in childhood. The study found that parents were able to make clear distinctions between their child's seizure types as well as distinctions between length of seizure, beyond the expectation of the study. The study noted that parents would often perceive seizure timings as longer than physicians, which was hypothesised as being due to parental worry or concern. Overall, the study found that there was low concordance between parents' and physicians' ratings of seizures. The study cites parental beliefs in facts that weren't medical facts as the main reason for discrepancy, with parents rating seizures as more severe and physicians as less severe as they often "did not fully appreciate parental report of seizure severity until they observe the seizure themselves" (Ryan, Speechley, Levin & Stewart, 2003, p365). The study was able to find a large, representative sample from which the results are derived. However, owing to the nature of the quantitative design, the study was not able to provide insight into why there was discordance between the professional and parental perspectives.

The lack of conflict between the parental-practitioner relationships was highlighted in Case (2001). The reason given in the study was an increase in the authority given to parental knowledge and decision making. Within the study, parents were seen by services as consumers of services, thus elevating their own expert power and credited by professionals as holding expert knowledge of their own child and family, while the professionals were credited with expertise of professional knowledge. What is more, the study highlighted the shift towards a negotiation model of working, underpinned by collaborative negotiation and active listening. Despite this relatively positive finding, as Hornby (1994) explained, it is important for therapists to consider that expertise does not necessarily equate to competence. Involving parents in the intervention increases the efficacy of therapy, since parents provide an important resource to the child. Therefore, parents require more than possession of knowledge of their child's condition, which is often thought of as expertise, but also the right professional support, guidance, and advice to build self-esteem and confidence to implement interventions (Glendinning, 1983).

McNamara, Dickinson and Byrnes (2009) describe how mothers journeyed from a state of feeling ignorant about the care of a child with a tracheostomy to a state of independent and expert practice. Within the study, mothers explained that they had gained knowledge and skills, become practiced in care and developed specialised routines. As a consequence, the mothers explained feeling empowered and more knowledgeable than some healthcare professionals. Within their expert role, they then took on the roles of teaching other parents. Following their initial training within hospital settings, the mothers then had to adapt the routines to suit their home life.

Green (2007) also reported this finding with parents of children with Autism, whereby positive parental reports of interventions were shared and knowledge was passed on to parents of children who had recently been diagnosed. Redmond and Richardson (2003) also highlighted this finding while Tierney (2005) found that parents would "glean information from everywhere" (Redmond & Richardson, 2003, p216). As a consequence of having acquired expert knowledge in McNamara, Dickinson and Byrnes's (2009) study, parents felt that they were even more obliged to stay with their child in hospital to support their child both with the physical intervention as well as emotionally. This sentiment was also highlighted in Clarke and Fletcher's (2004) paper on parents of children with cancer, who expressed the ingredients of expertise was partly to demonstrate strength, courage, and intelligence and to guard against and protect their child from what they perceived as mistakes, carelessness, and unkindness that their child would "otherwise have experienced at the hands of the medical system" (Clarke & Fletcher, 2004, p123). In Clarke and Fletcher's paper, parents described themselves as becoming 'advocates in the face of surplus suffering (Clarke & Fletcher, 2004, p123).

Redmond and Richardson (2003) found that mothers talked about the expert skills that they needed to acquire for parents of a child with a learning disability. The expertise of care spanned exercise routines, pharmacological interventions, co-ordinating care, and technological equipment. The authors comment that as improvements in neonatal care have increased the chance of survival for technologically dependent children, parents have had to adapt to the increasingly sophisticated aids and equipment needed to support their child's daily care. This study used a mixed methods design and therefore was able to produce rich data to explore the views of mothers within the study. However, no fathers were interviewed, therefore the paternal experience is missing.

1.4.3 The challenges the family face

Within the research there was a common theme around challenges faced by the family, in particular the parents. Some of these challenges include but were not limited to, making time available to care for their child both practically and emotionally, making practical adjustments to their home and routines, witnessing the change or limitations imposed by the illness, as well as coping with their own distress (Benedetti, Garanhani & Sales, 2014). Since parents are typically new to managing therapeutic care, they initially lack knowledge, experience or the power to negotiate services for their child as they begin their journey to becoming lay experts, which brings its own set of challenges (Middleton, 1998). For many parents the decision to seek help in the first instance when they realise they might not be able to manage the situation alone can be challenging as often when they reach this point they can be tired, demoralised and anxious about their child's future (Tierney, 2005). Parents of disabled children and children with learning disabilities face additional challenges, as children typically have difficulty advocating for their own rights, meaning that the child's choices often go unrecognised and parents become the "caretakers" of their rights (Corker & Davis, 2000).

Challenges that parents face often start before diagnosis. In the Clarke and Fletcher (2004) study of parents of children with cancer, parents talked about the uncertainty they faced before their child had been diagnosed. The paper was able to provide a rich data set and used triangulation, meaning that the data was robust. However, interviews were taken from parents asking for retrospective accounts which might have been subject to memory bias. Within cancer diagnoses there is great variation, with some children demonstrating common signs such as lumps and bruising. For others the journey to diagnosis is arduous, whereby parents explained how they had to fight for their perception of their child's sickness to be taken seriously, which led to gathering opinions from several doctors and misdiagnosis. De-Haan, Welborn, Krikke and Linszen (2004) also reflected on the difficulties parents had with recognising the severity of the symptoms in their study for young people with psychosis, although the study relied heavily on self-report measures. The study highlighted how parents associated psychosis with drug-misuse and how they were fearful of the stigma associated with diagnosis.

Clarke and Fletcher (2004) found that parents often reported a sense of feeling powerless. From this powerlessness came a need to become a guard and advocate for the treatment that their child received which often led to conflicts with staff. The advocacy appeared to be directed towards the medical mistakes, wrong-doing and failures within a confused medical system as opposed to being directed towards the suffering and treatments dictated by the disease. The conflict appeared to arise with parents feeling both responsible for their child’s care while also lacking knowledge and control over treatment. Singh (2003) highlighted conflicts between parents around using medical interventions for behavioural problems. In narrative terms, parents described themselves as having to be the heroes of their own stories, taking on the role of the ‘good parent’ by neglecting their own needs and caring for their children in sometimes dramatic situations, often against heavy odds. Redmond and Richardson (2003) found that when mothers were facing the tremendously difficult reality of organising palliative care for their child, they still came across these bureaucratic and service level challenges.

Hospitalisation of a child can be a common challenge faced by parents whose children are undergoing treatment. Tierney (2005) found in her study on adolescents with anorexia, that parents reported an initial and short-lived sense of relief. However, parents then reported experiencing a tremendous amount of guilt, especially if they were not able to visit their child every day, often transpiring when treatment services were not local. Parents explained that while their child was away they were constantly in their thoughts. This led to some conflicts with other siblings who were reported as “coping extremely well” to “bottling things up” or “becoming resentful”. Further to this challenge was the parent’s ability to then obtain information about their child’s case. The study gives examples of parents becoming confused and lost with questions such as “what do I say, how do I approach it? I don’t want to make it any worse” (Tierney, 2005, p375), being left unanswered. Hospitalisation had a significant impact upon the family, with parents often left feeling disempowered. The researcher in this paper had herself been admitted to hospital with anorexia, which might have impacted upon her views, however, this was addressed within the reflexivity of the paper.

As well as challenges faced within the home families can face challenges within the local community. Mothers in the Redmond and Richardson (2003) study talked about the difficult task of gathering together information about local services when they “neither had the time or the energy to undertake the often labyrinthine task of finding the most appropriate service, benefits and entitlements for themselves or their family" (Redmond & Richardson, 2003, p213). This was also highlighted in the Jones, Rodger, Broderick and DeMonte (2009) paper which looked at parents' experience of implementing treatment for their child with idiopathic arthritis. All of the parents within the study commented that communities lacked awareness of the condition, particularly as it is not commonly associated with children, meaning that they encountered problems with their child accessing facilities such as hydrotherapy pools or understanding why adaptations to common services were needed in order for their child to participate. Inadequate information, services and provisions meant that many local facilities became challenging to access for most families.

Within the Singh (2003) study the participants, fathers of boys with ADHD, highlighted a further personal challenge which was around their sons appearing or acting differently to other children. Fathers talked about feeling embarrassed over their son's lack of control with one father admitting that he would alter his son's medication when he took him to football matches. One father is quoted as saying: "I'd probably be proud if he was the best baseball player and he's not going to be. So I have to think about what the best is he can do…" (Singh, 2003, p313). One might hypothesise that facing the social consequences of having a child either with physical or mental health difficulties must impact upon parents in such a way that can challenge their ability to participate in typical day-today activities with their children.

In terms of being able to meet the demands imposed upon them by both the child's illness and the impact the illness had on their own lives, McNamara, Dickinson and Byrnes (2009) described the need for parents to actively meet and manage the demands as opposed to merely coping. The researchers found that the underlying psychosocial processes demonstrated by parents paralleled with leadership and management literature. Within the study, processes such as checking matched with monitoring, becoming expert matched with adapting and learning, families pulling together aligned with burden sharing and electing preferred treatments matched with balancing. Management styles was also a consideration within the McNamara, Dickinson and Byrnes (2009) paper who found families synthesised with the Knafl and Deatrick (2003) model of floundering, struggling, enduring, accommodating and thriving, within their management style of children with tracheostomies. This finding is particularly significant for considering how broadening psychological models beyond health, and indeed considering how interdisciplinary insights might add value and benefit to further our understanding of how parents can thrive in difficult situations, beyond the coping literature.

1.4.3.1 Money

One considerable challenge for families undertaking more involved interventions with their child was the financial impact that they incurred. Higher expenditure and a loss of income can have wider effects on the family as well such as reducing parents' opportunity to participate in their social and recreational life as well as preventing them from attaining career aspirations. Depending on how the country of residence supports families, these costs can vary significantly. For example, Clarke and Fletcher (2004), who completed their study in the USA on children with cancer, found that 13 families within the sample of 29 reported a loss of income with financial support to cover medication reaching 80% of costs.

Jones, Rodger, Broderick and De Monte (2009) found that many parents found continuing with paid work difficult since they had to fit work around attending various health appointments for their child. Government schemes to reduce financial stress appeared to work well, whereas employers were not always able to offer flexible working hours. Redmond and Richardson (2003) found however, that mothers who worked part time reported less stress than those who were at home full time.

Redmond and Richardson (2003) found that owing to the waiting times for some services as well as some families not meeting eligibility criteria, in order to attain services families would pay for private provision. However, not all families were able to buy in such services. The study notes how consumer directed payments had been particularly effective when offered to some families.

1.4.4 The distress and uncertainty of the parent

A core theme within the systematic review was that of the distress and uncertainty that affected the daily lives of not only the sick child, but also the family unit. In terms of diagnosis, Case (2001) found that parents of a child with a learning disability were likely to react with shock at initial stages of being informed. However, in their study parents noted that they had received the initial diagnosis in a sensitive and informative manner, which had helped to abate other stressors. However, Jones, Rodger, Broderick and De Monte (2009) in their study into children with idiopathic arthritis, found that parents reported feeling shocked and helpless as well as feeling that the situation was out of their control. Within the study parents were found to introspect with questions such as "Why us?" and "Did I do something wrong?" featuring prominently. One parent is quoted as saying: "…every time a therapist came there was not just one thing to do, or think about, there was between 10 and 20 … I understand that they were being professional and want to make sure you are informed, but in that 6 months I was still just trawling through the fact that my daughter had arthritis and she was really sick". In Tierney's

(2005) study into the treatment of anorexia, parents noted that once diagnosis was received, they became uncertain about the course of their daughter's conditions. The parents also expressed distress at feeling ill-informed by health care professionals. This suggests a difficult situation for staff, who have to inform parents while also holding an awareness that parents might not be at a stage where they are ready to take on the information that is being presented.

At the time of interview, Redmond and Richardson (2003) found that 88% of mothers of a child with a learning disability were experiencing elevated levels of strain with 71% reporting high levels of unhappiness and depression. Within the study 77% of the mothers reported not being able to concentrate on what they were doing and 94% reported not being able to enjoy day-to-day life. Owing to the uncertain nature of the life expectancy for children within the study, parents also worried about their child being within services where other children had different or less complex needs. This sentiment was also echoed in the Turner, Salisbury and Shield (2011) paper investigating parents' views in managing their child's obesity, which highlighted concerns of parents that their child would be bullied or singled out for their weight and additional needs as a result of their weight. Therefore, this limited parents' ability to access some mainstream and respite services, increasing the necessity of work within the family home. However, the results of the study have limited generalisability and the researchers reported that data saturation was not reached, suggestion that the findings may not allow us a broad view of the parents involved.

One of the reasons for fear when accessing services was concern over being blamed as a parent. Turner, Salisbury and Shield (2011) found that parents were often concerned about accessing services because they felt that they were to blame, or that they would be blamed for the difficulties that their child had around food.

The distress and uncertainty experienced by parents was highlighted in the Singh (2003) paper. The fathers' often unspoken concerns, both within and without the home, led to psychological consequences such as feelings of personal failure and weakness, as well as disappointment in their sons and themselves. Singh (2003) hypothesised that becoming a "silent partner" in terms of not offering their perspective served to both protect and better the relationship with their spouses. However, again within this paper data saturation levels were not reached and there is limited ability to generalise the findings owing to the qualitative nature of the study.

Unplanned events such as problems with mental health and physical illness can be highly stressful for families. Benedetti, Garanhani and Sales (2014) in their study into childhood cancer, found that parents would report feeling 'defeated' by losing the dream that they had for their child and the childhood they had hoped their child would experience. In particular, parents noted the distress they experienced knowing that their child would be deprived of playing and studying, as well as dietary restrictions and living with the physical changes that cancer brings. Aligned to this were feelings of awkwardness and impotence with regards to the future the parents imagined for their child. For example, one parent whose child had to have his feet amputated owing to bone cancer is quoted as saying: "I thought he would not make it, a child without feet, how will it be? How will be stand up? How will he walk? … You know, these silly thoughts". It was not uncommon in the study for parents to report feeling as though they were facing a battle for which they were both uncertain about and unprepared for. In particular, parents questioned why the disease, cancer in this instance, had invaded their lives.

Clarke and Fletcher (2004), in their study into children with cancer, found that parents often emphasised a high degree of responsibility for their child, but found this at odds with the gap in their knowledge, skills or ability to control or sometimes effectively manage the situation. This was also highlighted in McNamara, Dickenson and Byrnes (2009) where parents explained that the reward for successful management was a state of running smoothly. This was exacerbated by sometimes complex and difficult relationships with staff, and where families had acted upon mistaken information provided to them. The Clarke and Fletcher (2004) study made clear that while there was additional "surplus suffering", often with its origins within service provisions, there were examples of good practice such as helpful intervention groups aimed at parents and individual counselling for parents, which helped to reduce both distress and uncertainty.

The McNamara, Dickenson and Byrnes (2009) study highlights the proactive stance that many parents felt that had to take in order to abate their distress and uncertainty. The parents were described as 'living worried' whereby they were trapped in a state of constant worry and what ifs? This finding was also presented in the Tierney (2005) paper under the narrative title "hoping for the best, but fearing the worst". The parents therefore had resolved some of these worries by acquiring knowledge, adapting to the problems they encountered, and developing new routines. This finding is supported by previous researchers such as Jerrett (1994) who reported on the transition parents make from 'turmoil and confusion' to 'taking charge' in parents adapting to supporting their chronically ill child. Such a transition is usually a reaction of the parents to hyper-vigilance, resulting in burnout, and stress if they are not able to adapt or have access to respite (Carnevale, Alexander, Davies, Rennick & Troini, 2006).

For parents where the condition was particularly serious or life-limiting, parents had to anticipate being able to manage with the worst possible outcome. Within the Benedetti, Garanhani and Sales (2014) study parents explained how they had witnessed other children on the same ward as their own child die of cancer. Having witnessed this, even if this was not the prognosis for their child, parents reported having a lingering thought around death: “I saw many children die there and I had that in my mind; is my child also going to die?” The authors note that the parents had their lives invaded by cancer which meant for many having to live with the fear of the unknown. In many cases parents had not shared these fears with the healthcare professionals or other people around them which led to reports of parents feeling lost and dismissed, particularly by care staff. Reflecting on their own mortality was a factor in Case’s (2001) study of parents of children with a learning disability, where parents concern about the uncertain future for their child led them to consider how their death would impact on the care the child would receive when they were gone.

For parents in the Green (2007) study into treatments for children with Autism, Green found that parents were often uncertain about the expectations on both them and their child during interventions. While some parents had high expectations of miracle interventions others held no real expectation about what the intervention might be able to achieve for their child. Within one experimental condition, parents of children on a Vitamin B6 and Magnesium supplement were mainly hoping for “any kind of improvement”. However, the data generated by this study is not generalizable, and was collected by different interviewers including students, meaning that there could be some variability in the information that was able to be collected. For parents in the Tierney (2005) study this uncertainty carried over into the recovery stage; post treatment, while the young person had been able to move on with their lives, the parents remained fearful about remission. This leads to an enquiry about how well informed the parents were about the treatments available, as well as the kinds of improvements they might see and how containing relapse prevention plans might be for parents. It appeared that many of the parents’ goals were about improving day-to-day life such as being able to eat more foods, become more reciprocal or be calmer outside of the house.

Several of the parents within the studies included in the systematic review, commented on the lack of control that they felt they had. Benedetti, Garanhani and Sales (2014) found that parents expressed a particular difficulty over the lack of control they had over the illness itself. Part of this appeared to be whilst their child was suffering, but also because they felt impotent in determining their child’s future. Furthermore, the psychological cost in terms of false hope of miracle cures or treatments that will bring about radical changes was distressing for parents.

1.4.5 The relationship parents had with health staff

One of the more cynical critiques of the medical model is that it treats the symptoms of illness or disability without attention or focus on the needs, concerns and problems of the patient.

Oliver (1996) described this as a form of social oppression, whereby the medical profession operates within what Foucault (2012) labelled a “clinical gaze”, which can medicalise the family unit and disempower both the patient and parents, who have to navigate and negotiate within medical systems. Ultimately, this can cause a friction between staff and parents whereby parents do not feel that there is an equal working relationship that is set up between medical staff and themselves. It is important to note that within modern NHS practice, patients are increasingly expected to be active in the development of their own intervention (Department of Health, NHS 2014/15 Choice Framework, 2014).

For most families who take up the burden of illness, the parent-practitioner relationship becomes just as important as the patient-practitioner relationship. Literature investigating patient-practitioner relationships demonstrates that therapists are not always aware of patients’ perspectives or do not agree with them (Di Blasi, Harkness, Ernst, Georgiou & Kleijnen, 2001). Turner, Salisbury and Shield (2011) in their study into childhood obesity, found that many parents were concerned about being blamed, which was a reason for delaying treatment. This unfortunately, was confirmed for some parents who found their initial interactions with staff particularly blaming and dismissive, consequently damaging the patient-practitioner relationship.

Tierney (2008) in his study into parents of children with anorexia found that some parents reported feeling “fobbed off” by their doctor when getting a diagnosis and were made to feel that they were over-reacting. In a number of cases their daughters received misdiagnosis such as glandular fever or stress. Most of the parents within the study commented that the difficulties continued after diagnosis with many professionals appearing to fail to recognise the seriousness of the condition or having the knowledge of how to manage it. When outpatient care was unsuccessful, young people tended to be admitted. Parents commented that activities and therapy sessions were then frequently cancelled on the ward owing to staff shortages which left the young people “moping around” with little to do. Parents appeared to value the one-to-one work that their child completed with therapists, although where therapists changed or left there tended to be a bumpy transition in regards to the amount of time between the last session and the new therapist starting which led to deterioration in one case. Furthermore, parents were upset at the lack of communication and feedback that they received which led them to feel isolated and uncertain about their child’s prognosis.

Benedetti, Garanhani and Sales (2014) found that parents felt that health staff were desensitised to some of the difficult scenes that they witnessed on wards when looking after their child with cancer. They explained that feelings that they had of distress and concern were hidden from staff whom they felt had treated them with disregard and made them feel lost and insecure when they were in need of help. This might have been owing to the child being the primary patient with family members and adults expected to take care of themselves. One father in the study explained that he did not feel the staff team cared about his anxieties and that they were not helpful towards him. The authors note that the staff role in cases of treating life threatening illnesses was to supply provision beyond the child in order to promote growth for everyone involved and in order to help create meaning for the experiences that they were going through.

Ryan, Speechley, Levin and Stewart (2003) considered the difference in physicians' and parents' perceptions of childhood epilepsy. The results suggested a low degree of concordance between physicians and parents in terms of understanding the impact of a child's seizures. The study found that low concordance in this area impacted upon outcomes, such as adherence to treatment programmes and how the parents rated their satisfaction with care. The study found that one reason for low concordance with physicians gravitated around the parental concerns that were not consistent with medical facts. The parents expressed that they felt physicians did not fully appreciate the parental reporting of seizures or their severity until they had witnessed them themselves. The researchers express that both the parents and physicians' views were often necessary to provide a full picture of what was happening for the child with physicians having a breadth of experience and specialised training and the parents having a depth of experience with their own child's epilepsy.

Case (2001) found that parents reported conflict with professionals over service provisions. Parents expressed that they felt professionals failed to ensure that they had access to all of the information that they needed. A lack of appropriate information was also of concern in Redmond and Richardson (2003). The authors suggest that having an adequate understanding about a child's condition, would reduce the stress and anxiety of uncertainty for parents. As a caution, the author suggests that the information should be jargon free, since this was a barrier to most parents. However, parents also highlighted that staff were usually approachable, took their needs into account, and took action accordingly. Parents had different views on different professionals with physiotherapists held in highest esteem while they expressed extreme dissatisfaction with social workers. Parents noted that when counselling was available they much preferred to be offered the service than having to request it and overall expressed a desire for professionals to adopt a more pro-active approach.

Clarke and Fletcher (2004) found that there had been particular difficulties in the relationship between parents and staff in their study into children undergoing cancer treatments. The study highlighted the initial distress of misdiagnosis and having to battle with health professionals for their child to be diagnosed. Within the study parents' explanations of the difficulties they had with staff fell into three overarching categories which were mistakes, carelessness, and unkindness. Parents expressed confusion at how policy was sometimes explicitly stated to them while at other times was disregarded or ignored. This led to concerns for parents about what other rules might not be being adhered to when they were not present. Parents also talked about having to advocate on behalf of other parents' children. In one case, if a parent had not intervened a child would have been given the wrong medication. Despite the common goal of returning a child to health, it appeared that how this was achieved differed. Common experiences of mistakes led to a distrust of the services being provided. These relationships worsened when there was an increased sense of power/knowledge conflicts whereby parents were made to feel powerless, and yet needed to be powerful in terms of advocating for their child.

Redmond and Richardson (2003) found that parents were particularly frustrated by a lack of uniformity in all aspects of service provision and quality. Within the study, mothers expressed difficulty in obtaining relevant information which led to them having to ask at several sources i.e. hospital staff, paramedics, GPs and social workers. The process for obtaining useful information was described as "haphazard", often as different sources gave conflicting or inconsistent advice. A further frustration for parents was what services were available in their local area with some parents gaining access to good services while others who lived a few miles away were not able to access the same services. Further to this, mothers found that services were disconnected, each working from different care plans with a lack of communication between services, meaning that they had to act as lay care co-ordinators which increased tension and strain.

Cohn (2001) also highlighted the importance of staff striving to understand the parental expectations for the intervention as well as how they made sense of what was being asked of them. The author found that parental perceptions were an indicator concerning whether the intervention had positively influenced the child's life, in particular aspects deemed important by the parent. A similar finding was highlighted in the McNamara, Dickinson and Byrnes's (2009) study where parents used different methods of intervention to work with their child's tracheostomies. The study found that parents liked to be able to choose which intervention worked best for them, in this case between technologies that provided humidification. Parents' stated preference for different technologies for a variety of reasons and reported liking not solely having to rely on the health professional's recommendation. Therefore, non-adherence to a specific intervention might be viewed as an active decision on the parent's part to improve their own coping and the care they can provide for their child.

De-Haan, Welborn, Krikke and Linszen (2004) looked at the opinion of mothers in terms of treatment delay for their child with psychosis. They found that more than half of the mothers surveyed perceived factors relating to the delivery of professional care as a problem when initiating psychiatric treatment. A fifth of the mothers also had wished for professionals to ask more in-depth questions and act faster when it came to hospitalisation. The overall diversity of opinions of mothers within the study would make it hard for any professional caregiver to satisfy the diverse needs of the population in questions; however, the authors conclude that the degree to which the treatment corresponded with the expectations of the mothers was related to the working alliance built between parent and professional, making the parent-practitioner relationship central to the intervention.

Stewart, Chapple, Hughes, Poustie and Reilly (2008) in their study into childhood obesity, found that for parents the support and attitude of the dietician was significant in the continuation of parents with the treatment programme, as well as their perception of the outcome of the treatment. The researchers note that, as obesity is a chronic condition, the perception the parents have of the last health professional can affect the likelihood of engaging in further episodes of treatment.

Singh (2003) found that the medical understanding of ADHD potentially contradicted fathers' understanding of their son's and even their own experience of boyhood. Participation within the medical process therefore brought with it the risk of confrontation with staff between the fathers' authority and the medical staff's authority. Fathers' withdrawal from the process of intervention therefore might sometimes have been a defensive stance which allowed fathers to maintain their own narratives about their son's behaviour. The risk for families was around parents not agreeing and therefore undermining the objectives or work completed by practitioners.

The broader picture emerging from these papers is that, while there is evidence of good practice from the reports of parents, often they lack reliable, appropriate, responsive, and accessible services. This can be exacerbated by fraught relationships with staff from a variety of backgrounds which provided inconsistent information or were not sympathetic to the needs or concerns of the family. Read (2000) explains that the voice of the parent should be recorded within services, not to devalue the voice of the professionals, but to legitimise the parental perspective.

1.5 Methodological Considerations

This review into the experience of parents implementing therapeutic interventions for their child highlighted a number of methodological limitations. Broadly, these included a high proportion of qualitative studies which produced a low overall sample, limiting the conclusions that can be made, a lack of fathers who were included within parental samples and a broad range of treatment approaches which might limit conclusions made as to whether enhanced engagement improves treatment outcomes. Additionally, the work is limited by the available research evidence. Furthermore, the systematic nature meant that evidence is pooled from a restricted parameter dictated by the inclusion / exclusion criteria in line with systematic procedures and did not include parents' experiences of, for instance, training programmes or group interventions.

While this review assessed the quality of the research papers included by using the CASP, there are limitations to this approach. The CASP was rated individually and not checked by further researchers to help improve inter-rater reliability. Furthermore, the CASP rates each of the dimensions equally for both qualitative and quantitative papers, therefore the overall score for each of the papers does not pertain to the exact nature or quality of the dimensions it tests and can be misleading to the true nature of the quality of a paper. Furthermore, Taylor, Reeves, Ewings, Binnes et al (2000) found no evidence that the use of the CASP framework helped to improve the ability of participants to appraise evidence critically in their systematic review of the effectiveness of the programme for clinicians. Other systems can be employed to complete the same critical appraisal of research, such as the Standards for the Reporting of Diagnostic Accuracy studies (STARD), which also provides a more comprehensive and systematic process for evaluating research evidence, beyond the scope of the CASP.

The higher proportion of qualitative papers was an expectation for the review in consideration of the question that led the review search. One of the benefits of reviewing a larger proportion of quantitative research is that a wider range of opinions can be captured and evaluated. The purpose of qualitative studies is to capture and understand in detail smaller and more localised phenomena. The continuity of themes between both qualitative and quantitative papers and indeed across cultures within the study, however, suggests that there may be common themes among parents who implement both physical and psychologically informed interventions. An appropriate surmise from this finding is that the review would be able to comment on the effect of parental engagement on treatment outcomes for the child. However, the studies did not provide enough scope to meaningfully evaluate this dimension.

Although one of the papers within the review specifically investigated the perception of fathers, largely the paternal perspective is missing from the sample. This appeared to be the case in both papers of a qualitative and quantitative nature, both for the physical and psychologically orientated interventions, as well as across the limited range of cultures from which the papers were drawn. Therefore, when this review and the papers which constitute the review discuss the parental perspective, often it is making reference to the maternal perspective. Therefore, this review is again limited in its ability to draw conclusions about what fathers have found to be the accommodating factors as well as the barriers to engagement.

The studies highlight the experiences of parents who engaged within the therapeutic process and were willing to further engage in research. Therefore, the review was not able to voice the opinions and contributions of parents who, for whatever reason, were not engaged in the therapeutic process. This limits the conclusions that the study is able to produce as the core themes that appeared within the papers may relate to parents who ultimately engage within therapy. The review is not therefore able to comment on the population who were not engaged.

Furthermore, the literature examined within this review was pooled from a small group of researchers, many of whom had a specific interest in parental experiences. While many of the authors endeavoured to provide a reflexive approach to their research interest, there is potential that their own experiences might have distorted the focus of the research. A more varied and broader group of researchers working within this area might help to abate these concerns and provide a more balanced investigation of the evidence.

1.6 Clinical Implications and Areas for Future Research

This review aimed to understand parental experiences of implementing interventions for their child by utilising a systematic methodology to review the evidence within the research literature. The review found that many of the papers commented on the changes that families faced when a child is diagnosed with a mental or physical health condition, including the impact upon the relationships they were able to have with friends and family around them. Some of the studies noted the positive changes families felt that they had made in light of sometimes difficult circumstances. Further to this, the papers within the review commented on the journey that many parents make from lay understanding to expert roles. The literature recognised, and highlighted, some of the challenges that families experienced both within the home environment as well as in the local community and additional financial constraints that having to give up work to care for their child in addition to the cost that care incurred. Parents within the studies talked about their own sense of distress and uncertainty for the personal journey they made when coping with their child’s illness. Furthermore, a frequently visited theme was around the positive and negative relationships that parents had with health staff. These key findings are outlined in the review (Appendix B). The high degree of concordance for these particular themes occurring within these papers from both a physical and psychological background, as well as across a number of cultures, suggests that the themes hold a degree of trustworthiness.

One of the encouraging findings from this review for clinical psychologists is that each of the themes alludes to a body of literature that is both of interest and under the scope of psychological understanding and research (Appendix B). This suggests that clinical psychologists might have a role to play in improving and understanding parental experiences of implementing interventions for their child, whether the intervention is typically more physical or psychological in orientation. Furthermore, within the leadership and teaching role of clinical psychologists there is an expectation that the profession would disseminate this understanding to health colleagues within services that claim or endeavour to offer this provision.

The findings of this review might also have an important impact on clinicians working within settings where parents are likely to be involved within interventions. A better understanding of the role of the family will help clinicians to involve the parent as a co-therapist in a meaningful way which might help to improve attendance, adherence and outcomes, for example the implementation of CBT diaries, behavioural activation work, completion of hierarchies in graded exposure tasks, mindfulness meditations or sleep interventions etc. Going beyond simply involving parents in clinical work, but rather having an evidence informed understanding would surely produce a more efficacious way of working for clinicians, in line with a modern philosophy of care (NHS England, 2014). As outlined in Staudt’s model (2007), clinicians would, therefore, be better equipped to provide meaningful attitudinal and behavioural orientated engagement in order to improve and facilitate a child’s engagement within therapy.

This review has generated some broad future directions for research within this field. One of the key areas for researchers conducting work within this field is for better measurement of what constitutes engagement within interventions and how this might impact upon outcomes, since this was a methodological flaw in many of the studies reviewed. Haine-Schlagel and Walsh (2015) recommend that decisions regarding how to operationalise and measure parental participation outcomes can have a significant impact on accurate evaluations of intervention effects, suggesting that engagement outcome should be measured in accordance with conceptual frameworks, for example Staudt (2007). A further finding and methodological limitation of the review, is the lack of paternal perspectives on engagement within the limited pool of literature that exists. In both clinical and research terms, one should not be talking about engaging parents without talking about engaging fathers. This is a distinct gap within the research and further research needs to be completed around fathers' experiences. Furthermore, there is little discussion about the impact upon siblings, both in terms of understanding the nature of the difficulty their brother or sister might be facing as well as the change in relationship that they might experience with their parents and the wider impact on the family. In order to understand this impact, further investigation will need to be completed. Furthermore, research could be conducted with the child in question, as to their experiences of having their family involved in their treatment.

There are a number of ways in which the studies reviewed within this review have influenced the subsequent empirical paper. The limited number of studies available for review suggested that more research was needed, so that the role of parental experiences can be better understood, both to increase understanding for professionals in order to improve the parental and child engagement, but also for the sake of parents undertaking these roles, in particular that of the co-therapist. One of the reasons this research will be important is to look at the risks that come from managing particularly difficult circumstances i.e. prolonged adjustment or medical complications that might mean that parents experience more extreme occurrences of the core themes this review has highlighted. One area where this might be particularly pertinent is within the field of learning disability, where parents will need to adjust to complex and life-long difficulties that their child will face, often which are both physical and psychological in nature. Furthermore, there is increased pressure on the parental role as children with a learning disability are typically more dependent upon parental figures to deliver care, even after childhood.

Chapter 2: Empirical Paper: An investigation into how parents of a child with a learning disability experienced services for their child.

2.1 Introduction

Supporting a child through illness, whether physical or psychological in nature, can be a particularly difficult time for parents and families (Gravelle, 1997; Jones & Passey, 2004). During this time parents often begin an unfamiliar journey, navigating their way through a complex and bureaucratic healthcare system, while integrating a carer's role into their parental identity, which can increase stress and test familial resilience (Rolland & Walsh, 2006). Ultimately, the stress that parents and families experience can result in a strain within the patient-practitioner relationship and difficulties can occur around engagement in therapy.

More recently, difficulties in engagement have become particularly troubling for service managers as attrition rates, non-adherence and parental dissatisfaction can affect treatment efficacy and outcome. A recent government report entitled: 'Children's and adolescents' mental health and CAMHS' concluded that there was a "lack of reliable and up to date information about children's and adolescents' mental health" and that "CAMHS services have been operating in a "fog"" (Children's and adolescents' mental health and CAMHS, 2014, p3). Furthermore, the report suggested that parents and young people had to "battle" for access to services with long waits for treatment, partly accounted for by cuts to funding. For services in a time of political austerity, it has become increasingly important to demonstrate worth, often through a payment-by-results method which is measured in part by therapeutic outcome. Demonstrating financial worth helps to safeguard the service's ability to attain provision from commissioners.

For services to provide efficient treatments that also improve their overall quality of care, it is important for them to understand the underlying process of child and family engagement. Participation and engagement in therapy is an essential indicator of quality, and evidence suggests that parental engagement improves outcomes for young people (Fawley-King, Haine-Schlagel & Trask, 2013). However, while engagement in treatment as a concept has a high degree of face validity, researchers such as Staudt (2007) have argued that the term lacks clear epistemological definition, leading to a lack of theory and knowledge around its relationship to treatment processes. While research has focused on quantifiable indicators of engagement, such as the number of appointments attended and completion of treatment, there has been little research into the parental experience of services and engagement within therapeutic interventions for their child. Understanding engagement in interventions from the parental perspective might elucidate important insights into how services and therapists can better engage parents within the therapeutic process. Improving the quality of service for families and outcome for young people might further help to procure government level funding and safeguard investment in mental health services for future generations.

2.1.1 Services for children with a learning disability

Within the professional boundaries of the United Kingdom (UK) a learning disability is defined by the British Psychological Society (BPS) as a significant impairment of intellectual functioning, significant impairment of social/adaptive functioning and having an age of onset before adulthood (BPS Definitions and Contexts, 2000). Typically, the degree of learning disability has been further categorised into three tiers: mild, moderate or severe/profound, although currently the BPS has suggested a transition into a two tier system of classification, those being: Significant (IQ 55-69 with intermittent or limited support needs) and Severe (IQ<55 with extensive or pervasive support needs) (British Psychological Society, 2000).

Children with a learning disability are particularly vulnerable to developing mental health conditions which means an increased likelihood of parents of a child with a learning disability working with mental health services (Emerson, 2003). A co-morbid learning disability can lead to greater complexity within the mental health work, which can increase time spent in services, resource and therapeutic longevity (Emerson & Glover, 2012). For a group which has historically struggled to attain a powerful voice within society, a time of political rationing and financial cost-cutting will likely impact upon parents' ability to receive the support they require.

Emerson, Hatton, Dickson, Gone, and Caine (2012) report that there are around 236,000 young people (under eighteen) in England known to services with a learning disability, and an expectation that this number will increase. Overall there are a total of 1,144,000 people in England with a diagnosed learning disability known to services (Emerson & Glover, 2012). With a proposal to extend the years which CAMHS teams see young people from eighteen to twenty-five to avoid the 'cliff-edge' of transition, this could see an immense pressure put on specialist healthcare and CAMHS-Learning Disability (CAMHS-LD) teams in England with numbers of clients increasing (Department of Health, 2014).

For those who do access learning disability services, white papers and audit tools published by the Department of Health such as Valuing People Now (Department of Health, 2010) and the Green Light Toolkit (Department of Health, 2013) which looked at improving mental health services for people with a learning disability and autism, recognised that services in England do not always provide adequate provision for people with a learning disability. The revised Green Light Toolkit (Department of Health, 2013) recognised that there are pockets of “imaginative and positive practice” within mental health teams but “few mental health services have comprehensively and systematically audited their practice and redesigned their delivery arrangements to ensure that people with autism or learning disabilities obtain fair access and effective interventions” (Department of Health, 2013, p12). It is important to note that the recommendations from this audit paper related to services provided mainly for adults and the paper recognises that it “does not fully consider the needs of children” (Department of Health, 2013, p12). Nonetheless, it is not uncommon for parental involvement to continue into adulthood for some people with a learning disability (Pascall & Hendey, 2004; Greenen, Powers & Sells, 2003).

A paper published by Mencap, entitled Death by Indifference highlighted the seriousness of the consequences of services not recognising the unique needs of people with a learning disability. One parent is quoted as saying:

> “We believe that Mark died unnecessarily. Throughout his life we encountered medical professionals who had no idea how to deal with people with a learning disability or what it is like to be a parent of someone with a learning disability – to know their suffering, to see their distress. If only they would listen…” (Mencap, Death by Indifference, 2007, p1).

The lack of adequate service targeted towards adults with a learning disability and the “fog” of services targeted towards children, highlighted in the papers discussed, demonstrates the need for research into how consumers of these services experience them.

2.1.2 Parents of children with a learning disability

Evidence suggests that parents of a child with a learning disability can have increased vulnerability to stressors over parents of a child without a developmental disorder (Hastings & Taunt, 2002; Hastings, 2002; Lardieri, Leigh & Swanson, 2000). Historically, parents have expressed high levels of dissatisfaction with how they were informed about their child’s learning disability. Typically, they have highlighted the time lapse between first suspicion and diagnosis being slow, and the certainty of a diagnosis and the sensitivity with which this information is relayed as being particularly poor (Pearson, Simms, Ainsworth & Hill, 1999).

Research into caring for a child with a learning disability has highlighted several factors which can impact upon family life. For children with a severe or profound learning disability there can be increased practicalities including attending to personal care needs, washing and dressing, feeding and lifting (Petry, Maes & Vlaskamp, 2005). Further to this there is the role of attending to the child's medical needs such as administering medications, completing health orientated interventions and working with technologically sophisticated equipment (Brett, 2002). Increased time attending to personal care, attending medical appointments and hospital visits can impact upon the parent's ability to spend time with the child's siblings and extended family, impacting the family unit.

Many research papers have discussed the increased isolation that parents of a child with a learning disability can face, owing to the limits imposed upon their own social lives and ability to access employment (Case, 2001; Leyser & Kirk, 2004). This can also lead to difficulties with family finance and accessing treatments or services, such as respite services which are often run privately, beyond NHS provision (Thurgate, 2005). The relationship between not being able to attain employment and therefore having decreased funds to access respite, can create negative cycles around isolation. Furthermore, research has demonstrated that many primary carers can find it difficult to trust another person to be capable to deliver the care that their child requires, further limiting the parent's ability to access respite.

In learning disability literature, extensive research has previously been directed toward understanding parental stress while, within the past decade, research has orientated to learning about how parents cope and the role of familial resilience (Redmond & Richardson, 2003; Heiman & Berger, 2008). Jones and Passey (2004) found that parents who utilised coping strategies around maintaining family integration, co-operation and optimism, were related to overall family cohesiveness and parental perception of reward or satisfaction in caring for their child. Furthermore, parents who demonstrated a high locus of control in leading on the care for their child reported lower levels of stress.

Naturally, bringing together narratives around family resilience and coping, despite increased family stress, is important to facilitate an understanding around the sense and meaning that parents ascribe to their circumstances, both at a micro-familial and macro-political level. Developing an understanding of the experiences of parents of a child with a learning disability, both through investigating stressors as well as demonstrations of employing resilience, should explicate how practitioners might be better able to engage a potentially hard to engage population.

2.1.3 Study rationale

Research suggests that parents of a child with a learning disability can be vulnerable to increased stress which can impact upon the family unit, particularly when seeking a diagnosis.

While literature pertaining to help-seeking behaviour and family involvement in treatment has been well-researched, the nature of parental engagement within therapy remains unclear, particularly concerning a better understanding of the parental perspective. While continued research into adapting therapeutic content for children with learning disabilities needs examining, this needs to include the process of facilitation, as the parental role is critical for engagement within therapeutic work. This is particularly pertinent for services, as engagement has been demonstrated to affect treatment efficacy and proficiency. The research question that this study therefore hoped to address was: what are the parental experiences of services for a child with a learning disability?

2.1.4 Research aims

The aim of this study was to explore parental experiences into how parents of a child with a learning disability experienced services for their child. The research question led to this study adopting a qualitative design, so that the individual and subjective meanings that parents reported about this process could be presented. The study aimed to detail the experiences of the parents so that it would be able to provide insights into how services and healthcare professionals might better engage parents in the therapeutic process. The purpose of gathering this information was in order to improve quality and outcomes for children with a learning disability in a resource-limited political climate.

2.1.5 Reflexivity

It is common in qualitative papers for the reader to be granted the opportunity to briefly learn about the researcher's background in order to understand their motivations for completing the research, which is often termed reflexivity. Furthermore, the research approach recognises that the researcher is himself, in essence, the tool in the approach to enquiry and therefore by highlighting the researchers own motivations this increases the transparency by allowing for questions as to how the researcher came to the conclusions that are made within the research (McCracken, 1988).

2.1.5.1 Area of interest

I have worked for a number of years in both adult and child mental health services for people with a learning disability. Working with families was a central feature of this work. A common dilemma in my work was how much of the available therapeutic time might need to be directed toward the parents, in light of decisions around the extent to which the parent might act as a co-therapist. Often parents would have several professionals involved, each demanding their time and input, beyond the requirements of typical family life. Consequently, realistic parental engagement needed to be tensioned with a collaborative effort to produce meaningful outcomes for both the parents and the child. Balancing this tension in clinical practice and a desire to learn more about some of the barriers to engagement that parents of a child with a learning disability might encounter, is what gave rise to the research inquiry.

2.2 Method

This study adopted a qualitative design and social constructionist approach to research in order to provide a rich and detailed account of parental understanding and experiences of services and implementing therapeutic interventions for children with a learning disability.

Phenomenology, or put simply the study of a phenomenon, draws on philosophical assumptions that privilege perceived meaning and understanding over a hypothetico-deductive approach of an objective reality; with the hope to meaningfully account for people's intentions, behaviours and beliefs. A further assumption of the phenomenological approach is an epistemological pluralism, or equality of multiple perspectives, whereby differing perspectives on a phenomenon are of interest for study, thus making IPA advantageous as the approach for enquiry when gathering data in the form of narrative accounts of a similar phenomenon.

IPA is a commonly used phenomenological approach to qualitative inquiry (Smith, Flowers & Larkin, 2009). IPA principally examines how people make sense of and engage with their major life events and comments on how people reflect on these experiences. Whether the experience is proactively sought after or uncalled for, experienced as positive or negative, or acutely or extensively time-bound, the common thread is the significance to each of the participants within the experience and how they have deduced meaning from the events they have been witness to. As IPA is concerned about experiences of a discreet phenomenon, sample sizes are often conservative and homogenous with regards to characteristics, so that something of the experience of each individual can be revealed. Therefore, the approach was able to give further depth beyond that of other forms of qualitative enquiry such as a thematic analysis, even though a thematic analysis could have captured a broader population and larger sample size.

There is a degree of overlap between IPA and other qualitative approaches. Beyond the method of enquiry, which is similar to thematic analysis, IPA also informs the ontological and epistemological underpinnings of how the research is conducted, i.e. during the interview and analysis process, which for this study was social constructionist. Therefore, this study went beyond collecting themes, to explore how the participants made sense of their experiences at an individual level. Therefore, the questionnaire and research interview was centred around the interpretation and meaning making that the parents did, in order to make sense of their experiences of working with services to deliver interventions. Consequently, the emphasis was on gathering a smaller group of individuals than a thematic analysis, which is mainly concerned about gathering together patterns of meaning across participants, where there is reduced need for a closely defined population. As first suggested by Reid, Flowers and Larkin (2005), fewer participants are the cost for greater individual depth in IPA. The researchers argued that fewer participants examined at a greater depth was preferable to a broader, shallow and a simply descriptive analysis of many individuals, as commonly seen in thematic analysis or grounded theory. Part of the desire to recruit larger numbers in research studies, including qualitative research, has come from the desire to generalise findings. Reid, Flowers and Larkin (2005) explain that within IPA research samples, the desire is to find similarities between likely similar groups, in the case of this study, parents of a child with a learning disability who have had contact with mental health services. Therefore, IPA appeared the appropriate methodology as this study used a social constructionist approach, in line with IPA epistemology, and was hoping to gather data on the basis of depth, beyond the depth that is typically delineated from a thematic analysis.

Within IPA methodology there is a double hermeneutic, or interpretation on behalf of the researcher about the interpretation made by the participant, which gives rise to the need for an elevated practice of reflexivity within the research process. Therefore, reflective journals (Appendix P) and reflexive notes (Appendix K) are included within studies to endorse a high degree of transparency regarding the hermeneutic process of the researcher.

2.2.1 Ethical considerations

Ethical approval to conduct the research was sought and granted by the University of Southampton Ethics Committee (Appendix D) and Solent NHS Trust Research and Development department (Appendix E).

Informed consent was an important part of the ethical considerations for this study, particularly owing to the qualitative nature of the work, which meant that direct quotations would be used in the final write up. In accordance with the British Psychological Society Code of Conduct (British Psychological Society, 2006), participants were informed that pseudonyms would be used and every effort would be made to preserve their anonymity, but however, the verbatim accounts that would be used in the empirical paper, compromised their confidentiality (Jones, Murphy & Crosland, 1995). It was further emphasised therefore that participants could withdraw consent at any time during the interview process without detriment. In light of this, an extra effort was made on behalf of the researcher during interviews to seek clarification and provide summaries back to the participant to ensure the researcher had an accurate comprehension of the participants' views and experiences.

Owing to the potentially sensitive nature of the information covered in the research interview, participants were given extra time after the interview was concluded to talk about how they felt about the discussion and to convey any concerns. All of the participants had regular contact with their child's clinical psychologist or nurse and were invited to contact them if there were any concerns that the interviews raised about their experiences of facilitating interventions for their child. To the best of the researcher's knowledge, none of the participants reported any adverse effects from talking about their experiences.

2.2.2 Recruitment of participants

Participants were recruited from two community services within Solent NHS Trust (Appendix F for Letter to Service). Purposive sampling was used to recruit a closely defined group of participants for whom the research question had particular significance and meaning in line with IPA principles (Willig, 2013). The target group was parents or primary caregivers of a child with a learning disability, where the child had received or was currently in receipt of input in the form of a psychological intervention, from a mental health service within the past year.

In terms of inclusion criteria, the study outlined that the child had a diagnosis of a learning disability and had received psychological input from a clinical psychologist or nurse, whereby the caregiver had acted as a co-therapist or been actively involved in the implementation of treatment. The study excluded parents who were undertaking an intervention owing to a court order.

The participants were initially informed about the study through members of the team with whom they were already engaged in working with. Once the parent had agreed in principle to participate, permission to contact the participants was granted from the respective clinical teams. The researcher had been a past member of both of the teams from which the parents were recruited (see Sample Demographics). Information sheets (Appendix G) and consent forms (Appendix H) were sent out ahead of the research interview. Parents were made aware of an incentive to participate which took the form of a £10 gift card.

The first interview was initially a pilot interview, which the participant was made aware of, in order to trial the nature of the semi-structured interview questions. No changes were made to the interview schedule following the interview as the questions appeared appropriate to the research aim and were ordered in a way that facilitated a helpful narrative flow. Consequently, all of the parents who volunteered went on to be interviewed and included in the final analysis. All interviews were conducted in participants' homes, although provision was made to conduct the interview in a private room within the community health service setting from which the parent was recruited. Following the written invitations, a total of eight parents volunteered to participate.

2.2.2.1 Sample demographics

The sample consisted of eight female participants of which seven were biological mothers and one was an adoptive mother. Seven of the mothers were white British, while one was white American. The first three participants (Angela, Hillary & Melinda) were recruited from one service within Solent NHS Trust and the remaining five participants were recruited from the other service, again within the same NHS Trust. All relevant participant demographics relating to the parent and their child are listed in Table 1.

Although the researcher had worked within both services from which the sample was recruited, he had not been involved in any way with the cases pertaining to the *child* in question, that the parent was interviewed about. However, the researcher had involvement with two parents, namely Melinda and Hillary, for a separate piece of work around six to nine months prior to the research interview. The researcher had had no previous involvement with the further six mothers who were recruited into the study.

Table 1: Participants demographic information

Parent Pseudonym	**Parent's Age Range**	**Ethnicity**	**Child Pseudonym**	**Child's Age**	**Child's Diagnosis**
Angela	31-40	White British	Jack	8	Learning Disability, challenging behaviour, Autistic traits
Hillary	31-40	White British	Amelia	4	Learning Disability, Challenging behaviour, self-harm
Melinda	41-50	White British	Olivia	16	Learning Disability, Autism, Sotos Syndrome
Janet	41-50	White British	Isla	17	Learning Disability, Self-harm, Autism, Hereditary Spastic Paraplegic

Mary	31-40	White British	Harry	9	Learning Disability, Cerebral palsy, hemiplegia, Autism
Christine	41-50	White British	Thomas	11	Learning Disability, Autism
Dilma	31-40	White British	Emily	10	Learning Disability, ADMP, microcephaly, sleep apnoea, self-harm, sexualised behaviour, smearing
Sheryl	31-40	White American	Jacob	6	Learning Disability, Autism

2.2.3 Co-therapy

Each of the parents within the study had been a co-therapist to the psychologist or nurse leading on the intervention for the child. As the clinical presentations varied, so did the exact role of the parent in terms of what they were asked to implement to support the intervention. Examples of co-therapeutic interventions included implementing scheduling and visual timetables, techniques for managing challenging behaviour, sleep hygiene and bedtime routines and creating and using social stories for their child.

2.2.4 Data generation and management

An interview schedule was constructed with the aim of using open-ended and enquiring questions to facilitate parents to provide detailed accounts of their experiences (Appendix J). It is recommended to use around six to ten questions for any given interview in IPA (Smith, 2011). This study used eleven questions, some with further prompt questions to facilitate the parent talking at length about their experience. No significant changes were made to the interview schedule following the pilot interview. All interviews were audio-recorded and transcribed verbatim. All digital recordings were stored securely according to the requirements of data protection legislation and following the transcription of the data, all audio recordings were destroyed.

2.2.5 Data analysis

The aim of data analysis in IPA is to provide a retained “commitment to an understanding of the participant’s point of view, and a psychological focus on personal meaning making in particular contexts” (Smith, Flowers & Larkin, 2009, p43). Although there is no fixed method of data analysis using IPA, this paper closely followed the guidelines set out by Smith, Flowers and Larkin (2009).

Each of the transcripts was read numerous times and audio recordings were played back so that the researcher could become immersed in the data to allow for a heuristic model of the participants account to develop. Initial noting was applied to each interview, particularly focusing on descriptive, linguistic and conceptual comments that framed experiences. Emergent themes were then identified, initially closely relating to the text. Broader themes subsequently emerged from the process of abstraction whereby patterns between themes could be clustered under superordinate and subordinate level themes from an idiographic reading of each interview. The themes for each of the transcripts were then evaluated, compared and mapped onto related ideas between transcripts and organised into themes which were most salient to the participants' accounts. For the purpose of rigour, emergent themes that were not recurrent in at least half of the sample were not identified as themes as they did not portray a generic account between participants (see Appendix M, Initial Themes Map).

2.2.6 Quality assurance

It is considered good practice within qualitative research that procedures are implemented to check the credibility of an analysis. As within quantitative methodology, validity and reliability checks are an important part of the research process. However, within qualitative investigation the research landscape is drawn from a naturalistic approach, therefore meaning that how these processes are accounted for is altered in comparison to the traditional positivist method of assessment (Golafshani, 2003). Stenbacka (2001) explains that the purpose of validity and reliability checks is to test quality, which in qualitative research is dependent upon the ability to generate an understanding through the provision of psychological explanation. Two ways this is commonly achieved are through reflexivity and triangulation of data.

Reflexivity within research is the process of the researcher providing transparent accounts of the multiple influences that they themselves have on the research process, as well as how the research process positions them in terms of the persons and situations they investigate (Gilgun, 2006). In order to achieve reflexivity within this paper, a reflective account of each interview was written within a twenty-four-hour period after the initial meeting and before transcription (Appendix K). These reflections were guided in part by Burnham's work around social "GRRAACCES" which encourage those undertaking the reflective position to also take into account their own culturally determined beliefs, values and attitudes (Burnham, 1993). Furthermore, a reflexive journal was used throughout the process of analysis so that the researcher could track how their process and methodology impacted upon the delineation from initial noting to overall themes (Appendix P) (Mays & Pope, 2000).

Triangulation of data helps to improve quality assurance by helping to control for researcher bias by engaging multiple perspective on the same data. Triangulation, within a social constructionist methodology, aims for a degree of concordance, although allows for diverse perspectives from different researchers. For this study, the analysis process was discussed with the research supervisors as well as with peer researches also undertaking IPA research (Appendix N). From the review, the initial themes were then reorganised into a new table of themes and a final map was produced (Appendix O).

2.3 Findings

Figure 3: Model of Superordinate and Subordinate Themes

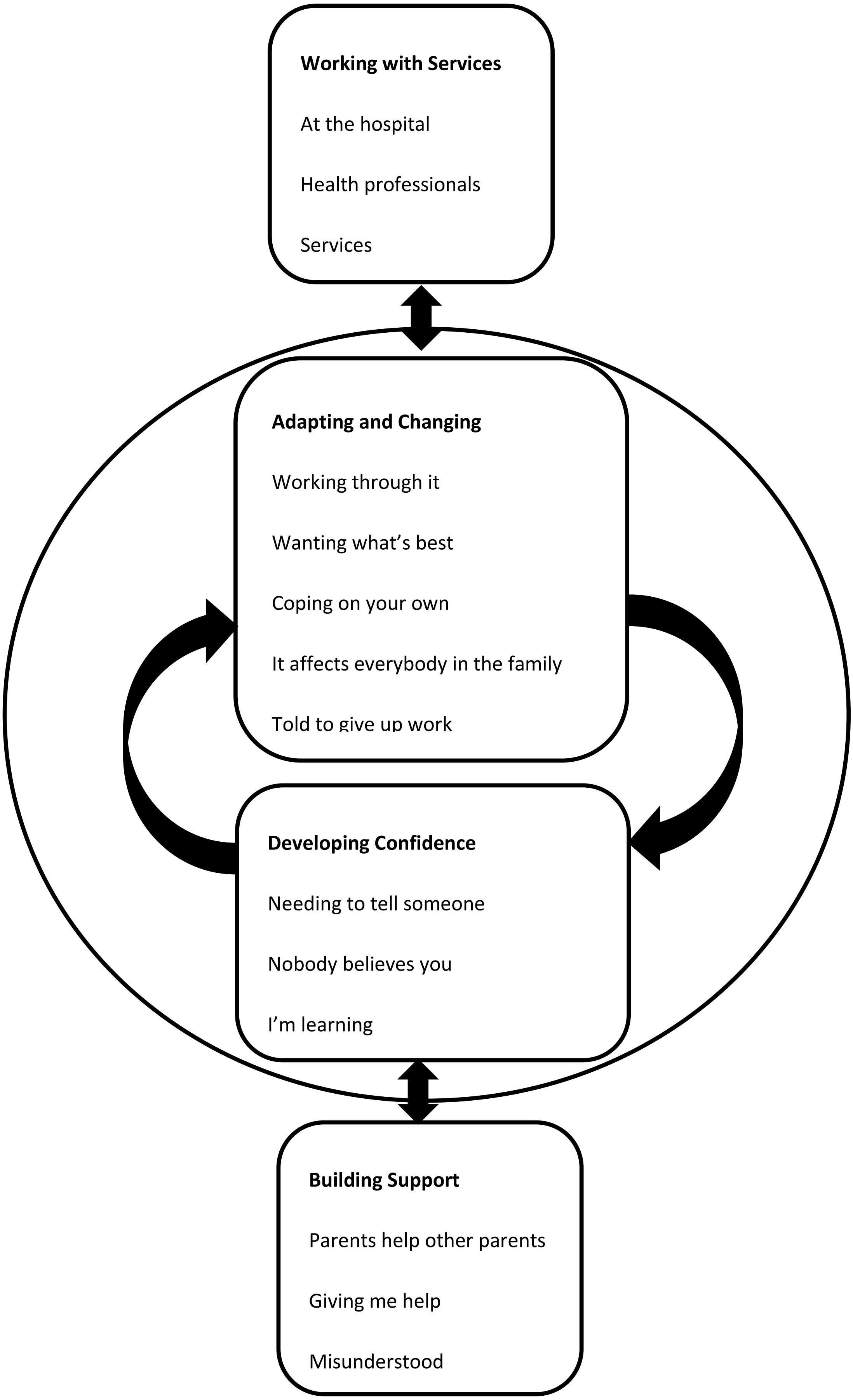


Figure 3 represents superordinate and subordinate themes and how they are clustered. The figure serves as a map to the themes that were derived from the research data. In order to arrive at this map an initial map was created during the coding stages as a heuristic model of the themes (Appendix M). The initial themes from this heuristic model were then given to two independent auditors (Appendix N). As a result of the comments received the themes were streamlined to create a more objective map of the themes, which is how they appear in Figure 3.

Within the family unit there was a sense of needing to adapt and change to accommodate the child's learning disability and mental health difficulty. Further to this, parents questioned their own role as both a carer and parent, often feeling isolated. This led to a developing of confidence as the child was assessed and received a mental health diagnosis. Parents also talked about the learning curve that came with implementing interventions.

Outside of the home environment, parents talked about working with services and spending time away from the family when their child was in hospital. They also discussed the importance of building support networks as well as the difficulties that occurred whilst trying.

2.3.1 Superordinate Theme: Adapting and Changing

All of the parents spoke about the adjustments that they had to make, sometimes at a practical level, but commonly on an emotional and psychological level, when coming to understand the nature of their child's learning disability and subsequent physical or mental health diagnosis. Part of this process was often played out whilst parents were in the process of either initiating or undergoing assessment or diagnosis at various stages of the child's life. Often this led to questions and comparisons for the parents about what was normal and how to manage uncertainty around the child's future. Furthermore, parents questioned and thought about how caring for a child with mental health difficulties and a learning disability affected their role as a parent, an employee and the rest of the family.

2.3.1.1 Subordinate Theme: Working through it

The subordinate theme was titled 'working through it' as this appeared to capture the nature of the process which involved an active component over a passive acceptance. Furthermore, the title does not suggest that the parents had necessarily finished their journey, as many of the parents were still working through it.

Parents discussed how they learnt about their child's learning disability and mental health diagnosis. In part, this process involved working through the loss of the expected child, as well as holding uncertainty about their child's future.

> Mary: “He’s got cerebral palsy, he’s got hemiplegia … So he’s always been in the system… I’ve always had a paediatrician so I’ve always had check-ups … So unlike lots of parents who fight to get a diagnosis … I’ve been, in a way, sort of lucky.” (Page 2, Line 68)

Mary described how she felt lucky receiving a diagnosis for a learning disability early, despite the many health complications Harry had. This sense of luck is contextualised as Mary alludes to the idea of a fight being a common narrative, and perhaps a reality for mothers in a similar position to her own. For Mary, being in the system appears to containing, as it provides access to specialist care.

Although all of the parents within the sample had received a learning disability diagnosis for their child, their stage of acceptance presented differently.

> Dilma: “…something happens and it’s like, it brings the whole lot back again. And it’s like you’re constantly grieving”. (Page 23, Line 1121)

Dilma talked about constantly grieving. As Emily grew older, Dilma talked about making peer comparisons for which the gap grew steadily bigger. This meant that the grief was able to re-surface and she was particularly sensitive to anything which might “bring(s) the whole lot back again”.

Despite knowing that her child had a learning disability, Melinda talked about not fully comprehending the scale of a learning disability.

> Melinda: “I knew she was a slow learner so I sort of thought, she will learn after a couple of years. Six years later, she still hadn’t learnt”. (Page 3, Line 106)

Melinda talked about the hope that she had for Olivia, and how she felt that her being a “slow learner”, a historical colloquialism often used to describe children with a learning disability, simply meant that Olivia would eventually catch-up with her peers.

Holding hope for the normality of the child’s future was difficult for parents when the future can appear so uncertain.

> Mary: “You want answers, you’re desperate for answers and you just don’t get them”. (Page 6, Line 255)

> Mary: “They didn’t know if he was ever gonna ever walk… they don’t like to predict and that’s fair enough, it’s a wait and see game”. (Page 5, Line 248)

Mary uses words such as “want” and “desperate” to describe her need for the answers to questions about Harry’s future and what the outcome of his health concerns might be, but then acknowledges that professionals and services do not like to predict, and that this was fair enough. This suggests that while Mary had been desperate to know, she had come to terms, in part, with having to hold this uncertainty.

Many of the concerns and uncertainties around the learning disability diagnosis connected to the process of receiving a mental health diagnosis.

> Angela: “…seeing (the Psychiatrist) that was bingo, yes, there is a problem with this child, this child is not normal and we have got some investigations to do”. (Page 2, Line 70)

Angela alludes again to a sense of fight. Whereas she did not have to fight when getting a learning disability diagnosis, she did with receiving a mental health diagnosis. For Angela the toil of the fight is summed up using the word “bingo” to describe external, professional validation to her concerns. This provides some degree of insight as to why some parents might be so keen for their child to receive a mental health diagnosis, which to those outside of the experience might appear unusual or even contentious at a cultural level.

Not all parents were necessarily advocating to receive a mental health diagnosis, and receiving one could come as a shock.

> Hillary: “When a child is older, it’s almost like you’re just thrown in the deep end, being like sat in this room, after his assessment… the outcome is, you know, we feel he’s got a developmental delay and high functioning Autism, and we just sat there and thought, oh my god, what, what, you know, what do we do?”. (Page 16, Line 769)

> Angela: “He is on the Autism spectrum, but he hasn’t scored enough points to be diagnosed an Autistic child. I am not saying I want my child Autistic … with a label, but when you have got something … you can deal with it”. (Page 9, Line 467)

Adjusting to Amelia having a diagnosis of a mental health condition was difficult for Hillary where she describes being uncertain of what to do following the diagnosis. For other parents such as Angela, not receiving a diagnosis also induced uncertainty. Knowing that something was wrong, and not having a diagnosis that appeared to fit, had implications for understanding Jack’s difficulties and made the road to diagnosis increasingly turbulent. This raises a dilemma for clinicians which ultimately was best managed by gaining a better understanding and collaboratively exploring what the diagnostic label meant to both them and the child.

Parents described a similar process of adjusting to a mental health diagnosis as with the child's learning disability.

> Hillary: "…the Autism is all going to go… and they're going to be, suddenly, a completely normal child again". (Page 17, Line 842)

> Sheryl: "…I've gone through my mourning … It was like I knew he was Autistic, it was getting my emotional side on board". (Page 16, Line 769)

Hillary hoped that the Autism would go away. This statement is followed by a desire for Amelia to be a "completely normal child again". The statement is temporally retrospective and therefore, like Sheryl, suggestive that the Angela had struggled at the time but had managed to get "my emotional side on board".

Adjusting to a family norm, which might sit outside of the social ideal, was described by some of the parents.

> Janet: "… every single person is different. Even if they've got the same label. And one label doesn't mean that if you follow that protocol that's how it's going to work". (Page 32, Line 1588)

Janet recognised the diversity that can occur, even when a child received a mental health diagnosis.

> Mary: "…it's like tonight I'm gonna take them out for dinner, which I couldn't do, just normal things … I'm just doing normal stuff, like anyone else wouldn't even bat an eyelid". (Page 40, Line 1998)

> Hillary: "… it's that tiny bit harder really than being a parent to a child that's functioning and developing normally, because you've got to do that extra bit all the time". (Page 10, Line 481)

Mary discussed how simple activities such as going out for dinner can be particularly difficult, which leads them to feel further from the norm, as she expresses how most people would not "bat an eyelid". Hillary also comments on how life can be harder while making the comparison to the child who develops normally, suggesting that perceived cultural norms are a particularly present and possibly sensitive comparison narrative for these parents.

2.3.1.2 Subordinate Theme: Wanting what's best

The subordinate theme title captures the parent's decision to balance the parental role against other demands and ultimately striving for wanting what's best. Parents talked about a duel role of being both a parent as well as a carer. Often, they called into question their own ability as a parent when reflecting on their ability to care for their child and ultimately they explained how they wanted what was best.

> Angela: "I want what is best for my son, my two children are my world, they are the love of my life and I will walk the Earth and back for them". (Page 14, Line 691)
>
> Dilma: "My child is different and she does need 24-hour care, but I should be classed as Mum". (Page 28, Line 1404)

Angela sums up her role as a parent by presenting an image of walking the earth and back to express her love for both of her children. The statement expresses her desire to do whatever it takes to get the best for both of her children, with and without a learning disability. In many ways this might be seen as an aspirational position of a model parent. Dilma recognises that her child is different because of the intensive care needs that she requires, but affirms her position as a mother over and above that of being a carer or co-therapist.

Balancing the dual role of being a carer and/or co-therapist, and a parent sometimes called into question the parents' ability to perform these responsibilities to the best of their ability.

> Sheryl: "I was told 'well, don't you think other parents have problems?'". (Page 15, Line 739)
>
> Hillary "Part of you as well, thinks, as a parents, that, you know, is it my fault that they're behaving like this?" (Page 4, Line 161):
>
> Melinda: "If I hadn't been a foster carer then I would have thought that you might think I'm a bad parent or something". (Page 4, Line 162)

Parents called into question their own ability as a parent if they struggled to manage their child's sometimes challenging behaviours. The problem becomes increasingly systemic as those outside of the family, as Sheryl comments, ask how they believe other parents might cope with difficult behaviours. Being a foster carer helped Melinda separate from some of these comments as her professional role protected her in some way from feeling that she had to offer explanations.

The paternal role was often absent from the conversations around who takes up the caring role.

> Sheryl: "(*My husband*) needs to be the one who brings the money in". (Page 15, Line 713)
>
> Angela: "In the end my husband did have a breakdown". (Page 3, Line 139)
>
> Mary: "I got my ex to go cos he wasn't really involved" (Page 29, Line 1458)
>
> Christina: "I kept him safe from his Dad but … I hadn't got a clue how to deal with Autism". (Page 5, Line 226)

Some parents commented that the father's role was to help support them and bring in finances where in some cases the mother had to give up work to look after their child. However, not all fathers were involved, Mary commenting that getting her ex-partner to go was in some way a frustration at the unfair division of parenting. For Christina, she had to keep Thomas safe from domestic abuse, amid trying to be a parent of a child with a learning disability and not understanding her son's diagnosis of Autism.

2.3.1.3 Subordinate Theme: Coping on your own

Within most of the interviews parents talked about a sense of feeling alone and isolated both before a mental health diagnosis was assessed for and also when trying to implement interventions as a co-therapist. This led to parents talking about their experiences of 'coping on your own'.

> Janet: "You're just sort of shaking your head and you've got tears streaming down your face because you just don't feel like you are getting anywhere". (Page 15, Line 726)
>
> Dilma: "…come and do this with Mummy and she's like having none of it… I'm thinking … Why am I even bothering?" (Page 11, Line 511)

Janet described an instance of being in particular distress. Her comments give the reader an understanding of just how difficult a situation can become where distress is paired with a feeling of not getting anywhere. Dilma describes a sentiment close to this when she was trying to get Emily to participate within an intervention without success.

For some parents when handling distress there were distinct instances or decision points where they had tried to access help. When help had not been forthcoming, parents found themselves in a vulnerable position.

> Christine: "And I started drinking, and I had no help from anyone". (Page 2, Line 67)
>
> Angela: "…parents unfortunately can reach the end of their tether and I think they were concerned about the child's welfare". (Page 1, Line 43)

> Sheryl: "…when I had my nervous breakdown I just completely stopped doing anything like that because I wasn't strong enough". (Page 22, Line 1100)

Feeling isolated led Christine to turn to alcohol for support with devastating consequences as subsequently Thomas was taken into care. Angela describes how parents can reach a breaking point when trying to cope alone which can call into question the child's welfare. For Sheryl, coping alone led to a nervous breakdown, or a breakdown in her mental health which she frames as not being strong enough to continue the coping she had previously managed before the downturn in her mental health.

Other parents utilised coping strategies that worked well for them but still alluded to the sense of coping being a struggle.

> Christine: "…I promised myself my sons come first and it doesn't matter how much it hurts. And I've stuck to my guns, and it has worked out". (Page 32, Line 1595)
>
> Mary: "I've chucked him to school in his pyjamas before because I haven't been able to get him dressed". (Page 25, Line 1226)
>
> Sheryl: "…We were looking at stuff on the internet, both my husband and I were trying to research it". (Page 8, Line 370)

Christine talks about putting Thomas first, no matter how much it hurts her. While this might be in line with her values as a parent, one can assume that she would need to count on many resources in order to not burn-out as a parent and carer. Mary talked about sending her child to school in his pyjamas. This leads us to consider the social stigma that Harry might have faced at school and questions that teachers might have had about her ability to cope. For Mary in that moment, coping looked like her child getting to school, no matter what. Sheryl explained that using the internet was a useful tool and utilising it was a proactive step to coping. However, Sheryl also noted that trying to research it could lead to many further unanswered questions as the diagnosis and rationale for intervention that Jacob received had not been fully explained to her.

2.3.1.4 Subordinate Theme: It affects everybody in the family

While implementing recommendations primarily affects the parent as co-therapist and the child for whom the intervention is designed, the family system is affected by the behaviours and the changes that are made meaning that it affects everybody in the family.

> Mary: “He was starting to attack (*Daughter*), head butted her, scratched her, you know”. (Page 36, Line 1827)
>
> Angela: “I have been told ‘be a bit more structured – put him back in his bed’… he just still did it and laid there screaming and shouting and kept us all awake every single night for five solid days”. (Page 8, Line 393)
>
> Melinda: “That’s impacted positively for her, but it’s not great for us because we have to avoid things” (Page 11, Line 521)
>
> Mary: “The residential overnight care is so important for me to spend time with (*Daughter*) on my own”. (Page 39, Line 1974)

Challenging behaviours can affect the parents and siblings. This can be realised both in a direct way, whereby siblings might be attacked as Mary described, and in the time it takes away from the sibling. Implementing interventions for sleep, as Angela depicted led to the family not getting sufficient sleep for the five days while the sleep intervention was carried out. While the impact can be positive for the target child, it is important for clinicians to think about the wider family consequences as this might affect motivation to participate, as Melinda describes.

2.3.1.5 Subordinate Theme: Told to give up work

A further duel role to balance with the parental role was a work role. This appeared to be problematic for many of the parents within the study as they reach decision points about the viability of continuing with work. Some mothers remained at work such as Dilma, despite being told to give up work in order to care for their child.

> Mary: “I’m thinking what’s more important? (*My child*) this moment in time, is the most important one. So I had… I stopped working, um during the day, I was still working in the evenings”. (Page 35, Line 1758)
>
> Dilma: “I didn’t want to not go to work, because I know that if I go to work, that keeps me going a little bit … you got told to give up work”. (Page 18, Line 875)
>
> Sheryl: “I was really angry at the fact I had to give up my life to be a carer”. (Page 18, Line 906)

Parents within the study had different employment statuses. For each of them the decision to either carry on with work or to take up the caring role full-time was a difficult decision. Giving up work for Dilma meant that she would lose part of her identity and therefore despite being told to give up work she decided to continue working. Sheryl expressed how angry she felt at feeling there was no choice but to give up work and become a carer for her child, perhaps making the caring role harder.

For some families the lack of money led to potentially serious consequences for the family.

> Angela: “Yeah we nearly lost this home, because we couldn’t keep up the payments because money was just going to keep my son in hospital”. (Page 3, Line 155)
>
> Melinda: “Angry. I just… I did say can you not argue about the money, just somebody pay for it”. (Page 13, Line 640)

Angela describes nearly losing her family home. At the time her child was in hospital so the family had to pay parking fees in addition to weekly costs so they could visit Jack. Melinda described a meeting where there was a conflict between services about who would pay for equipment that Olivia needed. Whether Olivia might not have ultimately received the equipment because of cost was particularly difficult for her mother to witness, potentially positioning Melinda in a powerless position.

Often parents explained that they were not made aware of the financial support that they could access.

> Christine: “No, no, I wasn’t getting any disability allowance or any- I didn’t even know about that either”. (Page 23, Line 1129)
>
> Mary: “What’s direct payments? ... I was taking him to the (*Day Centre*) paying for it … it was quite a bit of money”. (Page 9, Line 407)

One of the reasons parents found it difficult to cope financially was because they were unaware of the financial support that they were entitled to. Mary describes paying privately for things that she could have accessed via a government scheme called “direct payments” which could have eased the financial burden on the family. Part of the journey for parents was adapting to the changes in funding streams into their household as they had no previous experience of attaining government support.

2.3.2 Superordinate Theme: Developing Confidence

Parents were often new to having a child with a learning disability and mental health problem. They talked about a journey of trying to get their voice heard, to trying out interventions and learning more about their role both as a parent and as a co-therapist.

2.3.2.1 Subordinate Theme: Needing to tell someone

Many parents in the study found that getting their voice heard was particularly difficult despite needing to tell someone about the challenges they faced when caring for their child.

> Angela: “About four o’clock in the morning I made a phone call to the health visitor’s number”. (Page 1, Line 34)
>
> Janet: “So I’ll ask whoever and that’s what I do and I try and get passionate, cry anything like that. I’m never rude to anybody. I’ll cry at somebody but I’m never rude”. (Page 31, Line 1535)
>
> Mary: “Um, and that’s quite depressing really, you know, needing to tell someone that this is happening and not being able to get through, having to leave a message or ring back later”. (Page 28, Line 1411)
>
> Hillary: “There’s no point in shouting and screaming and hollering, it’s not going to get you anything quicker”. (Page 15, Line 713)

Parents resorted to different strategies in order to recruit professionals into giving them the help they felt they needed. Janet describes crying and becoming passionate but made the point that she believed she never became rude. Walking the boundary between being passive and aggressive appeared to be difficult for parents as they came up against barriers such as recorded messages on answer machines. Hillary noted that, even when parents do become more aggressive, it does not benefit them in receiving the help they felt that they needed.

As part of this learning parents described becoming advocates for their child. This was not necessarily a role that they had intended to develop, but a seemingly natural consequence when trying to recruit help.

> Angela: “Why am I fighting for my son for 24/7? If I didn’t fight for him with his bowels he would be sat here now in nappies all day”. (Page 11, Line 563)
>
> Mary: “She threatened to take his place away. And I thought, no… I don’t know, but she didn’t like that”. (Page 11, Line 541)
>
> Hillary: “I went up there and I said, I got so fed up of it, I said how are you teaching (*my daughter*)?” (Page 7, Line 341)

Angela questioned why receiving help and support was so difficult for her family. She comments on how diagnostic overshadowing led to professionals not picking up on a bowel condition that

Jack had, which meant that at the age of eight Jack would still have been wearing continence products and the condition would be going unchecked. Mary felt threatened by a health professional who learnt Harry was accessing two similar services. This was particularly difficult as the day service provided the family with important respite as well as providing benefit to Harry in her eyes. Therefore, Mary discovered that what you tell professionals could lead to negative consequences leading to her describing becoming more tactful about what she said to professionals following this event.

While referral procedures are often second nature to health professionals, several of the parents commented on the difficulty they encountered when going through referral pathways to mental health.

> Janet: “It’s quite a scary form to sign when you read it … So if I’d read that form alone I might not have seeked help you know”. (Page 6, Line 263)
>
> Melinda: “They all thought that she was understanding everything but she really wasn’t. It wasn’t until (*Psychologist*) referred her for the urm…skills test, or whatever it was, I wish that had been done earlier.” (Page 5, Line 242)
>
> Dilma: “She got referred to genetics, in Southampton. They noticed that something was a little bit different about *Emily*, her facial features.” (Page 5, Line 215)
>
> Angela: “I am getting really worried… he is really falling over a hell of a lot and she said ok, I am going to refer him to Occupational Therapy. Two and a half years later I am still waiting for Occupational health”. (Page 18, Line 932)

Janet described the concerns she had about completing the consent form and how this might have been a barrier to her seeking help had she not had the support of staff. Melinda talked about how she wished that things had been dealt with earlier, while Angela discussed how this was not always possible, as she had been waiting for over two years to have specialist input from the Occupational Therapist. In part, this highlights the lack of control that parents often experience, despite the sometimes impassioned and advocating roles they might assume.

2.3.2.2 Subordinate Theme: Nobody believes you

Within the study parents commented that when they did raise concerns about their child, nobody believes you.

> Hillary: “They said, no, she’s absolutely fine, all children go through and I just thought oh, ok then, perhaps it’s just me?” (Page 2, Line 97)

> Angela: “Please don’t tell me it because he has been ill because that’s all I keep getting. I’m sorry there is more to my child than being ill” (Page 1, Line 53)

> Sheryl: “Last time I tried to tell my Mum he was Autistic, she told me I was making it up”. (Page 10, Line 485)

Not feeling believed led to parents questioning again what was normal and whether their own experiences were valid in light of what others perceived their experiences might be like. Sheryl noted how explaining a mental health label such as Autism to a parent led to generational differences in understanding and a parental suspicion that she was making the label and condition up.

Parents also had particular difficulties with feeling that professionals and services believed what they were telling them.

> Mary: “I’d been coping with it for months and months and months, but until someone official sees it no one sort of really believes you”. (Page 26, Line 1303)

> Dilma: “The impression I got is that they thought we was just being lazy and not doing it with her”. (Page 9, Line 434)

Validation for Mary came in the form of someone official seeing what she had been describing. She linked Harry’s behaviour with her own coping and resilience for several months before a professional agreeing on input. Dilma’s experience was a sense from professionals that she was being lazy and not implementing the recommendations, perhaps pertaining to the difficulty of implementing strategies and possibly forming barriers to engagement and help seeking.

2.3.2.3 Subordinate Theme: I’m learning

Becoming a co-therapist and implementing strategies to help one’s child requires learning on the part of the parent. Of the parents interviewed there were several ways in which they were coached to implement interventions, from talking through interventions week by week to being tasked with completing activities such as creating visual schedules, social stories and behavioural experiments.

> Dilma: “Now, I have done controlled crying for half of Emily’s, three-quarters of Emily’s life and I am pissed off with sitting outside that bleeding room while she screams and cried to me to get in bed with her, I can’t do, it’s” (Page 9, Line 446)

> Hillary: “I mean some of them, I have to say, haven’t worked on certain things, and that’s a bit upsetting, like why is Amelia not doing it?” (Page 11, Line 537)

> Melinda: “Anything I did like sticker charts and things, nothing worked”. (Page 1, Line 32)
>
> Melinda: “I didn’t think they could do it because they were teaching me stuff that I’d already done with her and it didn’t work. I’d do it again but, I just thought ‘oh no’”. (Page 3, Line 107)
>
> Angela: “I’m with my child 24/7 24 hours a week. I know my child. What happened to the saying ‘the mother knows best’?” (Page 8, Line 414)

Parents explained how some of the interventions that they tried to implement did not work. Dilma talked strongly about trying an intervention several times over with different professionals and how frustrating it had been each time when the intervention did not work. Hillary explained the self-questioning about what Amelia was not doing and how this then became upsetting for her. Collectively there was a sense of frustration from parents about implementing interventions that did not appear to be working for whatever reason. Angela expressed wanting recognition for her own expertise when implementing interventions for Jack.

Often interventions involved parents using skills to create items for intervention or to implement interventions that had been explained to them.

> Angela: “She came up with the idea to do a calming box and we sat there and had great fun decorating the box”. (Page 6, Line 334)
>
> Melinda: “(*About schedules and sticker charts*) As you can see all over the door and the fridge. On her bedroom wall we’ve got like getting dressed … and social stories”. (Page 6, Line 273)
>
> Janet: “(*She*) did a chart thing where Isla would point to it with how much she was understanding”. (Page 19, Line 926)

For some parents, especially when interventions appeared to work well, they described enjoying putting together or implementing interventions.

Throughout interventions it appeared that the help of the health professional was key.

> Hillary: “We go through like forms about her behaviour and then she’ll give me strategies for each behaviour … I suppose it’s almost like having a teacher”. (Page 7, Line 331)
>
> Mary: “I would stay and do the therapy with him, it was hard work”. (Page 9, Line 437)
>
> Melinda: “Because I’m a foster carer, I do like challenging behaviour courses and things like that.” (Page 2, Line 57)

> Melinda: “I also went on Autistic courses to learn the way children think.” (Page 3, Line 135)

> Janet: “So I felt a bit more comfortable and – she still struggles Isla does but I’m learning … I’m learning that I have to readdress myself all the time”. (Page 8, Line 385)

Parents discussed a variety of learning methods from sitting with health professionals to attending courses in order to improve their knowledge about their child’s difficulties. Janet comments about putting the learning into practice, that it was not only about what Isla found difficult but also how she had to adapt her behaviour in response.

2.3.3 Superordinate Theme: Working with Services

Having a child with a learning disability brought parents closer to working with a variety of services.

2.3.3.1 Subordinate Theme: At the hospital

Often when the child was particularly young, parents within the interview cohort would describe frequent trips to, and their experiences at, the hospital.

> Angela: “As time went on Jack had a lot of hospital visits and I think I am on my twenty second ambulance now for him”. (Page 1, Line 25)

> Janet: “I mean we were at the hospital, um, at least once a week I think, at points we were possibly up there twice…” (Page 3, Line 135)

> Sheryl: “I was with him around the clock for six weeks”. (Page 7, Line 319)

Angela described how many times she had to call an ambulance when Jack was in a critical health condition. This was described as a frightening position, as one can imagine, for any parent to be in. For Janet, hospital visits were more regular and therefore had to be scheduled into the timetable for care for Isla. Other parents’ experiences were similar to Sheryl, who had to have a prolonged stay with Jacob in hospital. Again, when the parent has to spend this amount of time in hospital it can have a negative consequence for working and family life.

When at the hospital, Melinda described the need to stay.

> Melinda: “Because some of these Doctors were high up at the hospital and they hadn’t got a clue about (*her*) syndrome”. (Page 4, Line 197)

Melinda explained that because of Olivia's rare condition, the staff were often unaware of her unique needs or how to work with someone with a learning disability.

2.3.3.2 Subordinate Theme: Health professionals

Meeting and working with health professionals was a large part of the work for many of the parents.

> Hillary: "You talk to someone and it's almost like, you know, where they've experienced it, not maybe themselves, but…" (Page 6, Line 290)
>
> Janet: "(*She*) did everything she could do and she was talking to me through it". (Page 11, Line 519)
>
> Angela: "I think she's brilliant, I have got on really well with her. I found Speech very patronising people". (Page 6, Line 317)

Parents felt that it was useful to talk to professionals who appeared to have some understanding of what they were going through. Hillary noted that although the Psychologist she was talking to did not have any personal experience, her professional experience meant that she felt they connected and therefore she felt listened to. Angela noted a positive relationship with some professionals while a bad experience with some professionals from the same background, Speech and Language in this case, led to a sense of all of them being found to be "patronising" which could lead to future barriers in engagement.

At other time parents felt that both they and the professionals were in a state of being helpless to change anything.

> Mary: "A lot of the times you're just sat there and we chatted quite a lot because not really a lot she could do". (Page 3, Line 151)
>
> Melinda: "I kind of get annoyed with people over the years saying … blaming everything on global delay and that drove me nuts". (Page 5, Line 223)

Mary described how she felt that all they could do was chat through how things were, while Melinda described her frustration at her child's learning disability overshadowing other concerns.

2.3.3.3 Subordinate Theme: Services

Within the study parents described some of the difficulties that they had experienced when working with services.

> Melinda: “Banging my head against a brick wall with the school … I bring it up every time and send thing in for them to show them what we’re doing at home and they’re just not doing it”. (Page 7, Line 328)

> Mary: “Education, NHS, social services, and you’re trying to juggle all those three … pull them together, it’s difficult.” (Page 4, Line 166)

The difficulty of attaining consistency of an intervention across several different service settings often brought up challenges for parents as services across education, health and social services were not necessarily joined-up. This meant that the responsibility fell to parents to successfully negotiate individual approaches for their child.

In terms of accessing resources it appeared that some parents had different experiences.

> Angela: “Again it’s funding … if funding is tight then resources are tight, and if resources are tight then the parents are not going to get the support are they?” (Page 22, Line 1183)

> Janet: “I don’t know if everyone gets given the amount of time we had but no-one seems to say you’ve had your time or anything like that”. (Page 21, Line 1041)

While Angela felt that accessing resources had been particularly difficult, Janet commented that services appeared to be open-ended.

2.3.4 Superordinate Theme: Building Support

Support networks are important to most parents. Within the interview cohort they talked about the support they attained as well as some of the difficulties they encountered while building these networks.

2.3.4.1 Subordinate Theme: Parents help other parents

Having a child with a learning disability and a mental health diagnosis is a distinctive position to be in. Therefore, parents who have knowledge and experience of the services and systems that are frequently accessed can become an important source of knowledge and there were examples where parents help other parents.

> Hillary: “You talk to other Mums, you do realise that these children are going through the same things at home”. (Page 4, Line 172)

> Janet: “I can understand now why parents help other parents”. (Page 33, Line 1642)

> Angela: "She gave me this number and I rang it … as it turned out I was entitled to support and that was three years down the line." (Page 13, Line 638)
>
> Sheryl: "I've lost friends over this last year who are also parents of disabled children erm because they couldn't cope". (Page 20, Line 979)

Not all of the parents had a positive experience of the parental support network. While for some such as Hillary, Janet and Angela, they found that the network was particularly helpful to accessing knowledge, Sheryl explained that parents in a similar position of stress could lead to disagreements and fragmented friendships.

Parents within the study also talked about the difficulty recruiting their own parents to help.

> Angela: "(*My partner's*) Mum and Dad are no longer here, they passed away, urm my Mum is crippled with arthritis and osteoarthritis and my Dad is near blind". (Page 4, Line 183)
>
> Hillary: "Mum and Dad don't understand what you're going through with your child, because when they, they sort of, you know, they come around to visit and they're here an hour, but they're not here the whole day, they don't see…" (Page 20, Line 973)
>
> Sheryl: "I remember (*Partner's*) Dad was being a bit of a git and was like 'Oh you only call us when you need us, when you need something from us'". (Page 6, Line 295)

Intergenerational help was not always available to the parents within the study. Reasons cited tended to be around the parents having passed away, being in ill health, and not understanding the difficulties or support fatigue.

2.3.4.2 Subordinate Theme: Giving me help

Some parents were offered support by services which was directed towards them more specifically.

> Angela: "They might come a couple of times a week, just to chat to you and see and to help support the child". (Page 2, Line 79)
>
> Hillary: "You're getting help through your club as well, and what you should do to maintain it … but you're getting to air off your views … of how frustrated you feel". (Page 5, Line 246)

The ability to discuss how they were feeling and give an honest account of their experiences appeared to be particularly important.

> Mary: "So yes, it's nice to have recognition that you're trying, you're trying your absolute best or conformation that you're doing your best cos you do think you're struggling". (Page 31, Line 1528)

> Christine: "I had no help with anything after the court case, everyone just left me … But um, they diagnosed him when I was in rehab, um and then all of a sudden everyone was jumping on me and giving me help". (Page 2, Line 77)

Parents linked their struggling with the need to receive help targeted towards them. Christine explained the need for help and not receiving it, until things became particularly difficult and she was in rehabilitation for alcohol, when she received an abundance of help. The timeliness of receiving help therefore was an important factor for parents when seeking or needing additional support for themselves.

2.3.4.3 Subordinate Theme: Misunderstood

Miscommunications or misdemeanours in the community could lead parents to feeling misunderstood.

> Melinda: "We got asked to leave Tesco's because her behaviour was frightening the customers… It was actually them frightening her, because they'd trapped her in an aisle. They didn't mean to but that's how she saw it". (Page 1, Line 45)

Melinda's example highlights the difficult that some parents faced while in the community. Such difficulties could lead to parents avoiding busy places such as supermarkets, especially at peak times.

> Mary: "They'd put an inspector from Portsmouth City Council on the bus to assess him, I suppose, and obviously thought, no, that child's far too violent … and if his behaviour didn't change they would have to, um, stop the transport". (Page 25, Line 1235)

> Janet: "I think there's so many misunderstood – with not very good parents … They're not going to respect the adults in the school, which then makes the school have to work extra hard on these children that shouldn't be there in the first place … they've got lazy parents that shouldn't be parenting". (Page 27, Line 1336)

When accessing community services, there was not always a willingness to understand why someone might be behaving the way they were, which was particularly difficult for Mary. Janet explained that school's got a bad reputation because of, what she believed to be, bad parenting which led to a disrespect for staff. She commented on the confusion between a learning disability and difficulties with behaviour for some children.

> Sheryl: "Like a lot of English people already have their set lives, they already have their set groups and cliques, and that is just the way it is". (Page 16, Line 804)

For Sheryl, who is a foreign national, she found it difficult to infiltrate into social groups within England to become part of the local community, which left her feeling resigned that she might never be able to become part of a friendship network or group.

2.4 Discussion

This study aimed to explore parental experiences into how parents of a child with a learning disability experienced services for their child, to help foster an understanding about how healthcare professionals might better engage parents in the therapeutic process. Parental descriptions highlighted substantive issues such as the need for clinicians to take into account the 'bigger-picture' when implementing psychological interventions. The findings connected to published literature on parental experiences of implementing therapeutic interventions for their child.

Parents talked about having to fight to access services or receive an assessment in the first instance, in line with findings from the CAMHS report in 2014 (Children's and Adolescents' mental health & CAMHS, 2014), which elevated experiences of distress and feeling alone. This finding may be likely to be replicated under a severe cost-cutting culture within health care in the UK. Some parents commented on feeling shocked when their child received a diagnosis, as found by Case (2001), which further led to feelings of distress and uncertainty. These experiences were also present for parents when implementing interventions dependant on the level of support they had, as well as their own sense of confidence. Systemic effects of interventions could lead to difficulty for the entire family unit, with the father's role being discussed infrequently, suggesting a dominant cultural narrative around the mother taking the lead on caring roles within the family. This finding fits with literature on engaging parents within interventions, where the paternal experience and voice is often absent (Singh, 2003).

Parents talked about grieving for the loss of the perfect child, as outlined by Maxwell (1993), as well as coming to terms with and understanding their child's mental health condition (Benedetti, Garanhani & Sales, 2014). Often there were cases of diagnostic overshadowing, which has been a recurrent difficulty for clinicians when assessing children with a learning disability, owing in part to the complexity of cases (Jones, Howard & Thornicroft, 2008). Receiving a mental health diagnosis appeared to be a particularly critical time for parents as they gave accounts of not feeling believed, and therefore placed a high degree of emotional investment into attaining professional validation for the difficulties that they were experiencing. The mental health label, which for many parents within the cohort was Autism, a condition with high comorbidity for a child with a learning disability (Matson & Shoemaker, 2009), therefore carried meaning at different levels for the parents. This highlights a further issue around the need for clinicians to communicate what might be involved in the diagnostic pathway when diagnosing a child in order to help manage their expectations.

The parental role had to compete with occupational roles, as well as the caring role for parents, leading to questions about how parents aspired to being a model parent within unique circumstances. Part of these unique circumstances was managing difficult behaviour or mental health conditions for which most of the parents had little knowledge or prior experience. Adjusting to changes in family life, both in response to the child's learning disability as well as their mental health condition, could be particularly difficult for families as they redefined 'normal life' whilst holding onto cultural narratives around the 'norm'.

Parents often found, both before interventions started and whilst interventions were being carried out, that they felt they were coping on their own. This was particularly pertinent when they were facing challenges with implementation of recommendations or when interventions were failing. This led to threats to the mothers own mental health and a reliance on maladaptive coping strategies with sometimes serious consequences e.g. alcohol misuse. For some parents however, there were demonstrations of factors that fostered familial resilience such as maintaining friendships, learning about the child's mental health and becoming lay experts in their child's behaviour and conditions (Luthar, 2003).

Within the sample, the overall experience between the parents and the clinicians implementing the psychological intervention, had been particularly good. Often this relationship appeared at its best when parents felt listened to, believed and supported. However, when interventions did work well, parents found that there were additional barriers to implementation, which was around consistency of approach across services and a lack of joined-up-working, both between health professionals and especially between service providers. Parents emphasised the usefulness of multi-disciplinary team meetings.

Community settings, as well as hospitals, did not always accommodate or understand the needs of a child with a learning disability. Within the parents' local community, this could lead to them avoiding certain places or going to places at certain times when there was likely to be fewer people. As a consequence of this, it is likely that members of the local community do not see children with a learning disability as much, decreasing both their awareness and visibility, thus perpetuating the cycle.

2.4.1 Strengths and limitations of the study

This study offers a voice to parents of a child with a learning disability which is a group that historically has not been subject to a high level of research input. A low level of research input can be difficult for both policy makers and clinicians who have limited evidence from which to base guidelines and interventions upon. This is a greater problem for the learning disability population who are around four times more likely to experience a mental health problem than the general public (Emerson, 2003). The use of IPA allowed for a rich and detailed examination of parents' accounts beyond the scope of what is possible within quantitative research methods, such as correlational designs. The method also promotes openness within the research interview, allowing for participant expertise on a subject to be included within the research that quantitative methods do not allow for. In this study, an example of that was the emphasis that the parents gave to feelings of loneliness and isolation, which was a topic that was not originally prompted for within the research interview. The implication from the research therefore is that clinicians and researchers can be further informed and formulate an understanding about why parents of a child with a learning disability might act of behave in a certain way when they come into contact with mental health services.

As part of good practice within qualitative research, this study used reflexive explanations and triangulation to increase transparency for the reader of the researcher's influence upon the findings. This was completed, as a common critique of qualitative research is that the research is highly dependent on the skill of the researchers themselves.

As a qualitative research method, IPA is unavoidably subjective, as two researchers working on the same data are likely to attribute different meaning and outcomes to the data. It is recognised within IPA research that this is the case as each personal construction of meaning will be different which is the purpose of the work within this study to increase transparency e.g. examples from the researcher's reflexive diary and publication of the initial themes map from the data. One way to improve the validity and reliability of such studies is to have several researchers work on the same data. As this study did not have several analysist of the available data, this is a limitation of the study. Another way to account for the face-validity of the data within IPA is to present the data to the parents who took part in the research interviews. As this study did not present the research findings to each of the parents this too is a further limitation of the study.

Researchers such as Yardley (2000) and Smith (1999) have argued, however, that testing qualitative research for reliability, in the same way one might test quantitative studies, in not a useful test of the data. The researchers both argue that the themes maps and interpretation are acknowledged to be a small subset of the total themes from the data, namely, those which pertain to, or focus on, the specific research interest or question. Consequently, checks of inter-rater reliability might serve only as checks of an agreed upon perspective by two or more individuals, rather than a truly pure objective stance. Therefore, based upon these principles, the study did not further interrogate the data set, but focused upon transparency and reflexivity as a means to demonstrate the intension to provide a clear and credible account of how the data was treated and interpreted.

A key principle of IPA research is to recruit a homogenous sample. A limitation of this study was the sample being recruited from two different teams and including a wide variety of child's age ranges, mental health conditions and severity of learning disability, therefore reducing homogeneity. A consequential limitation of working with small samples is an inability to generalise findings to a broader population, for which larger scale research would be required.

A risk of qualitative research using social constructs to build evidence and insight is that the map is culturally and temporally bound. This means that ideas within the thematic map might reflect ethnocentric and cultural bias, again meaning that a further degree of caution needs to be given when applying or using the results of qualitative research to influence policy, service delivery or clinical interventions.

A further critique of qualitative research is that the process requires a labour intensive approach, for example, interviewing, categorising, re-categorising and recording. As all studies need to be workable within a budget and time-frame, this means that qualitative research does not enjoy the shorter time frames often found within quantitative research for administration of measures. As an example within this research, the research interviews often went over an hour, which was the expected time frame to have gone through the research interview. The over-running of the interview was owing to the curiosity of the researcher and hope for attaining further insight into the unique perspectives offered by the parents. However, the extended time of the interviews might have felt uncontained for the participants, leading to them talking in an extended way about items which were not directly related to the research question.

2.4.2 Clinical implications

An important part of the research process is to consider how services might be able to make practical changes based upon the research evidence. These are some examples drawn from this paper's findings:

Adapting and changing

- Health professionals should keep in mind that the parent is a mother or father, first and foremost. Opportunities can be taken to reflect with parents about how they believe the co-therapist role can be balanced with the parenting role.

Developing confidence

- Engagement appeared to be fostered by clinicians taking the time to listen to and validate the parents' concerns, whilst being mindful that the parent might not feel that they are believed.
- Cheerleading parental efforts provided parents with a sense of recognition for their role. Further to this, setting up expectations for parents about the difficulty of implementing interventions and what to do if interventions appear to be failing, so that the parent will not feel that *they* are failing if an intervention is unable to yield the desired outcome.

Working with services

- As this population have typically worked with several professionals and services before psychology, questions might be asked about previous working relationships, reflecting on what worked and difficulties parents have encountered, so that the clinician can improve the current experience, thus improving the parent's self-efficacy and sense of control.
- This paper highlighted the need for clinicians to ask parents about their experiences of assessments for their child's mental health diagnosis and what having the diagnosis would mean to them.
- Services could utilise parental feedback groups, alongside qualitative outcome measures to help capture good practice together with potential areas for service improvement.
- Provide education and training for local hospitals and GPs to help improve awareness and improve referral pathways.

Building support

- Clinicians could map systemic factors with parents whilst designing interventions, to account for how interventions might impact on the family e.g. through the use of genograms. Furthermore, mapping the parents' support networks such as friends, extended family and protective factors that will help to build or maintain familial resilience.

- Provide parents with information about where to receive support and help for themselves i.e. local well-being groups / IAPT services.

2.4.3 Future Research

In order for health managers and service commissioners to be more attentive and responsive to the parental experience of involvement in their child's therapy, it will be important to use measures that meaningfully capture the nature of engagement, for both the child and the parent. The inclusion of family and carers as part of care pathways has become increasingly important within care pathways and recommendations from organisations such as NICE (Garety, Fowler, Freeman, Bebbington, Dunn et al). Quantitative data will also need to be collected on the child's and the parent's experience of interventions as well as time spent within services. The aim of such data would be to highlight any gaps within parental attitudes around the usefulness of strategies and beliefs about their responsibility for the implementation of healthcare recommendations, including highlighting any barriers to engagement. Further to this, the data would provide information on the alignment for the triad between parent, child and therapist for the treatment goals and any gaps between the support the family believes they need, and what the service is able to provide. Once these gaps have been defined by services, reasonable adjustments can be made to find common ground with parents, for example, agreeing and contracting the involvement of both the parents and the service, to make the expectations from both sides clear at the start of a clinical intervention. This would help to improve parental engagement and thus reduce the burden of responsibility for change from the therapist as both would be working toward a common goal.

This research found out about parental experiences at a familial (micro) level and service / community (mezzo) level. However, little was discovered about how parents felt about their position at a media, cultural and governmental (macro) level. Future research could gain insight into this level of understanding to help services understand parental experiences of how they feel they are viewed at a societal level, and how this impacts upon them as a family and their desire to seek help and engage with services. Further to this, it is useful to not only capture the parental experiences of their anxieties and difficulties from micro to macro level, but to also capture narratives around how they have demonstrated strength and resilience, as there is validity in undertaking both positive, as well as problem based, research paradigms. Furthermore, it is important to consider how cultural narratives about raising a child with a learning disability and mental health problem might impact upon families, as some research challenges dominant discourses about increased stress and difficulty for parents (Clarke & Fletcher, 2004).

Often parents are the primary caregiver, but they will not be the only member of the family to undertake a care-giving role. Siblings of children with a learning disability and mental health problems, are themselves more vulnerable to psychological difficulties themselves over typically developing children (Cuskelly & Gunn, 2006). As this research discussed, interventions often involve the whole family and siblings might be either directly or indirectly involved in helping to implement them. Understanding the perspective of sibling carers and the sibling role in more depth could help to provide insight into the unique experiences that some siblings undertake. Furthermore, if clinicians or family members are asking siblings to become involved in delivering interventions, it would be ethically correct to screen for any potential difficulties that the sibling might have with undertaking this responsibility. As clinicians at this point would already be involved with the family they would be well placed to complete this assessment as wider systemic factors, such as poor sibling response to an intervention, might disturb the effectiveness of the intervention and have a wider consequence, such as set-backs in parental engagement.

Appendices

A. Descriptive Summary of Review Studies

B. Table of themes as they appear within the review papers

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Appendix A: Descriptive Summary of Review Studies

Reference	Design	Population	Aim	Results	Strengths	Limitations
Benedettie, Garanhani & Sales (2014) Quality Rating: 9/10	Qualitative, Heidegger's phenomenological assumptions	13 parents (5 fathers and 8 mothers) of 8 patients under the age of 19 whose child was undergoing cancer treatment or monitoring after treatment.	To understand the experiences of parents of children undergoing treatment for cancer.	Three core topics emerged: "Experiencing the unpleasantness of treatment", "Fearing the possibility of a frightening situation" and "Experiencing the carelessness of another person".	Phenomenological approach based on Heidegger's assumptions. Representation from both mothers and fathers. Attention to ethical considerations.	Limiting factor around not having generalizable results. Sample taken from a charity association providing only nursing and social care provision for poorer people.
Ryan, Speechley, Levin & Stewart (2003) Quality Rating: 7/10	Questionnaire	37 parents with children between the ages of 5-17 and 1 paediatric neurologist	To examine the extent to which parents could describe their child's epilepsy and its impact.	Parents were able to describe seizure types, characteristics and impact. Low concordance between parents' and physician's perceptions of global, medical and everyday aspects of epilepsy.	Efforts to find a representative sample via randomising from 129 eligible parents. Test-retest reliability assessed.	Study provides no insight into why there was discordance between the professional and parental perspective. Non-validated or standardised questionnaire.

Case (2001) Quality Rating: 6/10	Questionnaire	84 parents of 84 children with a learning disability with a mean age of 8.57 years.	To analyse whether the high degree of parental dissatisfaction with disability professionals is indicative of the modern parent-professional relationship with regards to service provision for learning disabled children.	Professionals are beginning to address the need for clear and appropriate information and intervention, an acknowledgement of parental needs and expertise, effective parental involvement and parents as service ‘consumers’.	Addressed positive impact of parenting a disabled child. Large amount of data collected from each respondent leading to broad understanding.	Non-validated or standardised questionnaire. Incomplete diagnostic information for the sample. Question response rate varied and overall was 82.9%. Parents only able to give ‘yes’, ‘no’ or no response limits an in-depth understanding of the results presented. Self-selected sample reduces generalisability of results.
Clarke & Fletcher (2004) Quality Rating: 9/10	Qualitative, narrative.	29 parents (4 fathers, 25 mothers) of children diagnosed with cancer at an	For parents to tell their story about their experience of their child ‘going through’ cancer.	Key topic of “Problems with the system / surplus suffering”. Parents reported on their perceptions of	Rich data from the parents who were interviewed. Triangulation of data.	The children in the study had been diagnosed with various types of cancer reducing the homogenous

	average age of 5.4 years.	mistakes, delays in diagnosis, errors, carelessness and unkindness during treatment.	nature of the group. Some interviews conducted by a parent whose own child had experienced cancer impacting results to an unknown degree. Reliability of interview’s reduced owing to different interviewers. Interviews based on retrospection where events had taken place several years before the research interview. Potential social desirability effects within interview setting. Lack of generalisability

						across time and place.
Cohn (2001) Quality Rating: 8/10	Qualitative, grounded theory.	16 parents (12 mothers and 2 husband and wife couples) of children between the ages of 4-10 years old.	To explore parents' point of view regarding their children's participation in occupational therapy using a sensory integration approach.	Parents valued understanding of their children's behaviour in new ways, which facilitated a shift in expectations for themselves and their children, having their experiences validated and being able to support and advocate for their children.	Case study approach leading to a rich data. Good detail of implications for practice and research. Researcher reflexivity. Data analysis adheres to grounded theory procedures.	Social desirability of interview method. Non-generalizable sample. Does not take other professional voices into account i.e. teachers / child.
De Haan, Welborn, Krikke & Linszen (2004) Quality Rating: 4/10	Questionnaire	61 mothers of children and young people between the ages of 16 and 26 years old.	Parents of children seeking help for their first psychotic episode were questioned about their views on the nature of the symptoms at first occurrence and their views on the main reason for psychiatric treatment, the	57% of mothers did not think that their child had a psychosis at first occurrence, most of the mothers who did felt that this might be caused by street drugs. 33% thought that patient's reluctance to seek help was a major obstacle.	Use of open ended questions.	Non-validated or standardised questionnaires. Cross-sectional design. Relies heavily on self-report. Non-generalizable sample of mothers of mostly males.

			perception of problems in initiating treatment and suggestions for getting treatment at an earlier point.	Mothers emphasized that a more active approach by professionals could reduce treatment delay.		Population characteristics: most of whom had used drugs at some point in time. Lack of statistical power.
Green (2007) Quality Rating: 6/10	Qualitative, thematic content analysis.	19 parents of 19 children with autism between the ages of <5 years - >21 years.	Parents interviewed on their experience of three treatments for autism, namely applied behaviour analysis, sensory integration and Vitamin B6 and Magnesium.	Parents found information out about the treatments via the internet, other parents and Occupational Therapists. Ease of implementation, time commitment and perceived effectiveness contributed to the continued use of treatment even with treatments that lacked empirical support.	Use of open ended questions within the interview schedule. Diverse population of children with autism ranging from mild to severe.	Non generalizable as parents selected from those who had taken part in a previous study. Some interviews conducted over the phone meaning non-verbal descriptions might have been lost. Students conducted the interviews meaning a potential lack of reliability and training in the interview technique.

						Owing to an oversight not all parents were asked some of the questions.
Jones, Rodger, Broderick & De Monte (2009) Quality Rating: 10/10	Qualitative, thematic content analysis.	16 families consisting of 2 fathers and 15 mothers of children with idiopathic arthritis aged between 8-18 years.	To investigate parents' perspective regarding the factors that influence participation in their children's treatment regimens and home exercise programmes.	7 key themes emerged: the difficult process of diagnosis, the emotional toll, medications, exercises, life revolves around arthritis, parents' relationships with their child and other family members and paid work.	Direct application to practice. Interview protocol based on MDT experience and relevant literature. Reflexivity addressed. Declaration of researcher bias and how this was addressed.	Prolonged engagement between researchers and participants may have effect the interview situation. Small sample size limits the conclusions that can be drawn. Other research into idiopathic arthritis has typically used slightly larger sample sizes. Low participation rate of fathers.
McNamara, Dickinson & Byrnes (2009) Quality Rating: 8/10	Qualitative, grounded theory.	9 mothers with fathers present for three of the interviews of children with tracheostomies	Qualitative phase of a randomised-controlled trial in children with tracheostomies comparing two	Core category of parents managing the child's care in response to a set of problematic and constraining states.	Grounded theory Rich data	Data saturation not reached by own admission. Limited sample size.

		aged between 11 months and 2 years.	techniques for providing humidified inspired gases.	Parents were seen to utilize strategies of constant checking, becoming the expert, the family pulling together and electing preferred technology.	Randomised-controlled crossover study.	No triangulation Interviewer bias and reflexivity not addressed.
Redmond & Richardson (2003) Quality Rating: 7/10	Mixed method, questionnaire and narrative.	17 mothers of children aged 4 and under, some with complex medical and life-limiting conditions.	To explore mothers' views of the usefulness of the financial, practical and emotional supports being offered to them and their suggestions for service improvements.	Mothers were engaged in stressful but skilful care with a clear wish to continue caring for their child in the family home. Mothers found gaining useful information as 'haphazard' and most services offered were uncoordinated, unreliable and difficult to access. Children's needs often fell between service gaps leading to the private finance of provision.	Rich data describes unique and complex phenomena. Mixed methods design	Specific and non-generalisable sample from a charity offering grants. No fathers interviewed. Lacks reflexivity. No triangulation.

Singh (2003) Quality Rating: 9/10	Qualitative, grounded theory.	39 mothers and 22 fathers of boys with a diagnosis of ADHD.	Interview were conducted using a picture-based method to elicit detailed narratives around parental experiences, particularly focusing on the father's experience of having boys with ADHD.	Father's perspectives categorised their son's behaviours largely as either "reluctant believers" or "tolerant non-believers". Within these perspective further themes around resistance to understanding their son's behaviour using a medical framework, identification with son's symptomatic behaviour and resistance to drug treatments with stimulants were identified.	Addressed the absence of fathers from research in this area. Theory driven approach.	Non-generalisable findings. Homogenous sample in terms of demographics. Lack of reflexivity. All participants' accounts were retrospective. Data saturation not reached.
Stewart, Chapple, Hughes, Poustie & Reilly (2008) Quality Rating: 9/10	Qualitative, thematic analysis using 'Framework' method of content matric data analysis.	17 parents of which 14 were mothers, 2 fathers and 1 grandmother. Children were aged between 5-11 years.	To explore the thoughts and feelings of parents whose children had undertaken dietetic consultations either employing	Parents who took part in the behavioural change technique applauded the process while those who received	Practical and immediate theory-practice links. Triangulation of data.	Limited participant numbers meaning it was difficult to test part of the original aim around which intervention was preferred.

			behavioural change techniques or delivered by dieticians with no formal training in the technique.	standard care was less well received.	Inclusion and use of pilot study.	Data Saturation not reached.
Tierney (2005) Quality Rating: 8/10	Qualitative, thematic content analysis.	6 sets of mother and father and 2 mothers seen without a partner of girls with anorexia aged between 13-18.	To explore parents views of the treatment received by their children.	Parents had a mixed view about the care provided for their child. Parents recalled having to adopt a proactive stance to ensure their daughters received appropriate services.	Researcher reflexivity addressed. Interview schedule based on previous findings and research.	Researchers own experience of working with and having been hospitalised for anorexia may have impacted on interviews. Lack of generalisability.
Turner, Salisbury & Shield (2011) Quality Rating: 8/10	Qualitative, thematic content analysis.	15 parents (14 mothers, 1 father) of children aged between 5-10.	To explore parents' views and experiences of primary care as a treatment setting for childhood obesity.	Parents viewed primary care as an appropriate setting in which to treat childhood obesity but were reluctant to consult due to fear of being blamed for their child's weight and concern about the child's mental well-being. Parents varied in the extent	Detailed information provided from data. Novel contribution to the research base.	Limited generalisability. Data saturation not reached by own admission. Lack of fathers in study.

to which they found the consulting practitioner useful.

Appendix B: Table of themes as they appear within the review papers

Paper	**Change**			**Experts**	**Challenges**		**Distress**	**Staff**
		Friends	Positive			Money		
Benedettie, Garanhani & Sales (2014)	✓	✓			✓	✓	✓	✓
Ryan, Speechley, Levin & Stewart (2003)	✓			✓				✓
Case (2001)	✓	✓	✓	✓	✓	✓	✓	✓
Clarke & Fletcher (2004)	✓			✓	✓	✓	✓	✓
Cohn (2001)	✓		✓		✓			✓
De Haan, Welborn,				✓	✓			✓

Krikke & Linszen (2004)								
Green (2007)	✓	✓		✓	✓		✓	✓
Jones, Rodger, Broderick & De Monte (2009)	✓	✓	✓	✓	✓	✓	✓	
McNamara, Dickinson & Byrnes (2009)	✓	✓	✓	✓	✓	✓	✓	✓
Redmond & Richardson (2003)	✓	✓	✓	✓	✓	✓	✓	✓

Appendix C: Quality rating chart using the Critical Appraisal Skills Programme (CASP)

Paper	Clear statement of the aims	Appropriate methodology	Research design appropriate to address the aims	Recruitment strategy appropriate to the research aims	Data collected in a way that addressed the research issue	Relationship between researcher and participant been	Ethical issues taken into consideration	Data analysis significantly rigorous	Clear statement of findings	Value and contribution to practice	Total quality rating score*
Benedettie, Garanhani & Sales (2014)	YES	YES	YES	YES	YES	NO	YES	YES	YES	YES	9/10 HIGH
Ryan, Speechley, Levin & Stewart (2003)	YES	YES	NO	YES	YES	NO	NO	YES	NO	YES	7/10 MEDIUM
Case (2001)	YES	YES	YES	NO	YES	NO	NO	NO	YES	YES	6/10 MEDIUM

Clarke & Fletcher (2004)	YES	YES	YES	YES	NO	YES	YES	YES	YES	YES	9/10 HIGH
Cohn (2001)	YES	YES	YES	NO	YES	YES	NO	YES	YES	YES	8/10 HIGH
De Haan, Welborn, Krikke & Linszen (2004)	YES	YES	NO	YES	NO	NO	YES	NO	NO	NO	4/10 MEDIUM
Green (2007)	YES	YES	NO	YES	NO	NO	NO	YES	YES	YES	6/10 MEDIUM
Jones, Rodger, Broderick & De Monte (2009)	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	10/10 HIGH

McNamara, Dickinson & Byrnes (2009)	YES	YES	YES	YES	YES	NO	YES	NO	YES	YES	8/10 HIGH
Redmond & Richardson (2003)	YES	YES	YES	NO	YES	NO	NO	YES	YES	YES	7/10 MEDIUM
Singh (2003)	YES	YES	YES	YES	YES	YES	NO	YES	YES	YES	9/10 HIGH
Stewart, Chapple, Hughes, Poustie & Reilly (2008)	YES	YES	YES	YES	YES	NO	YES	YES	YES	YES	9/10 HIGH
Tierney (2005)	YES	YES	YES	YES	YES	YES	NO	NO	YES	YES	8/10 HIGH

Turner, Salisbury & Shield (2011)	YES	YES	YES	YES	YES	NO	NO	YES	YES	YES	8/10 HIGH

*Yes = 1 / No = 0. Low = 0-3/10, Medium = 4-7/10, High = 8-10/10.

Appendix D: University Ethical Approval

Approved by the Ethics Committee in **31 day(s)** on 4/06/2015

Approved by RGO in **25 day(s)** on 30/06/2015

Date	Activity	Comments
6/07/2015 11:52 am	Note added	University of Southampton insurance certificate attached
30/06/2015 2:04 pm	RGO reviewed and approved	Submission ID : 13964 Submission Name: A qualitative study investigating caregivers' experiences of being co-therapists within psychological interventions for carers of a child with a learning disability. Date : 30 Jun 2015 Created by : James Southwood
30/06/2015 12:09 pm	Submitted to RGO (Cat A)	
8/06/2015 2:48 pm	RGO reviewed and require revision	Please attach draft of IRAS application - many thanks Submission ID : 13964 Submission Name: A qualitative study investigating caregivers' experiences of being co-therapists within psychological interventions for carers of a child with a learning disability. Date : 08 Jun 2015 Created by : James Southwood
4/06/2015 5:41 pm	Reviewed and approved by the ethics committee	
4/06/2015 12:42 pm	Approved by supervisor and sent to ethics committee	

Solent NHS
NHS Trust

Appendix E: NHS and Local R&D Ethical Approval

Ref: SW / cl

18th August 2015

2nd Floor Adelaide Health Centre

Weston Community Hospital Community Campus

William Macleod Way

Southampton

Hampshire, SO16 4XE

Mr J Southwood

University of Southampton

Building 44

Highfield Campus

SO17 1BJ

Dear Mr Southwood,

Study Title: **A Qualitative Study Investigating Caregivers' Experiences of Psychological Interventions within Child and Adolescent Mental Health Services, for Caregivers of a Child with a Mild to Severe Learning Disability**

R&D No.: **SR/025/15**

CSP No.: **N/a**

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and permission from the Department of Research and Development (R&D) prior to commencement.

Solent NHS Trust has reviewed the documentation submitted for the above research study and I am pleased to confirm NHS permission. The **Sites** where you are permitted to undertake the research are listed in the attached appendix. The addition of a new site(s) **must be notified** to Solent Research by submitting an SSI form and for PICs, a revised R&D Form.

I would like to bring your attention to the attached list of conditions of approval and specifically to:

a) The mandatory requirement to record the recruitment for all sites within this Trust onto the e-dge™ database (**information about this is attached**).

b) The mandatory requirement to report annually to the Trust on the study progress, and submit all publications resulting from the study to Solent NHS Trust for them to share with patients and staff.

c) The understanding that your study will be subject to monitoring and / or audit by the research team.

d) Please forward you Research Passport, at your earliest opportunity for validation.

Documents Reviewed

Document	**Version**	**Date**
Protocol	V1.0	06/07/15
Participant Information Sheets	V1.0	18/02/15
Consent Forms	V1.1	18/02/15
Indemnity / Insurance		07/07/15
Sponsors Letter		11/08/15
CV – Chief Investigator – Mr James Southwood		

I wish you every success with your study. If you require support or assistance at any time with the involvement of Solent NHS Trust in this study, please don’t hesitate to contact us.

Yours sincerely

Dr Sarah Williams

Head of Research & Clinical Audit

Appendix F: Letter to Services

James Southwoood
Building 44a
Psychology Department
Southampton University
University Road
Southampton
SO17 1BJ
02380 595000

Project Reference No: 13964
Ethics No:
Version 1

Service Address

Dear *Sir/Madam*

My name is James Southwood and I am a Trainee Clinical Psychologist based at Southampton University. I am hoping to complete qualitative research into the experiences of having been involved in psychological interventions as co-therapists for parents/caregivers of a child with a learning disability.

Ideally I am looking to recruit around seven parents/primary caregivers in total from a few local services. The parent/primary caregiver would need to:

- Have worked alongside a Clinical Psychologist or other health care professional who is able to deliver psychological interventions e.g. Mental Health Nurse, within the past six months or is currently at a stage of nearing the end of the work.
- Have had a role in the therapy as a co-therapist i.e. they played an important part or key role in the delivery of the intervention for the child.
- Have <u>not</u> undergone an intervention owing to court order.
- Not pose a significant risk to the researcher beyond that of the usual risk nature of clinical and research work.

Those who have just started or are yet to start an intervention will also not be suitable as they would not have had enough experience of working as a co-therapist however it might be possible to include parents who have been working with the service for a long time and yet are still not at the end of the intervention. I would be happy for you to contact the family ahead of myself to query interest in participation

If the family are willing to participate they would be required to complete a short informal interview with myself to talk about their experiences. The interview should take no longer than 60 minutes and will take place either at their home address or at Southampton University. If both of these locations are not suitable an alternative arrangement can be made.

The interview will be audio recorded. The only people who will be allowed to listen to the audio recording will be myself, the transcriber and my project supervisor at Southampton University. That is all that will be required from them and as a thank you they will receive a £10 Amazon gift voucher. Please find the additional information they will receive on the study overleaf.

I will contact you in the near future to see if you are willing to participate and would be able to identify any participants as described. If so, I will need the participants address and telephone number so that I will be able to send out a letter outlining the purpose of the study and their telephone number so that I can contact them to arrange opting in/out of the research.

I am hoping this will be a really valuable piece of research and I appreciate your time with this.

Kind regards,

James Southwood, Trainee Clinical Psychologist

Appendix G: Participant Invitation Letter and Information Sheet

James Southwoood
Building 44a
Psychology Department
Southampton University
University Road
Southampton
SO17 1BJ
02380 595000

Project Reference No: 13964
Ethics No:
Version 1

Participant Address

Dear *Sir/Madam*

My name is James Southwood and I am a Trainee Clinical Psychologist based at Southampton University. I am hoping to complete some research into the parent's/caregivers experiences of having been involved in psychological interventions for their child or the child that they look after. In particular, I am keen to complete some research into how services can work better for people such as yourselves, who look after children with a learning disability, as there is currently very little research in this area. Therefore, your contribution would be really valuable!

I believe that you were involved in completing a psychological intervention within the past six months for your child/the child you look after at a local mental health service. In particular, I believe that you were asked to play a key role in delivering this intervention which is sometimes referred to as being a 'co-therapist' who works with the health professional/s that you saw at the service.

If you would be willing to participate you would be required to complete a short informal interview with myself to talk about you experiences – there are no right or wrong answers! The interview should take no longer than 60 minutes and can take place either at your home address or at Southampton University at a convenient time. The interview will need to be audio recorded so that I can have a record all of the information that you provide. The only people who will be allowed to listen to the audio recording will be myself, the transcriber and my project supervisor at Southampton University. That is all that will be required from you and to say thank you for participating you will receive a £10 Amazon gift voucher!

Once the interview has been written up, the audio recording will be destroyed. Your identity will be kept strictly confidential. Direct quotes will be used in the research project write up, but the quotes will not reference from whom they have come and participation in this research will not affect your ability to access services in the future should you need to.

Please consider participating in this research and I will contact by phone you in the near future to discuss any queries you might have. If you do not wish to participate you can let me know at this point and you will not be contacted again about this research.

Please find additional information on the study overleaf.

Kind regards,

James Southwood, Trainee Clinical Psychologist

Study Information Sheet

Study Title: A qualitative study investigating caregivers' experiences of being co-therapists within psychological interventions for carers of a child with a learning disability.

Researcher: James Southwood (Trainee Clinical Psychologist) **Study ID: 13964**

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This project hopes to better understand the expectations, needs and experiences of primary caregivers for children a with a learning disability, with particular attention paid to their experiences of working with health professionals to deliver a psychological intervention. Leading on from this, the research hopes to reflect upon how health professionals work with parents/caregivers of children with learning such as yourself and what works well and what needs to be improved.

Why have I been chosen?

You have been chosen to participate in this research as you have been involved in working with a health professional within the past two years to help deliver a psychological intervention for your child/the child you look after with a learning disability.

What will happen to me if I take part?

You will be contacted by telephone to arrange a convenient time to participate in the research. You will have the option of completing the interview either at home or at Southampton University at a convenient time. If both of these locations are inconvenient it may be possible to book a room at the therapy service, you were involved with (although this cannot be guaranteed). I will ask a few broad questions about your experiences of the service such as gaining access to the service and the intervention you helped to deliver. It's not a test and there are no right or wrong answers so please think about it as more of an informed chat! I am really interested in getting a better understanding of your perspective.

As I need to remember all of the details of the interview an audio recording device will be used so that the interview can be recorded and then written up. The recording will be kept in a secure location and then destroyed once the interview has been written up. The transcription will be kept on a password protected computer.

Are there any benefits in my taking part?

It will really benefit the local service if you are able to take part. This research will help Clinical Psychologists and therapists to develop the most effective practice that they can in the local area for parents/caregivers such as yourself.

Are there any risks involved?

We believe that there will be no risks involved in you agreeing to have a short chat with us. If you are worried about anything however, please feel free to contact us so that we can discuss your concerns. You can contact us using the phone number at the top of this sheet.

Will my participation be confidential?

Your participation will be kept confidential and all information and data that you provide us with will be handled in compliance to the Data Protection Act and under the University policy for conducting research. Although the research will use quotes from the interviews to develop general themes that will be fed back to services. However, several interviews will be conducted and what you say specifically and your identity will not be fed back to the service that you were involved with.

What happens if I change my mind?

You are entitled to withdraw from the research at any time without having to give any explanation. There is no penalty or loss of right if you decide to change your mind about your participation in the future.

What happens if something goes wrong?

In the unlikely event of a concern or complaint you can contact Dr Martina Prude, Head of Research Governance (02380 595058, rgoinfo@soton.ac.uk). Dr Prude is an independent party in this research and any complaint or concern can be directed toward her.

Where can I get more information?

If you would like any more information on this research or why this research is being carried about you can contact me at js1e12@soton.ac.uk.

Appendix H: Participant Consent Form

CONSENT FORM (Version 1)

Study title: A qualitative study investigating caregivers' experiences of being co-therapists within psychological interventions for carers of a child with a learning disability.

Researcher name: James Southwood, Trainee Clinical Psychologist (University of Southampton)

Study reference: 13964

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (18.02.2015 version 1) and have had the opportunity to ask ☐

I agree to take part in this research project and agree for my ☐

I understand my participation is voluntary and I may ☐

I agree to be audio-recorded so that the interview may be transcribed. ☐

I understand that the audio recording will be destroyed following transcription and that the transcription itself will be kept on a passwo ☐ **protected computer. Quotes from the interview will be used in the research report.**

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of participant…………………………………………………………**..**

Date………………………………………………………………………………

Appendix I: Risk Assessment Form

RISK ASSESSMENT FORM

Study ID NUMBER: 13964

Date: 18.02.1015

Version 1

Brief outline of work/activity:	Up to ten individual interviews to be conducted with adults who are primary caregivers of a child with a learning disability who has been involved in psychological work within the past year to two years. The caregivers/parents will be recommended to the researcher and would have been known to the service from which they are recommended.

Location:	Interviews will be conducted either at participants' houses or the University of Southampton.

Significant hazards:	Lone working risk when conducting interviews at participants' houses. The service that recommends the caregiver/parent is likely to not have an up to date risk assessment completed. The researcher will have to complete his own risk assessment on entering the property, during the interview and on leaving.

Who might be exposed to the hazards:	The researcher.

Existing control measures:	The researcher is an experienced community worker (five years) and will operate a ‘text-buddy’ system where the researcher will text a supervisor (Dr Emma Hines, Dr George Johnson, Dr Helen Fairchild) before entering the house and then again once the appointment is completed. The appointment is not expected to last over 60 minutes. If a text is not received by the supervisor after 60 minutes the appropriate course of action will be taken by the supervisor (calling the researcher, calling the house number, calling the police). The supervisor will be made aware of the arrangements (i.e. address that the researcher is attending) and dates and times so that they are available to complete the buddy service. Within the exclusion criteria addressed to the service it is highlighted that families that might pose a risk to the researcher should not be referred.

Are risks adequately controlled: YES

Appendix J: Interview Schedule

Date:

Time of Interview: Start:

Finish:

Proposed Interview Length: 40-60 minutes

About the interviewee:

“My name is James Southwood and I am a Trainee Clinical Psychologist at the University of Southampton.”

Introduction:

“Thank you for agreeing to participate in this interview. As you are aware I will be audio-recording this interview and I will start recording from now.”

(Turn on Audio-Recorder)

“I would like to remind you that you do not have to answer any of the questions that I ask today and you can stop the interview at any point if you wish without having to give me any explanation. Once again, the purpose of this interview is to gain an understanding of your experiences of working together with health care professionals to deliver a psychological intervention for your child / the child you look after.”

Do you have any questions before we proceed?

Are you happy to proceed?

Questions:

*(**Prompt questions** to be used if the interviewee struggles to answer the question or if the interviewer needs to direct the interviewee back to the original question)*

1. Can you tell me a little bit about what led up to your child being referred to a Child and Adolescent Mental Health Service (CAMHS) or psychology service”?

    Prompt: Why did the GP/Paediatrician/School refer you to CAMHS/psychology?

2. What was your initial experiences of the service?

    Prompt: How did the team achieve this?

    What were your fears or concerns?

Was there anything that might have prevented you from seeking help from CAMHS?

3. Did you feel that the service or health care professional had a good understanding of how to work with your child and you as their primary caregiver/s?

4. What was your role within the psychological intervention?

   Prompt: *In what way were you asked to support the assessment and/or intervention process?*

   How did you feel about implementing any recommendations?

5. How was your role explained to you?

   Prompt: *What is your understanding of the term 'co-therapist?'*

6. How was the assessment and/or intervention tailored to meet the needs of your child's learning disability?

7. Can you give me an example of something that went well during the assessment and/or intervention?

8. Can you give me an example of a difficult experience during the assessment and/or intervention?

9. What could the health professional or service have done differently to have improved your experience of the intervention?

   Prompt: With the benefit of hindsight, how could your experience have been improved?

10. What do you think are the main priorities for improving the service from the staff's point of view?

    Prompt: What do you think are the main difficulties that the staff or service need to work on to improve the service?

11. Is there anything else that we haven't covered that you would like to tell me about that relates to your experience of the psychological intervention that you received from the CAMHS or specialist team?

Final comments:

Appendix K: Extracts from Reflexive Notes

Interview 1 (Pilot)

As I arrived the Mum explained that she was having a busy morning. A gardener had been to cut some of the big hedges, she had been minding a neighbour's house who was away and because of a rat infestation in the local houses a pest control officer was coming in and out of the house as we spoke. Although she did not appear stressed it led me to consider how it was not just the network around her child that she had to co-ordinate, but it was also the day-to-day events which meant that her life was busy.

Aware of my own agenda during the interview, I became slightly frustrated that the Mum kept bringing in examples of the wider service whereas I had been keen for her to talk about her experience of the psychological intervention. I reflected on whether I had made a mistake in my wording of the interview schedule or whether I had not made my point well enough. I realised from my reflection that the reason for this might have been because Mum categorised NHS professionals as constituting one service i.e. the health service, whereas, having worked in several healthcare settings, I thought as the service as made up of several composite parts, almost forgetting that all professionals are under one NHS banner. Therefore, while I had been trying to get to the experience of 'psychological services' Mum appeared to hear 'NHS services. As a consequence, I will keep the questions the same and see if other participants make this same assumption.

Interview 2

As I entered the house to start the interview the Mum had her young daughter running around and watching TV. I quickly realised that the interview would have to be conducted under that kind of environment which raised my curiosity about how well the Mum would be able to concentrate and reflect on the questions I would be asking. I had met the Mum before when I worked with her with her older son and so was aware that the home environment was often busy. However, there was something very 'live' and real about the nature of the interview. Beyond what was said it gave me a taste of what life was like for that Mum. It also led me to reflect on my own social GRRAACCESSS and rules that I would wish to adhere to if an interviewer were to come to my house and ask me questions. I was curious, as I do not have any children, about how my social-etiquette rules might change if I did, and more specifically if I have three children with learning disabilities.

It appeared that Mum was nervous about providing the 'right' answers to the questions in the interview schedule. Therefore, I decided to allow some extra time at the end to go 'off-piste' and allow Mum some time to freely recall her own experiences. This appeared to work well although, not anticipating this spur-of-the-moment decision on my part, I felt that the questions I asked were not well thought through or articulated particularly well. Nonetheless, I felt that Mum was able to respond well, without the pressure of 'getting it right'.

Interview 3

On starting the interview, the Mum said that she thought the statement that I read out at the beginning sounded like a police caution. This worried me in terms of setting a tone to the interview, by which she might over-think or be cautious about her responses. However, it appeared that she laughed this off in the first instance and was able to talk freely. I had noted the formal nature of the statement when I first read it aloud but her comments brought this thought to the front of my mind. On future interviews I will make sure that the parent is ready for the formal nature of the statement as opposed to changing the statement, as I believe the content is important.

It appeared that she was nervous about some of her answers and also explained before the interview began that she had mild dyslexia which she felt might impact the interview in terms of her not answering the questions that I might be asking. During the course of the interview I did feel that I was working hard as an interviewer to extract information. I also get the sense that she might have been holding back. My reflection was that this might be because as a foster carer she perhaps approached the interview in more of a professional manner than she might have done otherwise. The theme of being a mother to her adopted child as well as being a foster carer did come up during the interview.

Interview 4

The conversation that the Mum had to have with her daughter about self-harming was particularly emotive within the interview. I felt that I was witnessing some of the distress she was experiencing as she recounted discussing self-harm with her daughter alongside the confusion she had been experiencing at the time. This has led me to reflect upon how I discuss self-harm with patients within my working role. The reason for this reflection was the Mum's ability to now reflect and discuss self-harm in both a professional way as well as, as a mother, highlighting the dual role that parents undertake.

Interview 5

One of the things that struck me in the interview was how the Mum ended up losing her job as she needed to look after her child. This led me to reflect on what it would mean for me having to give up my role as a psychologist and the loss I might feel for that. It was a complex balance of finding a new role as a Mum, but moreover the Mum of a child with complex needs. In this role she had become expert over the needs of her child and yet reported a battle around trying to get her voice heard by professionals.

The sense of a battle between the Mum and services in this interview were particularly present. I felt myself coming alongside the Mum in terms of her position of having to fill out unnecessary forms, experiences of bureaucracy, long waits and then services she had attained being threatened to be taken away from her. There appeared to be an ever presence sense of jeopardy that services would be taken away and she was battling to either attain them or keep them, adding to her parental stress. As she talked about this I could see her becoming more frustrated and I felt I could empathise with her position.

Interview 6

The Mum disclosed within the first few minutes of the interview that she had been an alcoholic and previously experienced domestic abuse. Her drinking had led to her having her son taken away from her and put into care. As I had not been aware of this before the interview, the information took me by surprise and I found it difficult to walk the line between being a researcher and a clinician. I appreciated the courage it must have taken for the Mum to agree to the research interview.

Interview 7

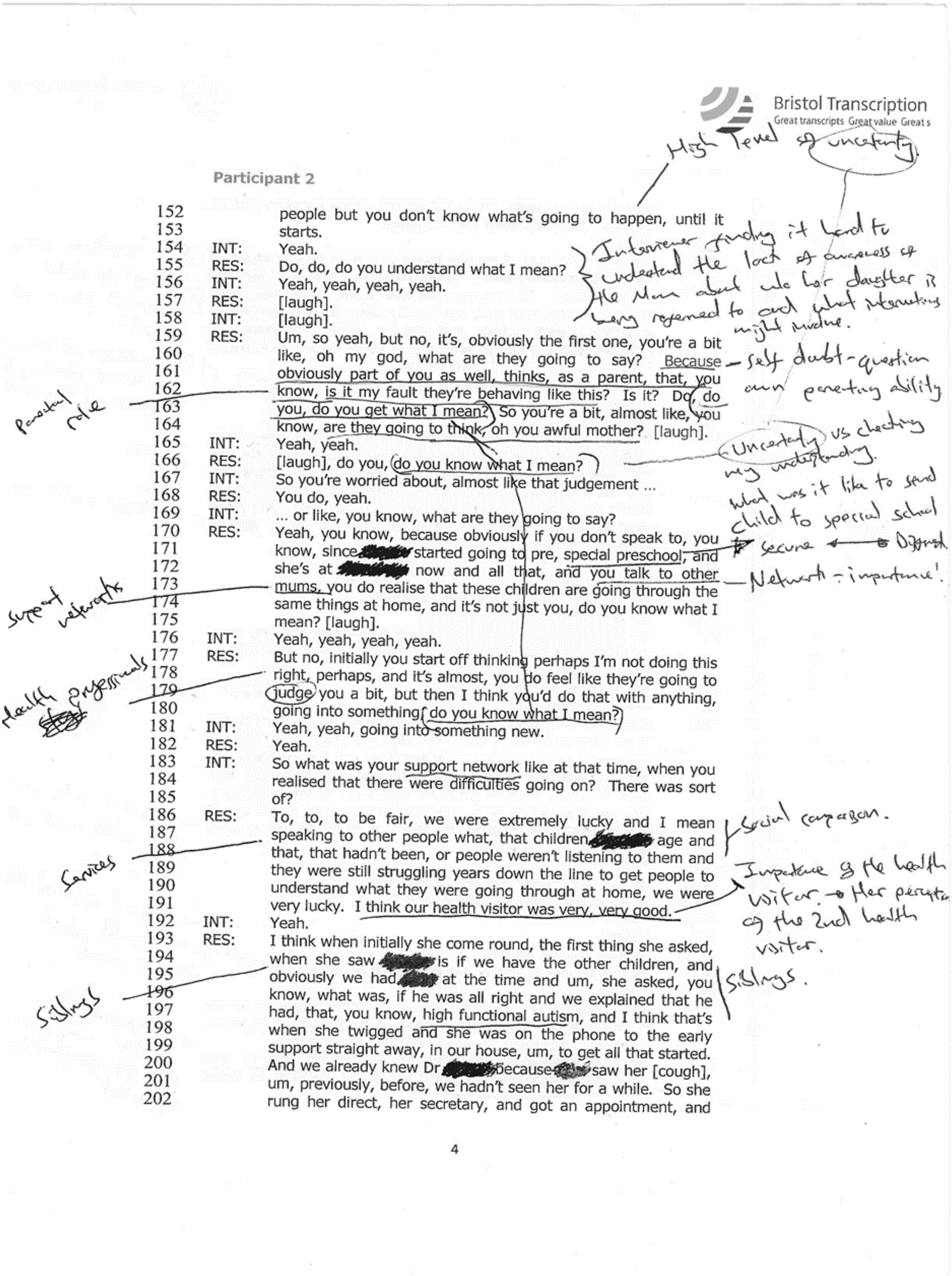
As the interview progressed Mum's partner, who had been cooking dinner, came over at points to add her contribution to the discussion. As Mum's partner was also Mum I wondered about the role of secondary caregivers. I was keen to have her included within the discussion but Mum's partner kept a degree of distance, allowing Mum to take the lead in the interview. Despite this, from the discussion it was clear that Mum's partner was heavily involved in the care for the daughter. This has raised a curiosity as to why my sample will be entirely mothers. Having worked within the team before, I have mainly worked with mothers and partners appear almost as 'characters' that the mother talked about, as they remained mostly invisible to my work.

Interview 8

The interview was conducted in the café of the leisure centre that the Mum attended as there were decorators in the house. My fear was that the Mum would be less willing to discuss personal matters and therefore keep the interview running at a fairly superficial level, as there might be people around us that she knew. However, the area in which we sat was quite private and Mum appeared to be able to talk freely.

The Mum talked about how recently she had experienced a mental health breakdown. She explained that she had started feeling better only a few weeks prior to the interview. Her character appeared very engaging and charismatic and I wondered about how many people I might walk past in my local leisure centre that might have been through, or were currently going through particularly difficult times.

Appendix L: Example IPA Coding



Bristol Transcription
Great transcripts Great value Great s

High Level of uncertainty.

Participant 2

people but you don't know what's going to happen, until it starts.

INT: Yeah.

RES: Do, do, do you understand what I mean?

INT: Yeah, yeah, yeah, yeah.

RES: [laugh].

INT: [laugh].

Interviewer finding it hard to understand the lack of awareness of the Mum about who her daughter is being referred to and what interventions might involve.

RES: Um, so yeah, but no, it's, obviously the first one, you're a bit like, oh my god, what are they going to say? Because obviously part of you as well, thinks, as a parent, that, you know, is it my fault they're behaving like this? Is it? Do, do you, do you get what I mean? So you're a bit, almost like, you know, are they going to think, oh you awful mother? [laugh].

Parental role

Self doubt - question own parenting ability

INT: Yeah, yeah.

RES: [laugh], do you, do you know what I mean?

Uncertainty vs checking my understanding.

INT: So you're worried about, almost like that judgement ...

RES: You do, yeah.

INT: ... or like, you know, what are they going to say?

What was it like to send child to special school

RES: Yeah, you know, because obviously if you don't speak to, you know, since [redacted] started going to pre, special preschool, and she's at [redacted] now and all that, and you talk to other mums, you do realise that these children are going through the same things at home, and it's not just you, do you know what I mean? [laugh].

Secure ←→ Disjointed

Network - importance!

Support networks

INT: Yeah, yeah, yeah, yeah.

RES: But no, initially you start off thinking perhaps I'm not doing this right, perhaps, and it's almost, you do feel like they're going to judge you a bit, but then I think you'd do that with anything, going into something, do you know what I mean?

Health professionals

INT: Yeah, yeah, going into something new.

RES: Yeah.

INT: So what was your support network like at that time, when you realised that there were difficulties going on? There was sort of?

RES: To, to, to be fair, we were extremely lucky and I mean speaking to other people what, that children [redacted] age and that, that hadn't been, or people weren't listening to them and they were still struggling years down the line to get people to understand what they were going through at home, we were very lucky. I think our health visitor was very, very good.

Services

Social comparison.

Importance of the health visitor. → Her perception of the 2nd health visitor.

INT: Yeah.

RES: I think when initially she come round, the first thing she asked, when she saw [redacted] is if we have the other children, and obviously we had [redacted] at the time and um, she asked, you know, what was, if he was all right and we explained that he had, that, you know, high functional autism, and I think that's when she twigged and she was on the phone to the early support straight away, in our house, um, to get all that started. And we already knew Dr [redacted] because [redacted] saw her [cough], um, previously, before, we hadn't seen her for a while. So she rung her direct, her secretary, and got an appointment, and

Siblings

Siblings.

4

then in about two weeks we had someone from Portage come round to set up a Portage homeworker with her. Um, and then that's when we had our first TAC meeting and, because of her behaviours, that's when Dr [redacted] decided that she'd get [redacted] in, on board as well ...

New agency.

— Sudden expansion of support seen as a positive thing.

Interaction examples

INT: Yeah.
RES: ... to try and sort all that out, yeah. So, and that was it, so we did have a lot of support.
INT: Support, yeah, so you felt lucky like that? And especially?
RES: It's all right, it's the cat, don't panic.
INT: [laugh], like what's that?
RES: [laugh].
INT: Especially because it's through a shadow ...
RES: I know [giggle].
INT: ... as well, I was like, is it lizard? [laugh].
RES: God [inaudible - 0:09:00].
INT: Um, okay, so what, what made, er, it sounds like you had quite a good experience, your initial experience. What made that experience good? So you went there, you had sort of maybe feelings of oh, you know, I wonder if they're going to judge me or? Was there anything that happened in particular that sort of helped that or?
RES: Yeah, it did, because you feel more at ease. I think it's the point of before meeting the person, you know, you feel more at ease when you meet, initially meet the person and like you talk through what's ...
INT: Yeah.
RES: ... and it's quite nice really I suppose for a parent, because it's someone [child shouting], to listen, to what you're observing your child doing [child laughing], do you know what I mean?

What was helpful was someone listening.

Health professionals

INT: Yeah, yeah.
RES: And what's you're, you're watching the child go through, because it's not nice when, you know, you've got a two year old that should be talk, you know, you think who should be talking and saying things, but they can't communicate with you, so the frustration must be awful ...

Social role

— Seeing things from the child's point of view.

Behaviour description ~~examples~~

INT: Yeah.
RES: ... for when they want something and they can't [cough]. And I think, you know, when you're explaining that to someone and [child playing] they understand what you're saying and, and can relate to how you feel, because they know about that thing, sort of thing ...
INT: Yeah.
RES: ... and it, it does make it a lot easier. Because as you're getting help through your club as well, and what you should do to maintain it, maintain their behaviour, you're, you're also getting the support, but you're getting to air off your views, do you know what I mean? Of how frustrated you feel. Because, and it does make you feel, when your child has got issues, it does make you feel like you're doing something wrong or you know, you're bound to compare [child playing noisily], this

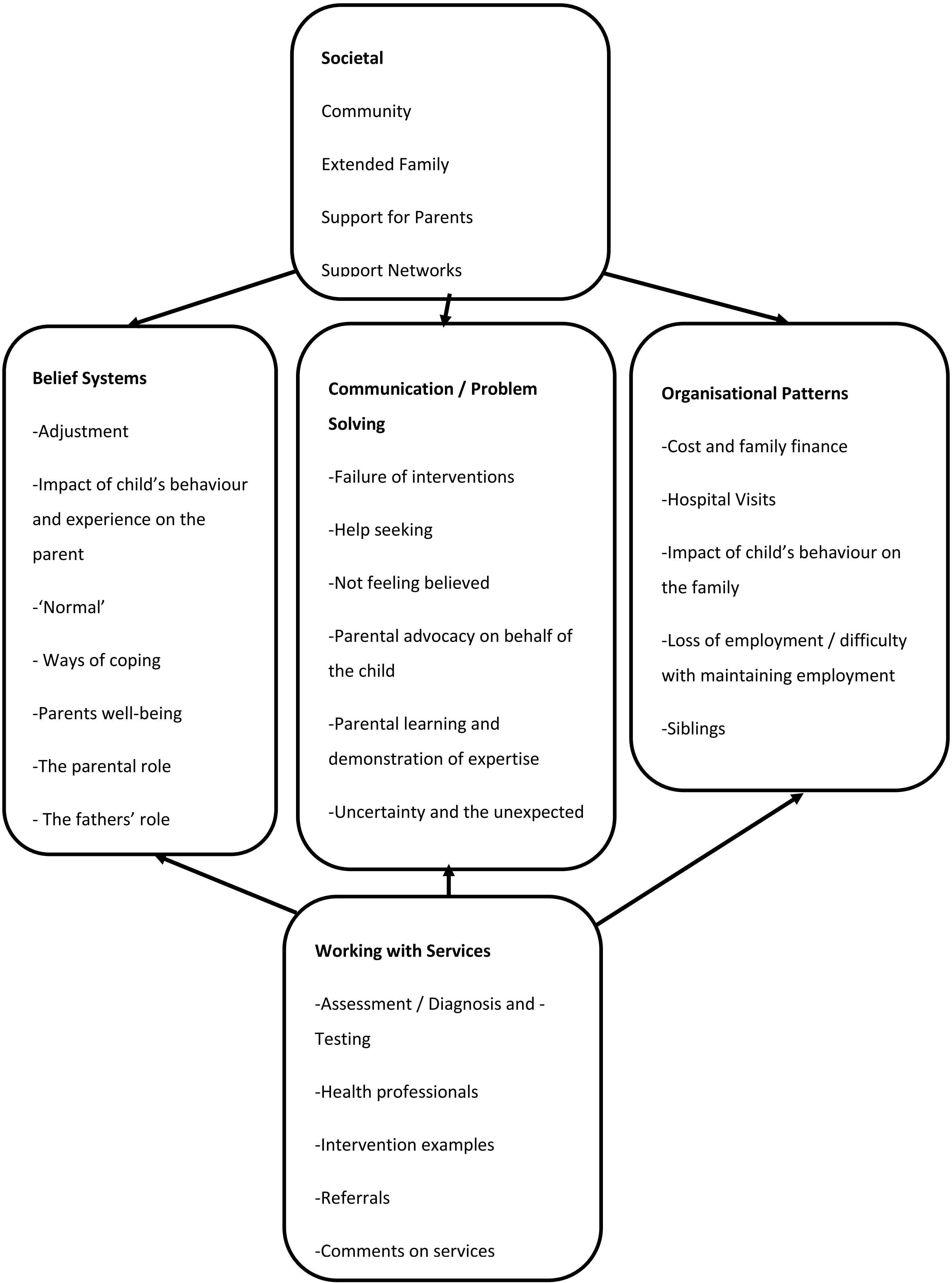
Need to 'vent' to other parents - vital.

Support

Social comparison to healthy child.

Parental role

Appendix M: Initial Themes Map



Appendix N: Independent Auditors Comments

Original Theme	Auditor 1 Comments	Auditor 2 Comments	Outcome	Final Theme
Adjustment	I wonder about 'adjustment' on the basis of the quotes, I wonder if there is another way of describing this journey. I like the description! It feels like grieving process from the quotes to me	Title could be expanded to capture the emotional component of adjustment process (tears, grieving, and emotional side)?	Merged with Normal / Assessment and Diagnosis / Uncertainty and Unexpected	"Working through it"
Impact of child's behaviour and experience on the parent		Could be collapsed with Parents well-being.	Merged with Parents Wellbeing / Ways of Coping	"Coping on your own"
'Normal'		Some overlap with Adjustment.	Merged with Adjustment / Assessment and Diagnosis / Uncertainty and Unexpected	"Working through it"
Ways of coping		Example could be about the impact on parent / parent's well-being as sounds like she is struggling to cope in these two examples? Other examples do sound more like coping (I know	Merged with Impact of Child's Behaviour on the Parent / Parents well-being	"Coping on your own"

	you've included failed strategies too though!)		
Parents well-being	Could collapse with Impact of child's behaviour and experience on the parent – Impact on parent? Or ways of coping	Merged with Impact of Child's Behaviour on the Parent / Ways of Coping	"Coping on your own"
The parental role	Clear	Merged with Fathers role	"Wanting what's best"
The fathers role	Could father's role be collapsed into the parental role?	Merged with The Parental Role	"Wanting what's best"
Cost and family finance	Clear Could develop title to demonstrate the struggle of managing finances?	Merged with Loss of Employment	"Told to give up work"
Hospital Visits	Clear Title could include the pressure and emotional demands of hospital visits?	Re-named	"At the hospital"
Impact of child's behaviour on the family	Clear	Merged with Siblings	"It affects everybody in the family"
Loss of employment / difficulty with maintaining employment	Clear – quotes suggest issue is to do with having to "give up" work, questioning whether child or work is more important; could this be seen as an impact of the child's needs on the parent?	Merged with Cost and Family Finances	"Told to give up work"

Siblings	Could collapse with Impact of Child's Behaviour on the family	Merged with Impact of the Childs Behaviour on the Family	"It affects everybody in the family"
Failure of interventions	Clear	Merged with Parental Learning / Intervention Examples	"I'm learning"
Help seeking	Clear	Merged with Parental Advocacy / Referrals	"Needing to tell someone"
Not feeling believed	Clear	Re-named	"No one believes you"
Parental advocacy on behalf of the child	Clear Does help-seeking relate to seeking help specifically for their child's needs? Could advocacy and help-seeking be merged?	Merged with Help Seeking / Referrals	"Needing to tell someone"
Parental learning and demonstration of expertise	Clear – could Failure of Interventions and Parental Learning be merged and the differences be an example of disparity/divergence?	Merged with Failure of Interventions / Intervention Examples	"I'm learning"
Uncertainty and the unexpected	Clear	Merged with Adjustment / Normal / Assessment and Diagnosis	"Working through it"

Assessment / Diagnosis and Testing	Is this theme something about the value parents placed on diagnosis?	Clear Some overlap with adjustment, normal and with help-seeking.	Merged with Adjustment / Normal / Uncertainty and Unexpected	“Working through it”
Health professionals		Clear	Re-named	“Health professionals”
Intervention examples		Overlap with Failure of Interventions and Parental Learning?	Merged with Failure of Interventions / Parental Learning	“I’m learning”
Referrals		Clear Clarify referrals to other services (to distinguish from seeking assessment/diagnosis) A little overlap with help-seeking; frustrations in getting in the help needed?	Merged with Help Seeking / Parental advocacy	“Needing to tell someone”
Comments on services		Clear	Re-named	“Services”
Community		Clear	Renamed	“Misunderstood”
Extended family		Clear	Merged with Support Networks	“Parents help other parents”
Support for parents		Clear	Re-named	“Giving me help”
Support networks		Clear	Merged with Extended Family	“Parents help other parents”

Appendix O: Final Table of Themes

Superordinate Theme	No.	Subordinate Theme	Description	Examples
Adapting and Changing	1.1	Working through it	The parent's journey of coming to terms with the child's diagnosis and learning disability.	P2 (Line 842): "…the Autism is all going to go… and they're going to be, suddenly, a completely normal child again". P3 (Line 106): "I knew she was a slow learner so I sort of thought, she will learn after a couple of years. Six years later, she still hadn't learnt". P4 (Line 1002): "…there's a time I was in tears chatting away when we were working through it and everything". P7 (Line 1121): "…something happens and it's like, it brings the whole lot back again. And it's like you're constantly grieving". P8 (Line 769): "…I've gone through my mourning … It was like I knew he was Autistic, it was getting my emotional side on board".

	P1 (Line 70): "…seeing (the Psychiatrist) that was bingo, yes, there is a problem with this child, this child is not normal and we have got some investigations to do". P2 (Line 481): "… it's that tiny bit harder really than being a parent to a child that's functioning and developing normally, because you've got to do that extra bit all the time". P4 (Line 1588): "… every single person is different. Even if they've got the same label. And one label doesn't mean that if you follow that protocol that's how it's going to work". P5 (Line 1998): "…it's like tonight I'm gonna take them out for dinner, which I couldn't do, just normal things … I'm just doing normal stuff, like anyone else wouldn't even bat an eyelid". P1 (Line 467): "He is on the Autism spectrum, but he hasn't scored enough points to be diagnosed an Autistic child. I am not saying I want my child Autistic … with a label, but when you have got something … you can deal with it". P2 (Line 769): When a child is older, it's almost like you're just thrown in the deep end, being like sat in this room,

	after his assessment… the outcome is, you know, we feel he’s got a developmental delay and high functioning Autism, and we just sat there and thought, oh my god, what, what, you know, what do we do?”. P4 (Line 130): “So I went ahead and got a diagnosis and that’s what helped me to get her into (*Special school*)”. P5 (Line 68): “He’s got cerebral palsy, he’s got hemiplegia … So he’s always been in the system… I’ve always had a paediatrician so I’ve always had check-up’s … So unlike lots of parents who fight to get a diagnosis … I’ve been, in a way, sort of lucky.” P1 (Line 150): “I suppose it’s going into the unexpected, isn’t it? You don’t know what they’re going to do”. P5 (Line 248): “They didn’t know if he was ever gonna ever walk… they don’t like to predict and that’s fair enough, it’s a wait and see game”. P5 (Line 255): “You want answers, you’re desperate for answers and you just don’t get them”. P5 (Line 1894): “He’s going through a good period now … He does that but that can be six months… the up’s and down’s, so we’re just going through a good period now”.

			P8 (Line 76): “He suddenly started like crawling and then from there he completely stopped … and it all happened within like a week”.
1.2	Wanting what’s best	Comments and beliefs about the role of the parent in looking after their child.	P1 (Line 691): “I want what is best for my son, my two children are my world, they are the love of my life and I will walk the Earth and back for them”. P2 (Line 161): “Part of you as well, thinks, as a parents, that, you know, is it my fault that they’re behaving like this?” P3 (Line 162): “If I hadn’t been a foster carer then I would have thought that you might think I’m a bad parent or something”. P7 (Line 1404): “My child is different and she does need 24 hour care, but I should be classed as Mum”. P8 (Line 739): “I was told ‘well, don’t you think other parents have problems?’”. P1 (Line 139): In the end my husband did have a breakdown”. P5 (Line 1458): “I got my ex to go cos he wasn’t really involved”

			P6 (Line 226): “I kept him safe from his Dad but … I hadn’t got a clue how to deal with Autism”. P8 (Line 688): “And making sure your partner is on board with you” P8 (Line 713): “(*My husband*) needs to be the one who brings the money in”.
1.3	Coping on your own	How the parent understands, copes with and manages the child’s behaviour and their own welfare, before and during interventions.	P1 (Line 308): “I just look at it and that was a bad day or a bad morning, yeah there’s days I have had a cry over it … but then I pick myself up and do another day”. P3 (Line 53): “…it doesn’t matter what I did. Nothing was working”. P4 (Line 1137): “I was trying to talk to her at the same time and not cry because *(daughter)* doesn’t like crying”. P5 (Line 955): “…but he was very oblivious at that time… sometimes I didn’t even know if he knew who I was”. P7 (Line 511): “…come and do this with Mummy and she’s like having none of it… I’m thinking … Why am I even bothering? Do you remember that?”

	P1 (Line 43): "…parents unfortunately can reach the end of their tether and I think they were concerned about the child's welfare". P4 (Line 726): "You're just sort of shaking your head and you've got tears streaming down your face because you just don't feel like you are getting anywhere". P5 (Line 194): "…you don't see any other children that are like yours and you feel very isolated". P6 (Line 67): "And I started drinking, and I had no help from anyone". P6 (Line 425): "I think when you've hit rock bottom and there's nothing left and your son's in foster care, you have no fears anymore". P7 (Line 1034): "I've dropped her off and I'll be driving home and I'm getting myself really upset because I've left her there". P8 (Line 1100): "…when I had my nervous breakdown I just completely stopped doing anything like that because I wasn't strong enough".

			P2 (Line 960): "…being able to talk about how you feel about, about the children, as well, makes it a bit easier because you're getting it off your chest". P5 (Line 1215): "He's still having these behaviours, you're still sort of coping on your own". P5 (Line 1226): I've chucked him to school in his pyjamas before because I haven't been able to get him dressed". P6 (Line 1595): "…I promised myself my sons come first and it doesn't matter how much it hurts. And I've stuck to my guns, and it has worked out". P7 (Line736): "And that's what we need, we don't want bullshit, we want the truth". P8 (Line 370): "…We were looking at stuff on the internet, both my husband and I were trying to research it".
1.4	It affects everybody in the family	How the family has changed to accommodate any difficulties arising from the child's	P1 (Line 393): "I have been told 'be a bit more structured – put him back in his bed'… he just still did it and laid there screaming and shouting and kept us all awake every single night for five solid days". P3 (Line 521): "That's impacted positively for her, but it's not great for us because we have to avoid things"

			behaviour or learning disability.	P4 (Line 693): "But it's hard and it's challenging and it's causing a lot of issues for all my children. So it affects everybody…" P7 (Line 414) "Trying to keep a family down and trying to keep everything together, I'm working and trying to keep my head like above the water to keep going, and it's so, so difficult. P4 (Line 62): It turned out that my other daughter had noticed that there were little scratches on certain areas of her arms" P5 (Line 1827): "He was starting to attack (*Daughter*), head butted her, scratched her, you know". P5 (Line 1873): "So assumes that he was younger than her, I'm like no, no, no (*Child's*) your big brother". P5 (Line 1974): "The residential overnight care is so important for me to spend time with (*Daughter*) on my own".
	1.5	Told to give up work	Experiences of retaining or losing work as a result of the extra care	P5 (Line 1758): "I'm thinking what's more important? (*My child*) this moment in time, is the most important one. So I

	needed to look after the child and how the family have organised their economic resources.	had… I stopped working, um during the day, I was still working in the evenings”. P7 (Line 875): “I didn’t want to not go to work, because I know that if I go to work, that keeps me going a little bit … you got told to give up work”. P8 (Line 906): “I was really angry at the fact I had to give up my life to be a carer”. P1 (Line 155): “Yeah we nearly lost this home, because we couldn’t keep up the payments because money was just going to keep my son in hospital”. P3 (Line 640): “Angry. I just… I did say can you not argue about the money, just somebody pay for it”. P4 (Line 861): “…my husband lost his job. He was unemployed for eighteen months.” P5 (Line 407): “What’s direct payments? ... I was taking him to the (*Day Centre*) paying for it … it was quite a bit of money”. P6 (Line 1129): “No, no, I wasn’t getting any disability allowance or any- I didn’t even know about that either”.

Developing Confidence	2.1	Needing to tell someone	Experiences and understanding of how to recruit services to work with the family and the child, on behalf of the child.	P1 (Line 34): “About four o’clock in the morning I made a phone call to the health visitor’s number”. P2 (Line 713): “There’s no point in shouting and screaming and hollering, it’s not going to get you anything quicker”. P4 (Line 263): It’s quite a scary form to sign when you read it … So if I’d read that form alone I might not have seeked help you know”. P4 (Line 1535): “So I’ll ask whoever and that’s what I do and I try and get passionate, cry anything like that. I’m never rude to anybody. I’ll cry at somebody but I’m never rude”. P5 (Line 1411): “Um, and that’s quite depressing really, you know, needing to tell someone that this is happening and not being able to get through, having to leave a message or ring back later”. P1 (Line 563): “Why am I fighting for my son for 24/7? If I didn’t fight for him with his bowels he would be sat here now in nappies all day”. P2 (Line 341): “I went up there and I said, I got so fed up of it, I said how are you teaching (*my daughter*)?

			P4 (Line 486): “We’ve just raised money for a Downs Wheelchair Basketball Chair” P5 (Line 541): “She threatened to take his place away. And I thought, no… I don’t know, but she didn’t like that. P1 (Line 932): “I am getting really worried… he is really falling over a hell of a lot and she said ok, I am going to refer him to Occupational Therapy. Two and a half years later I am still waiting for Occupational health. P3 (Line 242): “They all thought that she was understanding everything but she really wasn’t. It wasn’t until (*Psychologist*) referred her for the urm…skills test, or whatever it was, I wish that had been done earlier.” P7 (Line 215): “She got referred to genetics, in Southampton. They noticed that something was a little bit different about (*Child*), her facial features.”
2.2	Nobody believes you	Experiences of health professionals, services and others not being certain	P1 (Line 53): “Please don’t tell me it because he has been ill because that’s all I keep getting. I’m sorry there is more to my child than being ill”

		about what the parent is explaining.	P2 (Line 97): “They said, no, she’s absolutely fine, all children go through and I just thought oh, ok then, perhaps it’s just me?” P5 (Line 1303): “I’d been coping with it for months and months and months, but until someone official sees it no one sort of really believes you”. P7 (Line 434): “The impression I got is that they thought we was just being lazy and not doing it with her”. P8 (Line 485): “Last time I tried to tell my Mum he was Autistic, she told me I was making it up”.
2.3	I’m learning	Experiences related to the parent in a learning capacity or demonstrating the outcome of learning.	P1 (Line 683): “It’s like the box thing, didn’t work”. P2 (Line 537): “I mean some of them, I have to say, haven’t worked on certain things, and that’s a bit upsetting, like why is (*Child*) not doing it?” P3 (Line 32): “Anything I did like sticker charts and things, nothing worked”. P3 (Line 107): “I didn’t think they could do it because they were teaching me stuff that I’d already done with her and it didn’t work. I’d do it again but, I just thought ‘oh no’”.

	P7 (Line 446): “Now, I have done controlled crying for half of (*Daughter’s*), three-quarters of (*Daughter’s*) life and I am pissed off with sitting outside that bleeding room while she screams and cried to me to get in bed with her, I can’t do, it’s” P1 (Line 414): “I’m with my child 24/7 24 hours a week. I know my child. What happened to the saying ‘the mother knows best’?” P3 (Line 57): “Because I’m a foster carer, I do like challenging behaviour courses and things like that.” P3 (Line 135): “I also went on Autistic courses to learn the way children think” P4 (Line 385): “So I felt a bit more comfortable and – she still struggles (*Child*) does but I’m learning … I’m learning that I have to readdress myself all the time”. P5 (Line 209): “I was having to do the stretches with him”. P5 (Line 437): “I would stay and do the therapy with him, it was hard work”. P1 (Line 334): “She came up with the idea to do a calming box and we sat there and had great fun decorating the box”.

				P2 (Line 331): “We go through like forms about her behaviour and then she’ll give me strategies for each behaviour … I suppose it’s almost like having a teacher”. P3 (Line273): “(*About schedules and sticker charts*) As you can see all over the door and the fridge. On her bedroom wall we’ve got like getting dressed … and social stories”. P4 (Line 926): “(*She*) did a chart thing where (*Daughter*) would point to it with how much she was understanding”.
Working with Services	3.1	At the hospital	The experiences of parents during visits to hospitals and staying away from the family home.	P1 (Line 25): “As time went on (my son) had a lot of hospital visits and I think I am on my twenty second ambulance now for him”. P3 (Line 197): “Because some of these Doctors were high up at the hospital and they hadn’t got a clue about (*her*) syndrome). P4 (Line 135): “I mean we were at the hospital, um, at least once a week I think, at points we were possibly up there twice…” P8 (Line 319): “I was with him around the clock for six weeks”.

	3.2	Health professionals	The parental experience of the patient-practitioner relationships.	P1 (Line 317): “I think she’s brilliant, I have got on really well with her”. I found Speech very patronising people”. P2 (Line 290): “You talk to someone and it’s almost like, you know, where they’ve experienced it, not maybe themselves, but…” P3 (Line 223): “I kind of get annoyed with people over the years saying … blaming everything on global delay and that drove me nuts” P4 (Line 519): “(*She*) did everything she could do and she was talking to me through it”. P5 (Line 151): A lot of the times you’re just sat there and we chatted quite a lot because not really a lot she could do”.
	3.3	Services	Parents explanations and experiences of health, social services and schools.	P1 (Line 1183): “Again it’s funding … if funding is tight then resources are tight, and if resources are tight then the parents are not going to get the support are they?” P3 (Line 328): “Banging my head against a brick wall with the school … I bring it up every time and send thing in for them to show them what we’re doing at home and they’re just not doing it”.

				P4 (Line 1041): "I don't know if everyone gets given the amount of time we had but no-one seems to say you've had your time or anything like that". P5 (Line 166): "Education, NHS, social services, and you're trying to juggle all those three … pull them together, it's difficult."
Building Support	4.1	Parents help other parents	Parent's experiences of networks of support that they build themselves and those designed specifically to help them and their child.	P1 (Line 638): "She gave me this number and I rang it … as it turned out I was entitled to support and that was three years down the line." P2 (Line 172): "You talk to other Mum's, you do realise that these children are going through the same things at home". P4 (Line 1642): "I can understand now why parents help other parents". P8 (Line 979): "I've lost friends over this last year who are also parents of disabled children erm because they couldn't cope". P1 (Line 183): "(*My partners*) Mum and Dad are no longer here, they passed away, urm my Mum is crippled with arthritis and osteoarthritis and my Dad is near blind".

			P2 (Line 973): “Mum and Dad don’t understand what you’re going through with your child, because when they, they sort of, you know, they come around to visit and they’re here an hour, but they’re not here the whole day, they don’t see…” P8 (Line 295): “I remember (*Partner’s*) Dad was being a bit of a git and was like ‘Oh you only call us when you need us, when you need something from us’”.
4.2	Giving me help	Experiences where the parent has found provision which offers focus and support for them.	P1 (Line 79): “They might come a couple of times a week, just to chat to you and see and to help support the child”. P2 (Line 246): “You’re getting help through your club as well, and what you should do to maintain it … but you’re getting to air off your views … of how frustrated you feel”. P5 (Line 1528): So yes, it’s nice to have recognition that you’re trying, you’re trying your absolute best or conformation that you’re doing your best cos you do think you’re struggling”. P6 (Line 77): “I had no help with anything after the court case, everyone just left me … But um, they diagnosed him when I was in rehab, um and then all of a sudden everyone was jumping on me and giving me help”.

	4.3	Misunderstood	Parental experiences of them or their child accessing community facilities.	P3 (Line 45): “We got asked to leave Tesco’s because her behaviour was frightening the customers… It was actually them frightening her, because they’d trapped her in an aisle. They didn’t mean to but that’s how she saw it”. P4 (Line 1336): “I think there’s so many misunderstood – with not very good parents … They’re not going to respect the adults in the school, which then makes the school have to work extra hard on these children that shouldn’t be there in the first place … they’ve got lazy parents that shouldn’t be parenting”. P5 (Line 1235): “They’d put an inspector from Portsmouth City Council on the bus to assess him, I suppose, and obviously thought, no, that child’s far too violent … and if his behaviour didn’t change they would have to, um, stop the transport”. P8 (Line 804): “Like a lot of English people already have their set lives, they already have their set groups and cliques, and that is just the way it is”.

Appendix P: Extracts from Reflexive Journal

Initial reading

Having completed the systematic literature review I find myself drawn to comments pertaining to the themes that were highlighted in the papers reviewed. As a consequence, I have tried to pay extra attention to the script I am reading, by making sure I am sticking close to the data and the parent's experiences. I am experiencing the parallels between the literature and the interviews as both exciting and saddening, as the parents have experienced some of the difficulties previously experienced by other parents. This is particularly difficult as parents have talked about feeling alone when there are clearly other parents in the same position.

Emergent Themes

The number of emergent themes appears to be quite broad and I have concerns that there are too many. I have tried to stay close to the data but because there is a high quantity of themes I have titled them under names that I find easily recognisable. I am cautious about whether to start new themes or broaden existing themes to abate this. I have decided that it is best to take this on a case by case basis.

Patterns across cases

There seems to be evident patterns that are starting to emerge between cases. It seems that parents have experienced similar experiences and made different meanings out of the events that have happened, in line with IPA expectations. This has led me to reflect on my own experiences of having worked in both teams, especially when there are comments pertaining to the parents' experiences of working with staff members. I have wondered about how parents had experienced me as a health professional and how I have previously addressed some of these experiences.

Independent audit

I am excited about hearing back from the two independent auditors. I have concerns that the themes I have developed are a little overwhelming and therefore might dilute the key messages from the interview data. I am particularly interested in how the independent auditors will experience the data.

Choosing quotes

In order to arrange the quotes, I have printed all of the quotes under each theme and cut them into paper strips. Then I have arranged them into a ‘story’ or a narrative that I believe relates to the theme. I have then reduced the quotes to pick the ones which best elucidate the thought or experience. I have kept quotes from a number of interviews so that each of the participants is represented within the write-up and their voice is heard, even if other parents have articulated similar experiences better. This has been particularly time consuming.

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