UNIVERSITY OF SOUTHAMPTON

PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR; A CASE STUDY OF DAY CARE IN WEST SUSSEX.

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ABSTRACT

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PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR; A CASE STUDY OF DAY CARE SERVICES IN WEST SUSSEX.

by Mary Frances Griffiths

The research project was divided into two parts. Firstly the development of Social Services day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour was described, both nationally and with particular reference to West Sussex. Secondly as a response to current philosophy, new activities (sessions in yoga or aromatherapy and massage) were introduced to four service users who attend a day centre in West Sussex. A holistic, person centred, methodology was evolved/designed to collect the data.

The study showed service development for this client group moving from repressive, devaluing attitudes to today's optimistic philosophies of Social Role Valorisation and Community Care. An assessment designed to understand each participant's communication pattern not only facilitated the practical intervention but has a wide application within care services. The results from the therapy sessions were positive, showing the four participants' behaviour to be qualitatively better, e.g. a dramatic improvement in interactive and social skills, than during normal activities. Suggestions for future service developments are discussed.

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DEDICATION

IN LOVING MEMORY OF MY FATHER,

HUGH CUTHBERT ROBINSON

INTRODUCTION

This research project can be divided into two main areas. The first, describes the development of Social Services day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour, both nationally and in relation to one local authority in England. The basis of this exploration is a literature review supported by archive material and local data. As the development is traced attention is paid to how social work practice has evolved to reflect changes in attitude and philosophy.

The second part, a practical intervention, looks at one new approach to working with people with profound learning disabilities or severe learning disabilities and challenging behaviour which embodies contemporary thinking. It adopts a non-behaviourist stance that is holistic and humanistic.

The intervention is designed to explore how people with profound learning disabilities or severe learning disabilities and challenging behaviour respond to two complementary therapies, i.e. yoga and aromatherapy, as part of their individual programmes within a Social Services Day Centre, in the North East division of West Sussex.

A concluding section brings together the two areas of the study and discusses the salient findings in relation to social work practice both nationally and in West Sussex.

BACKGROUND

In order to explain the choice of research area it is necessary to look at service developments in the late 1980s/early 1990s and the author's involvement in them.

In 1988 the author took up a new post as Assistant Manager in a Day Centre in Gasleigh. This Centre had just opened a Special Care Unit for people with profound learning disabilities and was also, at that time, involved in introducing people with severe learning disabilities and challenging behaviour, who had formerly been patients of a large 'mental handicap' hospital, into its day care setting.

These developments were in line with the government's approach to Care in the Community (DoH 1989b) which emphasised: a) the importance of enabling people to lead, as far as is possible, full and independent lives and b) the vital role public agencies played in tailoring services to meet individual needs. This optimistic philosophy was in direct contrast to the traditional hospital model of day care which advocated diagnosis and prognosis, where

'patients' were the passive recipients of medical care. (Gilbert and Scragg, 1992).

On taking up her new appointment the author was therefore asked to give much thought to extending the range of activities for these 'new clients' who frequently had profound, multiple disabilities or challenging behaviour, and needed a high level of support. The foundation for planning and delivering these activities was based on the Five Accomplishments (O'Brien and Tyne, 1981), e.g. that they were age appropriate, socially valued and adaptable to individual needs.

Complementary therapies in general, and aromatherapy and yoga in particular, were new activities introduced that met the criteria. The benefits of these latter two therapies had been confirmed after talking with therapists, yoga teachers and reading various articles. Both looked at the individual as a whole person. They did not identify malfunctioning organs but recognised the totality of the person with different strengths and needs. There also appeared to be, during the process of the therapy, an interdependence between the therapist/teacher and the client where power, information and responsibility were shared. In addition yoga and aromatherapy and massage are valued and age appropriate activities.

The initial responses of service users, the staff team and carers to aromatherapy and yoga were enthusiastic and individual success stories were frequently heard. More fundamental to the author, however, was the emergence of a different way of working.

From concentrating on:- what a person could not do,
- skills based programmes,
- behaviour modification,
- multitudes of tick lists,

to:- appreciating and knowing, in depth, a whole person whilst providing an activity that produced an "inner calmness", a freedom from tension and a feeling of success/enjoyment (Brosnan 1982).

It was this that enthused the author to the extent that she decided to formulate a research project in this field. The work commenced in January 1991 and despite a break of approximately six months early in 1994, was completed in December 1994.

METHODOLOGY

Perhaps the one most important consideration when developing the methodology was that it must reflect the raison d'etre of the study i.e. to look at the whole person, putting participants' needs and wishes first. Their rights,

individuality and well being were not only central but paramount to any research being undertaken.
The following research aims were therefore designed and subsequently executed to mirror social work practice:-

Phase I

- To define, for the purpose of this study the key terms: profound learning disability, challenging behaviour, yoga, aromatherapy and massage.
- To review and evaluate the existing literature.
- To look at a) the development and b) the present provision of Social Services Day Care for the two client groups, both nationally and in West Sussex.
- To investigate in detail the resources for service users in one Day Centre in the North East division of West Sussex.

Phase II

- To design the practical intervention and develop techniques to record responses.
- To implement the intervention
- To gather and record data during the intervention.
- To analyse and record the findings.
- To discuss the findings and produce recommendations.

A variety of sources and sorts of data were collected and combined to achieve the research aims. Phase I used documentation, material from key informants, observation and a questionnaire.

Phase II used video recordings, reports from participants, observation, informal discussion.
In this way a holistic methodology developed which was essentially qualitative and used a range of approaches.

TERMINOLOGY

The key terms which will be used throughout this document have already been utilised in the previous paragraphs, i.e. profound learning disability, severe learning disability and challenging behaviour, service users, day care, complementary therapies, yoga and aromatherapy.

The labelling and definition of people or resources is fraught with difficulties. The author has therefore tried to use terms that are meaningful, non judgemental and reflect the expressed preferences of the people concerned.

It is for this reason that the term 'people with learning disabilities' (chosen by a client led organisation known as 'People First') is used in place of such traditional terms as mentally handicapped and mentally retarded. The use of the chosen terminology also responds to current thinking, e.g. Normalisation (page 19) and the move away from the institutional/hospital model, hence the term 'service user'

in place of 'patient'. Definitions of these terms are discussed further in Chapter 2, pages 75/6.

Day Care is described by Carter (1981) as:

> "a form of communal care which care givers present in a non-residential and non-domicillary setting for at least 3 days a week and which is open at least four hours per day." (p. 2)

Nationally the range of day care/centres is wide, from commercially run shops to large institutions. However, most local authority provision has been made through Adult Training Centres (also known as Social Education Centres or Resource Centres), and it is this model (pages 88 - 96) that is predominant in West Sussex.

Complementary therapy/medicine traditionally described any forms of treatment, e.g. acupuncture, reflexology, which:

> "were not generally provided or taught to orthodox health care professionals such as doctors, dentists and nurses." (Woodham 1994, p. 1).

In contrast to 'alternative therapies', which are treatments given in place of conventional medical care, complementary therapies are intended to be used alongside orthodox medical treatment. In today's vernacular the term complementary therapy describes activities, treatments or techniques which take a holistic approach, recognising the interrelationship of body, mind and emotions. The two complementary therapies, yoga and aromatherapy, introduced to the participants during

the research project are described in the literature review (page 31 and 42) and in the methodology (page 121 and 122).

STRUCTURE OF THESIS

Chapter one reviews the pertinent literature, dividing it into two parts: firstly service development nationally and secondly an examination of writings appertaining to aromatherapy and yoga. Developing services in a local context is the subject of chapter two, the author describes and reflects upon the methodology used and details the findings. Chapter three presents the methodology for implementing the practical intervention. The participants' responses to the intervention are recorded and considered in chapters four and five. Finally chapter six concludes the thesis by considering the major findings in relation to social work practice both nationally and in West Sussex.

CHAPTER 1

LITERATURE REVIEW

INTRODUCTION

The literature reviewed during the course of this research project follows the design of the methodology and the research aims, i.e. it is split into two sections.

1. The historical development of Social Services day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour:- By examining and evaluating the views of the writers the author has systematically described service development, philosophy and practice. Particular regard was paid to how changes brought about in various ways, e.g. government policy, books/papers, have influenced the way society perceives people with learning disabilities and has shaped the ensuing day care services.

2. The use of Aromatherapy and Yoga in social care settings with particular reference to people with profound learning disabilities or severe learning disabilities and challenging behaviour:- Literary sources were reviewed and

appraised to elicit the value and benefits of aromatherapy and yoga, their use in care settings and the holistic nature of the interventions.

THE HISTORICAL DEVELOPMENT OF SOCIAL SERVICES DAY CARE FOR PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR

Early History

The earliest attitudes and descriptions of people with learning disabilities can be found in works by Plato and Socrates. These are detailed by Gilbert and Scragg (1992) quoting Socrates as preaching:-

> "the greatest blessings come by way of madness, indeed of madness that is heaven sent" (p. 27).

In this ancient world the general populous made little differentiation between the terms mental handicap and mental illness - being defined by the common term 'madness'. Indeed before the advent of medical science, medical 'abnormalities' of any kind were explained in terms of the intervention of supernatural forces, and epilepsy seen as spirit possession (Morris 1969).

O'Connor and Tizzard (1956) note a change in the early fourteenth century - a distinction was drawn for the purpose

of deciding whether a person could be allowed to inherit property. A man who had lost his reason through madness was presumed to be capable of recovering it, where as 'born fools' were believed never to have had any understanding and could therefore be properly deprived of their legal rights to manage their inheritance. However Brudenell (1986) describes an opposing view, stating that the mentally ill were often burned at the stake whereas the mentally handicapped assumed prominent positions in the community e.g. court fool, village idiot.

Religious Influences

During the course of the literature search the author found some evidence of how religious groups have also influenced attitudes and services. The Koran states explicitly that adherents to the Muslim faith should:-

> "maintain them (those of weak understanding) and clothe them and speak kindly of them" (Gilbert and Scragg 1992, p. 28).

Jewish society also accorded some respect and reverence to those who were deemed to be uttering what might be prophecies. Gilbert and Scragg (1992) contrast the philosophies of Paracelus who believed that childlikeness could be near to godliness with Luther and Calvin who preached that people with learning disabilities were filled

with Satan and that their birth was derived from sin by the parents, more particularly the mother.

The Eighteenth and Nineteenth Centuries

Very little is documented before the eighteenth century possibly because agricultural communities were able to sustain those who could not read and write. Generally people who could not be contained at home were cared for in monasteries and later in the workhouses.

Around the middle of the eighteenth century several things happened which, although no direct evidence was found, must have had an effect on people with learning disabilities. Firstly the industrial revolution demanded a wide range of specialised skills for new production methods (Encyclopaedia Britannica 1961); thus highlighting those who were unable to learn these skills. Secondly there was a move from country to town (Encyclopaedia Britannica 1961) and once again those with learning disabilities became more noticeable as a sizeable group of people who were unable to look after themselves. Thirdly with the establishment of the First Education Act in 1870 i.e. compulsory education, children were identified who had special educational needs.

The response to these changes was to build hospitals and asylums to care for, or at least confine 'lunatics'.

> "The asylum movement was an honourable attempt to remove mentally handicapped people from inappropriate confinement in prisons and workhouse and from the 'trade in lunacy' (i.e. private housing in which lunatics were confined) which Lord Shaftsbury fought against." (Report of the Committee of Enquiry into Mental Handicap Nursing and Care, Vol. 1, 1979, p. 11)

At the same time a publication in 1801 by Itard - 'Wild Boy of Aveyron' - recounts one of the first attempts to train people with learning disabilities. Itard describes how Pereire (a former teacher of the deaf) used the technique of sensationism, i.e. people will learn when skills are reinforced by sensations, to teach social skills and language to 'the wild boy'. Morris (1969) cites this approach thus:-

> "Reason was regarded as the mainspring of human behaviour, and it was assumed that people behaved in the way they did on the basis of the sensations they experienced, either pleasure or pain, of satisfaction or discomfit." (p. 8)

Gilbert and Scragg (1992) examine the subsequent developments; although often contrasting, several theories started to be introduced on "training defectives" by, for example, Pinel and Sequim, and specific institutions were founded. In Britain a small "school for idiots" was set up in Bath in 1846 and the following year an asylum for idiots was founded in Highgate. The Board of Control Act (O'Connor and Tizzard 1956) recorded, in 1886, the existence of four large hospitals which had been functioning for some years.

Legislative and Social Influences in the first half of the Twentieth Century

Starting in the latter part of the nineteenth century the Eugenics movement argued powerfully for the segregation and sterilisation of mental defectives.

> "People with learning disabilities were seen as being inherently inferior and bestial, and having heightened criminal and immoral tendencies." (Gilbert and Scragg 1992 p. 35).

Despite this the Government of the day was considering issues in the field of social policy and several acts of Parliament determined the attitudes and services for people with learning disabilities:-

- 1913 Mental Deficiency Act, defined the legislative criteria of subnormality and introduced four categories of defectives - idiots, imbeciles, feeble minded and moral defectives. The classification was based upon social competencies but its lack of detail gave a wide margin for interpretation. However by categorising people perhaps the first signal was given that people with different types of learning disability need different services. After a delay in implementing the act due to the first world war, 'occupation centres' run by local authorities slowly came into being (National Development Group 1977)
- 1927 Mental Deficiency Act, amended the 1913 act and added training and occupation of defectives to the duties of local authorities.

Other landmarks in the services for people with learning disabilities (National Development Group 1977) were:-

a) the evolution of the NHS. in 1948, whereby responsibility for providing institutions for those people with learning disabilities not living at home was transferred from local authorities to the new hospital authorities.

b) 1954 - 1957 Royal Commission and 1959 Mental Health Act which introduced new terminology - subnormality and severe subnormality and first introduced the notion of Community Care. The Commission recommended that hospitals should only be for those people that needed medical treatment or continual nursing supervision and that local authorities should provide small residential homes for adults. The existing statutory power for providing occupation/training centres under Section 28 of the National Health Service Act was spelt out in the Mental Health Act 1959 and became a duty.

From Hospital Care to Community Care

It is from this point in time that the separation began between the services provided in hospitals, for people with learning disabilities who need medical care or supervision (i.e. profound learning disabilities and severe learning disabilities with challenging behaviour) and those provided by the local authorities.

Not only was day care available within hospitals but as a result of a recommendation by the Ministry of Health in 1965 day hospitals were also established for 'severely subnormal' patients who lived at home.

In a pamphlet drawn up in 1968 by the Ministry of Health entitled "Model of Good Practice" it is categorically stated:

> "There is little place for special care cases (i.e. people with profound learning difficulties or challenging behaviour) in Adult Training Centres." (Ministry of Health, 1968, p.3, para. A3).

However questions were being asked whether these large institutions really were the right place for this client group with the consequence that the Ministry of Health also stated that they would investigate the place of local authority provision for special care clients

A study, to examine the range and quality of institutional provision, by Pauline Morris (1969), supported the Ministry of Health's misgivings about hospital care. Conducted during 1964 - 1965 and visiting nearly half the hospitals in the country, its aim was to establish the extent to which training and education were important in patients' mental and physical capabilities. Findings relevant to this study are as follows:-

- 64% of patients lived in wards which only had one day room
- 21.8% of patients lived in wards which only had two day rooms
- 2% of patients had no day room.
- Where toys, games and books were available they were kept under lock and key. Nursing staff appeared to feel donors would be upset if their gifts were damaged or broken.
- 13 of the 34 hospitals provided day time "schools" or evening classes for adults, but only 12.3% of those to whom these facilities were available actually attended the classes.
- All units visited provided facilities for Occupational Therapy or Industrial training.
- Less than a quarter of units integrated males and females.
- The summary concluded that very small numbers of patients receive benefit from the non-medical treatments offered and dissatisfaction and frustration was expressed by most of the staff.

In 1968 the Report of the Committee on Local Authority and Allied Personal Social Services, (Seebohm report), was published. It recommended the setting up of a single Social Services Department which would provide "social care" i.e. caring for people in the community. For people with severe learning disabilities this meant that apart from education, all other services would be provided by these new departments rather than the original local authority

departments. Many saw this as an opportunity to promote integration. However the reality was that with local government reorganisation and the economic situation at the time little headway was made. Extending services for people with learning disabilities was negligible yet alone creating a service for people with additional physical, sensory and behavioural disabilities.

Three years later, with the publication of a government white paper - Better Services for the Mentally Handicapped (DHSS 1971), a start was made. This was an important document as it reflected the Government's gradual move towards community care for this client group and included, for the first time, those people whose needs may best be met in a Special Care unit.

The paper advocated the closure of the large 'mental handicap' hospitals and the growth of Adult Training Centres. The target was 73,000 places in Adult Training Centres by 1991, estimated at an increase of 2,400 new places each year in England alone. The report also said that there was:-

> "scope for the development of Special Care Units by Local Authorities and of day places in hospitals. In many cases it will be desirable for hospitals and Local Authorities to arrange joint provision of appropriate staff and contribution to running costs." (DHSS 1971, p. 15)

Although a step in the right direction, it must be

remembered that this was only an advisory document and therefore had no force of legislation.

In order to ascertain the progress being made in these newly developed Special Care Units a study by Norris (1975) was conducted. His findings showed cause for great concern. He reported inadequate physical facilities, and poor back up support. Norris called for "an active review" to be undertaken by local authorities to investigate the need for the development of day facilities for the profoundly handicapped. From these findings it appeared that very little headway had been made.

Normalisation

Similar concerns and a growth of new thinking, on a wider scale, became increasingly evident. Not only were the Government and Local Authorities looking for ways to develop services for people with learning disabilities but on a global scale, particularly in Scandinavia and America, foundations for planning and running services were being defined. The Principle of Normalisation was one such trend. Normalisation was defined by Wolf Wolfensberger as:-

> "The utilization of culturally valued means in order to establish and/or maintain personal behaviours, experiences and characteristics that are culturally normative or valued." (O'Brien and Tyne 1981, p. 1)

This principle has been used as a tool to design and deliver

effective services which O'Brien (1987) asserts should have five main components :-

Community Presence, Promoting Choice and Protecting Rights, Competence Development, Status Improvement and Community Participation.

The Development of Special Care Units

The impact of Normalisation on services generally, was a shift from patients to people, from focusing on weaknesses to focusing on strengths and to finding the right balance between ordinary and specialised services. In the particular field of people with profound learning disabilities or severe learning disabilities and challenging behaviour, suggestions as to how this principle was to be implemented were made in a pamphlet issued by the National Development Group for the Mentally Handicapped entitled "Day Services for Mentally Handicapped Adults" (1977). The Special Care section was recommended to be an integral part of the Social Education Centre (the name they suggested for Adult Training Centres). Its aim was stated thus:-

> "The fundamental aim of the Special Care Section should be to act as a specialised resource area offering intensive treatment and support, which can be used as a base by the most severely handicapped students, but from which they are exposed to increasingly demanding tasks and experiences in the rest of the Centre. The Special Care Section should not be regarded as an isolated haven of care, segregated from the rest of the Centre and its activities. It should be an integral part of the Centre with the task of meeting the special needs of some of its students." (National Development Group 1977, p. 65)

This aim has been quoted in full as it is very important, for it is the first time a national body specified aims and objectives for the day care of people with profound learning disabilities in a community setting. These recommendations were long overdue on a) humanitarian grounds, i.e. a child having attended a Special Care Unit in a school for up to 12 years had a choice of remaining at home indefinitely or being admitted into a hospital and b) the emphasis of the 1971 White paper and subsequent government policy, i.e. preventing all but the most essential hospital admissions.

A study by Whelan and Speake; A National Survey of Adult Training Centres in England and Wales, 1977, indicated that the majority of Adult Training Centres had no Special Care provision. Of the 390 Adult Training Centres 332 were sampled.

82 had no Special Care Units, and no special care clients.
193 had no Special Care Units but had special care clients.
43 had Special Care Units.
14 did not state whether they had Special Care Units or not.

From this study it can, therefore, be assumed that day service provision for people with profound learning disabilities or severe learning disabilities and challenging behaviour was not high on local authority's agendas, with over half (58%) of the Centres having no specialised facilities.

This lethargy is confirmed in a review of Mental Handicap Services in England since the 1971 White Paper - Mental Handicap Progress, Problems and Priorities - (DHSS 1980), which documented the progress made towards the White paper targets for 1991 and considered whether it was necessary to modify objectives or study any areas further. Pertinent conclusions were:-

1. Although there had been an expansion in day care places the numbers still fell short of what was required.
2. The number of people in 'mental handicap' hospitals was in excess of what the White Paper suggested.

"Helping Mentally Handicapped People with Special Problems"

A milestone in the development of day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour began in 1981 with the recognition by the DHSS that the needs of people with learning disabilities who have additional problems required further investigation.

To do this a multi-disciplinary team was set up, assisted by Peter Mittler (DHSS. 1984). The remit was two fold: Firstly, services for 'mentally handicapped' people with special needs (included in this category are those who are 'behaviourally disturbed' and secondly day services for 'profoundly mentally and multiply handicapped people'. To

this end they looked at the service delivery for these groups in a variety of settings in different parts of the country. For people with challenging behaviour in addition to a severe learning disability the report considered their special needs and the kind of care they required. Several key points emerged:

1. Day Care facilities for this group can successfully be provided by Local Authority Special Care Units with support from National Health Service professional staff.
2. All staff working with this group should be aware of the principles of behaviour modification.
3. Staff ratios should be high enough to maintain consistent treatment.
4. Staff for these units should be carefully selected and should receive appropriate training.

The team stated:-

> "Profoundly mentally and multiply handicapped people have the same right of access to the primary care team, to social work help and to specialists services in the community as all other people."(p. 4)

They also categorised people whose needs are best met in a Special Care Unit as people who in addition to their profound handicap may be :-

1. non ambulant
2. may not use speech
3. have sensory defects

4. have physical disabilities

5. have behaviour disturbances.

Although seven years since the National Development Group publication this report advocated the same aims and objectives and the same suggested staffing ratio i.e. 1 instructor to 3 clients. Once again the urgency of development of Special Care Units was highlighted as was the need for joint planning and funding between Social Services and the Health Authorities. However numbers of Units were rising, 1982 saw 144 Special Care Units catering for 2,000 clients and only 14 Local Authorities did not have any form of Special Care Units.

Additionally the DHSS. team recommended design features for these Units. Ideally they would cater for between 10 and 25 clients, would be purpose built, probably as an extension to an existing Adult Training Centre. Each Unit would have a large multi purpose space with small linked areas in which sub groups could work. In addition there would need to be several small self-contained rooms for one-to-one work. Some areas would be soft carpeted, different levels of illumination would be needed and the small rooms, acoustically, well insulated.

This report highlighted the growing awareness by senior management, parents and other professionals that people with

additional problems should be included in the progress being made in learning disability services as a whole.

Social Role Valorisation

In this same period attitudes towards people with learning disabilities were once again influenced by the work of Wolfensberger who, in 1983, proposed a new term to supersede the word Normalisation and to add to its implications - Social Role Valorisation. Social Role Valorisation implies as much as possible that services make use of culturally valued means -

> "..in order to enable, establish and/or maintain valued social roles for people." (Mental Retardation, vol.21, no.6, p. 234)

Wolfensberger outlines his reasoning for the development of this new term by proposing that:-

> "..the single highest secular goal of human services is social role enhancement or role defence of the people served." (Mental Retardation, vol. 21, no.6, p. 234)

An Individualised Service

One resulting response to this was Individual Programme Plans (IPP's) or Individual Plans (IP's) i.e. tailoring activities and programmes to people's needs and preferences rather than offering predetermined services on the basis of stereo-typical notions. IPP's were originally developed in 1982 for 15 Service Users in Andover, Hants. who were

potential clients of a community based residential service for people with severe or profound learning disabilities.

> "An IPP is a written plan of interaction and action that is developed on the basis of assessment results and modified at frequent intervals with the participation of all concerned. It specifies goals and objectives and identifies a continuum of development outlining projective progressive steps and the development consequences of services." (Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Individuals, quoted in DoH 1987, p. 19).

1980 - 1990

An insight can be gained into the state of learning disability day services in the eighties by consulting a Social Services Inspectorate report (Social Services Inspectorate 1987). It drew attention to current issues and practices and listed many recommendations which they hoped would stimulate current thinking.

The Inspectorate visited a representative sample of 13 Local Authorities made up of 150 Units (including 30 in the voluntary sector). Certain themes transpired:-

1. All Local Authorities were committed to the provision of day care for people with 'mental handicap', including people with profound 'mental handicaps'. However there was concern expressed on how best to cater for people with challenging behaviour.
2. There was little evidence of joint planning.
3. Although there was much talk of normalisation, highest

potential and community care, few authorities appeared to understand the operational implications of such policies or had established an overall philosophy for the delivery and purpose of Day Centres.

4. Facilities for 'profoundly handicapped' people with additional severe physical 'handicaps' were provided or planned everywhere and such services were often commended by inspectors for their systems of assessment, clear individual plans and reviews - a picture rarely found in main stream Centres.

5. Services for people with profound 'mental handicaps' or challenging behaviour had developed considerably between 1981 and 1986 the number of places having doubled to 4,000 (source Adult Training Centres for mentally handicapped people at 31st. March 1986 A/F 86/8) These people were also in contact with a multiplicity of professionals. (n = 49)

62% contact with Social Worker
38% " " Community Mental Handicap Nurse
28% " " Psychologist
51% " " Speech Therapist
35% " " Occupational Therapist
43% " " Physiotherapist
31% " " Psychiatrist
44% " " Chiropodist

In general it appeared that there was still a great diversity of service provision throughout the country.

Despite their concerns in some areas, the Inspectorate felt that with the progress of some Local Authorities coupled with a dynamic staff force, services for people with a learning disability would move forward.

It is interesting to note that although progress was being made in the development of services for people with profound learning disabilities (the number of places having doubled in the previous 5 years) the service provision for the person with challenging behaviour had not really been addressed.

Care in the Community

The evolution of day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour moved another step forward with the 1989 Government White Paper - Caring for People - Community Care in the next decade and beyond (DoH. 1989). At the time of its publication there were 319 Units catering for 4939 clients (source Adult Training Centres for mentally handicapped people at 31st. March 1989). The emphasis of this document was consumer choice and the importance of human resources rather than plant. It advocated that Local Authorities need not necessarily provide services directly but should make maximum use of the voluntary and commercial

sectors in order to widen the choice, increase flexibility and stimulate innovation.

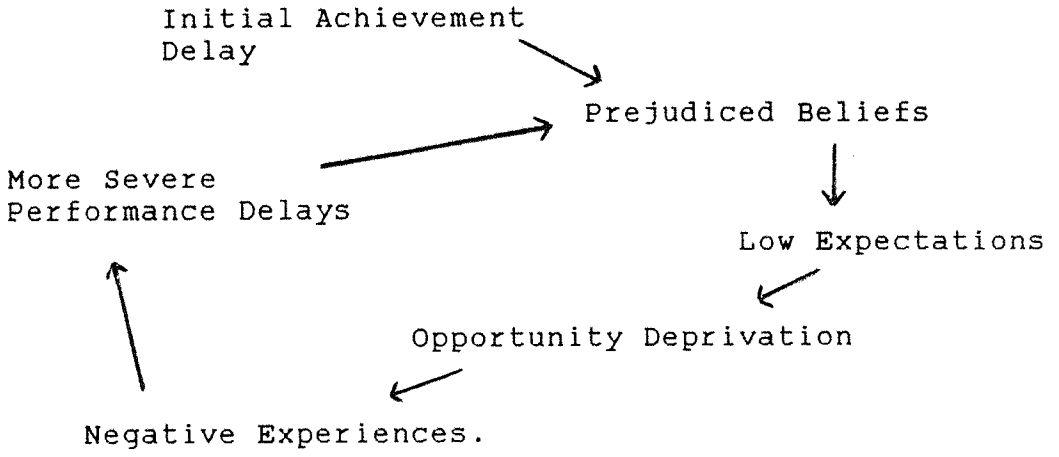
The ensuing act - NHS and Community Care Act 1990 - consolidated the white paper and highlighted the importance of a needs led service for individuals, developed from a multi-disciplinary assessment. Day services were seen as a major element of service provision.

Summary

It was evident from studying the literature that day services for people with profound learning disabilities or severe learning disabilities and challenging behaviour corresponded directly to the conditions and perceptions of society at any given time. For example the Eugenics movement produced a service response of control and segregation and even possible destruction.

More recently people with profound learning disabilities or severe learning disabilities and challenging behaviour were regarded as 'sick people' and spent the majority of their life in hospitals. Consequently service provision was isolated and segregated with people being 'nursed', expectations were low, leading to retarded development and

low esteem which in itself then led to behaviour problems. This is described by O'Brien and Tyne (1981) in diagrammatic form:



(O'Brien and Tyne, 1981, p. 7)

Breaking this circle was achieved by the move from hospital care to care in the community and the implementation of the Principle of Normalisation, thereby challenging the belief that people with profound learning disabilities or severe learning disabilities and challenging behaviour need to be segregated, giving them the same experiences as their peers. In this way the vicious circle was changed to a 'virtuous' circle in which everybody wins.

THE USE OF YOGA AND AROMATHERAPY AND MASSAGE IN SOCIAL CARE SETTINGS WITH PARTICULAR REFERENCE TO PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR

1. AROMATHERAPY AND MASSAGE

The author was unable to find any research relating to the responses of people with profound learning disabilities or severe learning disabilities and challenging behaviour to aromatherapy. This conclusion is backed by a letter, written in response to the author's enquiry, from the training manager of Shirley Price Aromatherapy Ltd. who wrote:-

> "So far as I am aware, no direct research has been carried out into the results/responses of people to aromatherapy."

Shirley Price is an internationally recognised authority on aromatherapy and, with two learning disability professionals, has recently published 'Aromatherapy and Massage for People with Learning Difficulties' - the only specialist book that was extracted from the literature searches.

In addition to this publication four explicit references were followed up plus many others which were indirectly related to the subject. There was evidence of some research into the properties of oils e.g. Toho University School of Medicine, Tokyo (Birchall 1990), but apart from these

experiments the value of aromatherapy appeared to be largely anecdotal.

Having reviewed the available literature there are several common themes which will now be discussed under the following headings:-

- Aromatherapy and Massage as a response to Normalisation/Social Role Valorisation
- Studies relating to Touch and Smell
- The value of Massage
- Examples of Aromatherapy and Massage

Aromatherapy and Massage as a response to Normalisation/Social Role Valorisation.

Sanderson et al. (1991) introduce their book by confirming that they believe aromatherapy and massage is a response to O'Brien's (1987) five accomplishments (page 20), and they have used this philosophy in their work and as the value base of their book. They suggest that aromatherapy and massage can connect all parts of an individuals needs, e.g. physical, emotional, spiritual, and also create a supportive, positive and stimulating environment in which the particular needs of the individual can be met. In addition the authors maintain that the environment where aromatherapy and massage takes place is, normally, socially valued e.g. natural health clinic, beauty salon, therapist's

home, and that touch can occur in an age appropriate and respectful manner.

A similar approach was adopted by a women's group in Oxford in 1987, whose members all had severe mental and physical disabilities (Houseman 1987). Aromatherapy and massage was used to help achieve the group's aim of helping the women develop social confidence and a feeling of self worth. Houseman states:-

> "I am firmly convinced that these therapies are of great value to severely disabled people". (Houseman 1987, p. 9)

One of the participants Jane Douglas is quoted as saying:-

> " One of my main aims is to promote massage and aromatherapy because they really do help us." (Houseman 1987, p. 8)

Physical touch (though not specifically aromatherapy and massage) is prominent in the system of Gentle teaching (McGee et al. 1987). It was developed in Nebraska and challenges paid staff to question and give birth to new values, moving towards mutually humanising and liberating teaching practices. Its essence, similar to Social Role Valorisation, is to model and teach the person that there is value and goodness inherent in human relationships (Brandon 1989). Touch is essential to the system as a method of demonstrating a belief in a person's value and also to develop warm relationships.

It is interesting to note that these are the only three

references that show aromatherapy and massage or touch as the means to achieve individual value and dignity rather than as a relaxation/stimulation activity.

Studies Relating to Touch and Smell

Massage and Aromatherapy are primarily linked to the senses of touch and smell and it is on these senses that Aromatherapists concentrate. For a person with profound learning disabilities or severe learning disabilities and challenging behaviour these senses are often impaired or opportunities have been denied for their development (Longhorn 1988).

In addition to general research on the benefits of touch e.g. Montague (1986) and Harlow (1965), experiments on animals prove that the absence of touch has profound effects on health. Prescot (1963) found that the absence or withdrawal of physical affection in early life, and even as an adult, may be responsible for many types of disturbed behaviour such as depression, violence, aggression and hyperactivity i.e. those problems that people with challenging behaviour often present. Shevrin and Toussieng (1965) suggest that 'rocking' is used as a form of tactile behaviour where touching is absent. Hogg, Sebba and Lambe (1990) affirm these ideas, suggesting that people in social care settings are rarely touched for their own sake, touch

is always perfunctory and can therefore lead a person to associate physical contact with unpleasant painful experiences. Consequently they may seek more accessible tactile stimuli e.g. head banging, masturbation, physical aggression.

This evidence suggests that elements of Aromatherapy and Massage may not only provide appropriate and positive experiences of touch but may also lessen negative responses linked to tactile deprivation.

At Warwick University the Olfaction Research group have shown that the olfactory system directly targets the limbic area of the brain which is concerned with both motor functions and emotional expression (Van Toller and Dodd 1988). Further studies by Tortora and Anagnostakos (1981) affirm that memories of smell are stored very efficiently in the brain and responses to particular aromas are tempered by past associations and images, as well as by the perception of it as a pleasant or unpleasant sensation. Whether these responses are learnt or are pheronomal (a chemical messenger that produces a specific metabolic effect) are argued by Birchall (1990).

For learning disabled people the importance of these findings are crucial. By incorporating the sense of smell

into relevant teaching programmes success may be achieved more readily.

The Value of Massage.

Massage is defined in the Concise Oxford dictionary (Fowler and Fowler 1964) as:-

> "Rubbing, kneading etc. of muscles and joints of the body with the hands, to stimulate their action etc."

It is an ancient technique used by Greek and Roman physicians as one of the principal means of healing and relieving pain (Lidell 1984). Whilst its popularity and application have continued in an unbroken line in the East, the West largely rejected massage, firstly in the middle ages and then in the early nineteenth century. This was initially due to contempt for the pleasures of the flesh and latterly with the onset of the scientific revolution which discounted these older concepts as unscientific. Today, however, massage;

> "has once more been recognised and it continues to flourish and develop throughout the Western world both among lay practitioners and professionals" (Lidell 1984, p. 12).

This development included massage for people with learning disabilities. The author found the following examples of the use of different types of massage:-

i.) Interactive massage cited by Sanderson and Harrison (1991) focuses on encouraging responsiveness, interaction

and participation. Passant (1990) describes the benefits of interactive massage with elderly people;

> "Massage brought many benefits to our patients. Touching in this beautiful and non-sexual way opened the doors to a closer relationship with us, allowing patients to speak of their dreams and hopes, and their fears and pleasures." (Passant 1990, p. 27)

McInnes and Treffry (1982) concur with this approach. They suggest that emotional relationships will most likely be established by physical contact.

ii.) Metamorphic massage was used in closed wards in a behavioural unit of a 'mental handicap' hospital and was described in the Nursing Times (1987) as:-

> " a simple massage of the spinal reflexes of feet, hands and head that can have surprisingly powerful effects on mental, physical and even emotional health". (Drake 1990, p. 15)

The practice was developed by reflexologist Robert St. John, in the 1960s, who believed that massage released pre-natal blocks of energy giving the recipient freedom from long standing traumas which subsequently improve general health. Several examples of the benefits of metamorphic massage at the hospital are quoted including one of a 24 year old man who is deaf, blind and mute. He is now able to show the nurse exactly where he wants to be touched and shows his enjoyment of sessions by smiling and laughing when his hands are massaged. The consultant psychiatrist at the hospital stated that the scientific benefits of the treatment were; a

decrease in tension, heart rate, galvanic skin response, blood pressure and metabolic rate.

iii.) Multisensory massage can be passive or interactive and aims to increase a person's awareness of the environment through tactile and olfactory stimulation (Sanderson and Harrison 1991). Often people with physical or behavioural disabilities have been unable to explore their surroundings - by encouraging a person with learning disabilities to use the senses of smell and touch new avenues can be opened to gain information and awareness of their environment.

Examples of Aromatherapy and Massage

Since 1984 Nursing Times has included submissions from health professionals and therapists on the use of aromatherapy and massage in their practice (Ryman, 1984; Wise, 1989; Armstrong, 1991; Buckle, 1992; Burns and Blamey, 1994). They report that whilst many nurses recognise that technological and non-contact nursing is valuable they miss the ancient tradition of the 'healing touch'. They feel that aromatherapy answers that need and also gives them 'permission' to have time being with, and talking to, patients. Aromatherapy was found to be beneficial in treating the following conditions:-

-stress related illnesses

-skin treatments

-arthritic and rheumatic conditions

-high blood pressure

-varicose ulcers

-premenstrual and post menopausal problems

-sinusitis and catarrh

-terminally ill patients

A six month pilot study assessed the value of aromatherapy for over 500 women in labour (Burns and Blaney, 1994). It was designed to collect a preliminary set of data that would generate information helpful in planning further work. The results indicated a high degree (62%) of overall satisfaction in using aromatherapy during labour/delivery on the part of women and midwives.

Another study (Tattam, 1992) was carried out on 100 cardiac surgery patients to reduce anxiety. A control group of 50 patients had no massage, 25 had massage alone and 25 had massage with neroli oil. The results showed that the 50 that had massage were judged to be less anxious than the control group. (There was no reference available to obtain more detailed results).

Two journals, Talking Sense and Information Exchange have published reports of actual work with people who have disabilities and have experienced aromatherapy and massage. The first is at a school for pupils with severe learning

disabilities and profound and multiple learning disabilities. At the time the article was written (1990) 15 pupils had aromatherapy sessions on a weekly basis, most of whom had profound and multiple learning disabilities and six of whom had a visual impairment. Each child had a book noting the following:- any relevant learning disability, relevant medical condition and medication, the objectives of each session, the oils used and their ratios, and comments from staff, parents/carers.

The sessions were conducted in a relaxed atmosphere, often with music playing in the background. Massage was concentrated on hands, feet, neck, shoulders and back. Teachers, who had consulted a physiotherapist, a peripatetic teacher for the visually impaired and had attended a workshop run by an Aromatherapist, ran the sessions. Experimentation with a variety of oils to determine the best results was done by staff observing effects on the children and particularly taking note of the reports sent from home.

> "Amongst the staff and parents involved a very positive attitude has developed. The pupils clearly enjoy the activity and in certain cases it has a calming effect when all else has failed.." (Ware 1990, p. 4.)

A Centre for deaf blind students in Glasgow ran a regular aromatherapy programme. Ruth Chappell (1991), Director of the Complementary Medicine Centre in Glasgow describes the benefits of this work:-

> "...we not only have the individual medicinal properties of the oils but also an excellent medium through which we can relieve tension and increase their receptiveness by reducing tactile defensiveness. Aromatherapy can also be used to provide encouragement, support and a general sense of well being." (p. 20)

Massage was used prior to activities that needed fine motor skills, this was found to enable limbs to move more fluently thereby enhancing positive feelings about the activities.

The article was illustrated by a case history of a 21 year old man who had lived for 19 years in a 'mental handicap' hospital. He had no sight, no hearing, epilepsy, severe anti-social behaviour and he self abused. He could not tolerate physical contact and would therefore not relax sufficiently for staff to help him develop the use of his hands.

The aromatherapy sessions started by introducing him to various aromas, noting his preferences, and then led on to brief physical contact which initially produced voluntary projectile vomiting. Eventually after nine months he could enjoy having his shoulders, neck and face massaged twice daily. Improvements were noted in his social behaviour, responses to signing and training activities. Whilst acknowledging that these changes could be due to many factors Chappell (1991) is sure that aromatherapy played an important part in the process of enabling him to relax and to accept physical contact.

Summary

The literary sources studied appertaining to aromatherapy and massage gave a very positive view of the benefits. However there was no evidence found of any direct research being carried out in this field. Common experiences of participants, therapists and professionals confirmed that:-

- aromatherapy and massage can help a person become more aware of the body's state - identifying when muscles are tight and enjoying the feeling of complete relaxation.
- aromatherapy and massage can help people to learn to trust, share and interact with each other.
- aromatherapy and massage can provide a service that helps people establish or maintain a feeling of self worth.
- aromatherapy is increasingly being used in the nursing profession
- aromatherapy and massage can be used as an aid to teach new skills.

2. YOGA

The literature studied can be categorised under the following headings:-

- The work of Maria Gunstone
- Books, Papers and Articles
- Research projects.

The Work of Maria Gunstone

Maria Gunstone, (nee Bullard), trained and subsequently qualified as a yoga instructor in 1976. Her interest and belief in the benefits of yoga arose from using yoga to aid her recovery after a serious car accident (Gunstone 1990). Initially she worked with a variety of groups in London making yoga more available for disabled people and finally specialising in teaching yoga to people with learning disabilities, their teachers, carers and parents.

A newspaper article (Independent 1991) and articles in professional magazines e.g. Bullard in GLAD (1985), Gunstone in Community Living (1990) describe the course of Gunstone's work, the benefits of yoga to people with learning disabilities and how she developed an approach to yoga called "YOU & ME" (Yoga Opening and Unfolding and Meaningful Experience) specifically for people with learning disabilities. YOU & ME is a yoga system of sound, colour and 'Whole Body Movements' which introduce the participants to 20 different postures and breathing techniques (Gunstone 1992). Gunstone believes that yoga for people with learning disabilities has made;

> "a substantial contribution to their physical and psychological well being. It can increase mobility, dexterity and mind and body co-ordination. It can generate self esteem and enhance self image. It can reduce stress and tension and promote relaxation and peace of mind." (Gunstone 1990, p. 7)

A major contribution to teaching yoga to people with learning disabilities was made by Gunstone when she was awarded a Churchill fellowship to travel to India to study the therapeutic value of yoga for disabled people. She travelled for three months through seven Indian states. The report on this venture describes two projects carried out in the 1980s by Dr. P. Jeyachandran on methods of teaching yoga to children. In the first project it was found that:-

- Special teachers with the most experience in handling pupils with disabilities were able to get the best results when teaching yoga.
- The children had:-

> "learnt and practised asanas (postures) diligently, were able to co-ordinate their minds and bodies....and were much less easily distracted." (Gunstone 1985, p. 6))

The second study is recorded in more detail. It was developed in conjunction with Krishnamacharya with the aim of training 21 special educators to teach 50 pupils to practice asanas and pranayama (breathing exercises). Children were selected on the basis of age and IQ. There were 36 boys and 14 girls with the average age being 12 years and the average IQ being 52. The method used was observations and case studies, consultation of parents, residential staff and course organisers. At the end of this study the following benefits were stated:-

- an encouraging degree of proficiency in yoga
- behaviour, eating, dressing and language development had improved.
- an increase in confidence which enabled the children to learn new skills.

Desikachar, son of Krishnamacharya, also assisted Jeyachandran in this work, he is reported by Gunstone (1985) as saying that the 12 week yoga programme -

> "was helpful to the retarded, particularly in view of a change of attitude, from regarding the children as almost inanimate objects, to treating them as persons in their own right who could be active participants in their own development." (p. 9.)

The programme used in these projects by Jeyachandran has now been approved by the Department of Education in India and is included in their National Curriculum for Special Education. It is on this programme that Gunstone developed the YOU & ME system of yoga.

Gunstone's report (1985) also contains details of two case studies that Dr. Jeyachandran and T.V. Ananthanarayanan presented at a scientific conference at the Indian Academy of Yoga, in Bangalore. Both case studies describe tasks/goals achieved by young boys, who had learning disabilities and challenging behaviour, during a period of twice daily yoga instruction. Previous to the introduction of yoga neither boys had been making progress achieving their goals. There were no therapeutic or behavioural

interventions during the time of the study. Results were very positive, e.g. being able to sit still for 20 minutes, putting a key in a lock and opening a door and buttoning up clothing.

The author has been unable to look in depth at the research carried out in India as Gunstone produces no references in her report and was unwilling to share any of her findings when personally approached on two separate occasions. However the case studies in particular show a methodical approach to introducing a new intervention and whilst not claiming scientific accuracy do give qualitative evidence of a positive response.

Gunstone claimed that the YOU & ME system that she devised was based on "years of research" (Gunstone 1985) - the author was unable to find any evidence to back this statement. This must not, however, negate the importance of Gunstone's work in this field, it was to her 'system' of yoga and published articles that the author was continually referred. The YOU & ME system takes into account a person's intellectual disability, using practical, concrete instructions and provides a training course for prospective yoga teachers which not only ensures that the philosophy is understood but also teaches the techniques.

Books, Papers and Articles.

The author was unable to find any books specifically relating to yoga and people with learning disabilities. However 'Yoga for Handicapped People' (Brosnan 1982) included people with a 'mental handicap' in its definition of disability. This book was written for teachers who would like to integrate people with a disability into their classes and for people with disabilities and/or their parents who might like to try yoga on their own.

Brosnan, a Bachelor of Medicine and Surgery, regarded Yoga as having more benefits than those traditionally attributed to it;

> "Herein lies the therapeutic potential of yoga; the production of increasing interior calmness and freedom from tension. This calmness is not 'apathy': 'awareness' and the ability to concentrate the mind are both increased." (Brosnan 1982, p. 11)

Two factors affecting the life and happiness of people with disabilities are mentioned by Brosnan;

- a high degree of tension
- a repeated lack of success, if not outright failure in all spheres (leading to low self esteem).

She stated that yoga reverses these negative attributes - it is non-competitive, people can work at their own pace, work alongside able bodied people, have a method of overcoming

tension and results are achieved quickly. In addition Brosnan affirms:-

> "The actual physical movements achieved with or without help improve the overall circulation and strengthen the heart. Consequently oxygenation is increased in the whole level of functioning." (p. 14)

These views were also described in two articles (Brosnan and Weir 1986) on the therapeutic value of yoga, and in addition examples of practical work, with people who have severe disabilities, were described.

Brosnan's book is essentially a manual for those wishing to learn or teach yoga and does not attempt to substantiate views with research findings. It is interesting to find that the author, trained in medical science adopts a person centred approach rather than the traditional medical model.

In contrast to the many references found, relating to aromatherapy and massage in the Nursing Times, only one on yoga was located in this search. Fields (1991) recounted her experiences teaching yoga using the YOU & ME technique to small groups of residents at a home for people with learning disabilities. She believes breathing is the key to yoga and teaches members of the group to make a sound (aah or blow) as they exhale, thereby combining the idea of breath and movement, which is often difficult for people with learning disabilities to co-ordinate. Fields reported that staff at

the home noticed that members of the yoga group were more aware of their bodies and that co-ordination improved. Fields included the views of key people in the life of a person with learning disabilities, this will be the primary method the author will use to 'measure' responses of the participants to therapies.

A study of yoga and concentration was carried out in the USA by Hopkins and Hopkins (1979). The purpose of the study was to evaluate the effects of two different "psychomotor programmes" upon the activity level and concentration of elementary school children who had experienced various types of educational problems. Yoga was to be one programme, the other was strenuous physical exercises e.g. obstacle courses. The design consisted of 34 children participating in a session of fine motor activities then either yoga or physical activities followed by a measuring of attention/concentration by means of an alphabetical coding task. The results showed that both yoga and the physical exercise were followed by more efficient completion of the coding task. Although the general performance level of those engaged in yoga was slightly higher this was not true to a statistically significant degree.

This study has some similarities to the research the author is going to undertake but the design has a feel of a 'laboratory experiment' which she is trying to avoid. For

example the alphabetic coding task was not part of the normal curriculum and the feelings of the participants and significant others were not recorded

Pathak and Mishra (1983) distributed a paper entitled 'Rehabilitation of Mental Retardation through Yoga Therapy'. They affirm that yoga therapy has been found to be more beneficial to learning disabled people than traditional medical approaches.

> "Yogic kriyas, asanas and mudras are side effectless, immediate acting and most useful tranquillisers which can be used very sagely by each mentally retarded child." (p. 156)

Another survey carried out, solely, by Pathak (1983) found that 'midly retarded' children following yoga exercises were:-

> "found improved by regular practices up to three months." (p. 157)

Other benefits noted by the authors were increased blood supply to the brain which they claim improves the mental subnormality IQ and socialisation, tranquillity of mind and diminishing hyperkinetic behaviour. No evidence was given by the authors to support these views.

Research Projects

The literature search revealed one study directly related to children with learning disabilities and yoga, carried out in

India. Three other studies were located via the Dissertation Abstracts International.

Harrigan (1981) designed a study to determine the effects of two types of yoga (diaphragmatic breathing and hatha yoga) on anxiety, personality and somatic/behaviour measures. The population selected was college undergraduates. Four groups were formed; Group 1 were taught breathing exercises only

Group 2 were taught postures only

Group 3 were taught breathing and postures

Group 4 (the control group) attended a lecture on holistic health.

The hypothesis stated, that using measures, inventories and checklists to calculate changes, group 3 would score significantly better than groups 1 and 2 which would score significantly better than group 4. Training in the yoga was carried out in laboratory conditions twice weekly for six weeks. Results showed that group 3 improved in mood, anxiety and their need for sleep was reduced. The other interventions did not show adequate results to support any firm conclusions.

A study by Garfinkel (1992) examined the effect of yoga and relaxation on osteoarthritis patients. Subjects were divided into a control group, who received no intervention, and a treatment group who received eight, 60 minute weekly, sessions of yoga and relaxation. Statistically significant

differences ($p<.05$) were found between the two groups with the treatment group improving.

The third dissertation (Rudolf 1981) studied the effect of hatha yoga on women's self concept. Data was collected from 215 female students, who were randomly assigned a hatha yoga class, or an Effective Interpersonal Relationship Development class or randomly selected algebra classes, over the course of ten weeks. The aim was to see if the classes could produce a change in self concept. The findings indicated significant change in concept for the hatha yoga group ($p = .006$) whilst the other group's changes were $p = .08$ and $p = .36$ respectively.

All three studies show a quantative approach on intellectually able people with evidence that yoga has positive results in a range of settings. Apart from gathering evidence of the benefits of yoga there were no parts of the designs that the author could use in her research project.

A more relevant study - 'The integrated approach of yoga: a therapeutic tool for mentally retarded children' (Uma et al., 1989) was conducted over one year on 90 children with mild, moderate and severe learning disabilities in four special schools in Bangalore, India. The children were divided into two groups, one group were taught yoga for one

hour each day for a year whilst the other group, the control group, was engaged in their usual school routine. Apart from the one hour of yoga, the yoga group was exposed to the same school curriculum as the control group. The children were assessed, before and after the commencement of the yoga therapy, for IQ. and social behaviour using psychological instruments e.g. Vineland Maturity Scale.

The results from this study showed that children with a range of learning disabilities improved considerably by using yogic practices.

This study appeared less 'scientific' than the afore mentioned ones; by the regularity of the sessions over the course of the year the yoga became part of the children's life. Uma et al. do not mention, however, whether being part of an 'elite' group could have brought about the positive changes as opposed to the yoga instruction.

Summary

In contrast to the literature reviewed about aromatherapy there was evidence of research into yoga. Not surprisingly most of the research into yoga had been carried out in India and whilst appreciating the content, the cultural and social differences must be recognised.

None of the research projects replicated the author's intended methodology - the participants were either able bodied people or children with learning disabilities and control groups were relied upon to produce results. There was no evidence of the participant acting as his/her own control; a method the author used. However a fairly similar methodology to the author's e.g. case studies and observation was used by Jeyachandran in one of his studies.

Apart from Gunstone there was a surprising lack of material showing evidence of yoga being used in Great Britain by the medical and social care professions. Gunstone has carried out a vast amount of innovative work with people with learning disabilities but as yet her results are unsubstantiated.

> "There is a rapid development of the awareness of self mastery, a progress in self discipline with its accompanying feeling on independence, a knowledge of being a person in ones own right." (Brosnan 1982, p. 15)

Although there were no direct references to yoga as a response to Social Role Valorisation this quote clearly illustrates that many of the benefits advocated by yoga adherents are akin to the these principles, e.g. exercising alongside able bodied people, increase in independence, increase in self esteem. Additional benefits found in the literature include:-

- increased mobility
- reduced stress and tension and an increase in relaxation and peace of mind
- co-ordination of body and mind
- increased confidence
- increase in performance/skills level

Conclusion

This chapter has evaluated the relevant literary sources which describe the development of social services day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour, and assessed texts which illustrate the use of aromatherapy and yoga in social care settings. Service development will be further examined in the following chapter by looking in depth at day care for these client groups in one local authority.

CHAPTER 2

DEVELOPING SERVICES IN A LOCAL CONTEXT

INTRODUCTION

This chapter continues to explore the development of Social Services day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour concentrating on one local authority. West Sussex is the initial setting with the study being developed in progressively more focused detail, finishing with a description of the day centre that is to be used for the intervention.

Firstly the chosen methodology is described and discussed and then the findings are presented under three headings:-

1. The development of Social Services day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour in West Sussex.
2. West Sussex - The current position (1991/2)
3. Day Care in the North East Division

METHODOLOGY

> "Let us be done with the arguments .....and get on with the business of attacking our problems with the widest array of conceptual and methodological tools that we

possess and they demand." (Trow 1957, quoted in Burgess 1982, p. 163)

To ensure reliability and validity and in keeping with the holistic principle of the research, the author, like Trow, felt it was important to use a whole range of approaches. In this way the research aims were matched up with appropriate research strategies, combining their relative strengths and associated techniques.

In the past, the two main styles of enquiry, quantitative research and qualitative research were seen at opposite ends of a continuum. Quantitative research being described as a structured, formal method of collecting data, both primary, i.e. collected by the researcher, and secondary i.e. material already available from other sources, which are summarised in a numerical design. Qualitative research, on the other hand, tends to be unstructured and is often used when there is no theory to work on. It may describe a phenomenon, an individual or a community. Generally the qualitative researcher participates, observing and recording the life of people. It is described by Bryman (1988) as an:-

"express commitment to viewing events, actions, norms, values etc. from the perspective of the people who are being studied.....it also entails a capacity to penetrate the frames of meaning with which they operate (p. 61)

Today, however, there is a growing tendency towards a more integrated approach and this is the stance the author chose to take when investigating the local context.

Within the chosen methodology ethical issues were regularly addressed. West Sussex County Council Social Services department does not have an ethical committee. However the department not only consented to the research project but also endorsed their support by sponsoring the author over the course of the study.

Kimmel (1988) argued that the researcher has to strike a delicate balance between the scientific (sic) requirements of the methodology and the human rights and values potentially threatened by the research. To ensure this balance was maintained and the ethical implications of the work were never forgotten the author constantly discussed and probed these issues during regular meetings with her supervisors and in meetings with the Deputy Divisional Director (D.D.D.). At all stages of the research the following safeguards were applied; permission was requested to obtain information, confidentiality was respected, progress reports were sent to the D.D.D. and the author offered to meet and share her findings with working parties, developmental officers etc. In this way an ethical framework became an integral part of the methodology.

West Sussex

A systematic search through memoranda, reports and papers held in West Sussex County Council archives was conducted to

find information concerning the evolution of a day care service for people with profound learning disabilities or severe learning disabilities and challenging behaviour. It was necessary to use these written sources conscientiously and appropriately as the author, as a researcher, had access to data which would not normally be available to someone in her position. In this role the researcher is described by Kimmel (1988) as 'vulnerable', as s/he attempts to offset organisational loyalty and professional objectivity. It was therefore essential, during the course of this study, only to employ and retain that which was relevant to the research project.

The understanding of this data and additional material was obtained by organising semi-structured interviews with the former Principal Officer (learning disabilities) who was in post during the negotiations for transferring 'patients' from the Health Authority to the Social Services department.

Current Position

Having traced the day care service from Health Authority to Social Services the next step was to find out how many people with profound learning disabilities or severe learning disabilities and challenging behaviour received Social Services day care in West Sussex and the resources available to them.

The first task was to produce a workable definition of both of these client groups. This in itself required an approach that was ethically sound. By the phraseology used, people can be either valued or disregarded. Such terms as 'the handicapped' or 'special care' denies people dignity and respect. The author wanted to acknowledge the participants' status as people first and thereby accord them deference.

The method used was a 'mini' literature review, gathering together the main definitions, from books, reports and journals and from these framing working definitions. These were piloted amongst colleagues, in order to gauge their ease of use.

Using these definitions to identify the service users a questionnaire was developed and piloted at two Adult Training Centres, one in Kent and one in East Sussex. After a few minor modifications to questions on staffing and daily attendance the questionnaire (appendix 2, page 253) was posted to all the Day Care establishments in West Sussex. The author felt it essential to widen the net to include all day care establishments, rather than those catering only for people with learning disabilities, as it could well be possible that some people may be wrongly placed. This indeed proved to be the case. In all, 19 Centres were targeted which comprised of; 7 multi-purpose centres, 6 adult

training centres, 3 day centres for people with physical disabilities and 3 day centres for the elderly.

The questionnaire covered the following areas:-

- staffing provision,
- number of clients attending,
- number of people with profound learning disabilities or severe learning disabilities and challenging behaviour (using the author's definitions) and their pattern of attendance,
- resources available to this group,
- aims and objectives for work with this group.

A few days after distribution each establishment was telephoned to see if they had any queries. A visit was also arranged to collect the completed questionnaire and go through it, with staff, in more detail. People who had nil returns posted the questionnaire back to the author.

North East Division

The Questionnaire provided the author with a profile of the number of people with profound learning disabilities or severe learning disabilities and challenging behaviour and the resources available to them in West Sussex. The next objective was to look, in greater depth, at the structure of one of the divisions of West Sussex - North East, and examine the services, for people with profound learning

disabilities or severe learning disabilities and challenging behaviour, provided by one of the Day Centres in that area. This was achieved by direct observation, semi-structured interviews and talking/working with key informants.

The role of the author began to change at this point, hitherto she had been an 'outsider' taking a look at a County resource, she now took on the qualitative stance of getting to know the key informants whereby:-

> ".....the researcher participates as well as observes, by developing relationships with informants..." (Burgess 1984, p. 81).

Research with this particular client group has many ethical issues to be resolved and it was with this first direct contact with the clients that, the author not only had to acknowledge these, but also make sure that their keyworkers were also aware of them. Firstly people with learning disabilities are, in many respects, a captive population. Their intellectual limitations make free choice and expression difficult and their language skills are often at a basic level, making comprehension of abstract ideas arduous. Finally, a large proportion of people have spent much of their lives in large institutions, where life was easier if you conformed - being assertive and expressing contrary opinions was often not encouraged.

Summary

Using the described battery of methods, namely documentation, questionnaire, informal and semi-structured interviews, observation and talking/working with key informants enabled the author to select the method most suitable to the area being studied. For example using a questionnaire to elicit information/ideas from service providers proved most successful. However this method would have been inappropriate to use with service users.

Another advantage in using a range of data collecting techniques was that by using more than one approach information could be double checked. This in fact happened frequently, e.g. - by visiting an establishment to go through the questionnaire, statements and information could be clarified by further questioning and observation (page 83) - by a semi-structured interview to clarify data found in the County archives (page 59).

Working in this manner ensured that the qualitative nature of the study remained central to this part of the research, the thoughts, ideas and needs of the participants were as important as the the acquisition of information.

1. THE DEVELOPMENT OF SOCIAL SERVICES DAY CARE FOR PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR IN WEST SUSSEX.

Introduction.

Prior to 1986 day care provision for adults with profound learning disabilities or severe learning disabilities and challenging behaviour in West Sussex was provided by the local health authorities. This day care was to be found in hospital settings i.e. Forest Hospital, Horsham, St. Nicholas Unit, Shoreham and Barnfield, Chichester. The alternative to health authority provision, at that time, was for clients to stay at home or receive day and residential care out of the County.

A description of service provision in one West Sussex hospital - Forest Hospital - is given by Gilbert and Scragg (1992) and the National Development Team (1985).
It was set up in 1812 as the Horsham Workhouse, well away from the main town. The original buildings were expanded by adding an impressive Victorian frontage and 'temporary' war time huts which became a permanent fixture.

> "Care was often provided in 60 place, single sex wards with recreation areas having bare wood or lino covered floors a few chairs and a boxed in TV. set in one corner." (Gilbert and Scragg 1992, p. 62)

In 1982 there were 226 patients, 119 being described as

Category IV (appendix 1 page 251), i.e. Profound Learning Disability or Severe Learning Disability with Challenging Behaviour. The National Development Team reported that there were two types of Day Care, recreational therapy and technical and occupational therapy. The "high dependency" patients went only to recreational therapy where they played with jigsaws and other simple toys:-

> "About 25 patients attended at any one time on a part time basis. Accommodation was too small and staff were too few for any meaningful activity to take place"
> "A number of less able patients did not leave their wards..." (National Development Team 1985)

One of the most common interventions used within the hospital to change/teach 'patients' new behaviour or skills was Behaviourism. The exponents of the behavioural approach believed that actions are determined by either stimulus or response, and that by controlling either of these, behaviour can be changed to bring about different outcomes.

The hospital finally closed in 1990 with 58 people initially earmarked to transfer their care to the Social Services Department.

Discussion and Development

Since the nineteen seventies, (DHSS, 1971, Norris, 1975, Whelan and Speake, 1977, NDG., 1977,) it had been recognised that hospitals were not an appropriate environment for this client group. Instead it was

acknowledged that these people were intellectually impaired rather than ill and therefore did not require the medical model of care but would most benefit from a move to small community based units.

It was in this climate of service development that West Sussex Social Services Department began to look to providing a day care service for people with profound learning disabilities or severe learning disabilities and challenging behaviour. There were three other major influences which also contributed to this proposed innovation:-

i. The National Development Team.

The National Development Team is an independent body which offers advice to health and social service authorities in England in the planning, development and operation of services for people with learning disabilities. Their remit is also to inform the DHSS. about the provision of learning disability services within the health and personal social services.

In 1981 the team approached West Sussex health authorities and social services department with an offer to examine the Counties "facilities for the mentally handicapped and their families." The offer was accepted and the team invited to visit West Sussex. The team arrived in January 1982 and stayed for ten days.

As a result of this visit a report was produced whose details were made available to the Social Services Committee in December 1982, the final report being published in September 1985. The report was divided into two parts - the first being comments and recommendations about the organisation of services, joint planning and finance, family support, community and residential care and general support services. The second part contained detailed assessments of individual projects and services across the County.

Amongst the many findings and recommendations three are of particular significance, to the development of specialised units, and had an immediate local impact. The first, a recommendation stated:-

> "With NHS. support a wider range of opportunities should be developed by all Training Centres to meet the extra needs of the more severely handicapped when they leave school. Special Care Units should be run as an integral part of the Adult Training Centre with the use of all the facilities available rather than being confined to one special area." (National Development Team, 1985, part 1, para. 29.5)

It is apparent from this that the Team not only acknowledged the lack of day care for people with profound learning disabilities or severe learning disabilities and challenging behaviour but provided a "blue print" for the design of a future service.

Secondly as a result of the Team's assessment and evaluation of the work of Forest Hospital, Mid Downs Health Authority

decided that it should close. A target date for the closure was March 1990. The results of this were twofold. Firstly the "patients" would need both day and residential care in the community and secondly with the land being so valuable there would be a vast amount of money to fund joint initiatives between the health authority and social service department.

The final recommendation of note was that the mental handicap register be updated and revised. The Principal Officer, Learning Disabilities, implemented this. He used the National Development Team's criteria which categorised clients with learning disabilities into four defined groups (appendix 1 page 251). In addition he added the following headings:- future potential, double incontinence, no speech/partial speech, non ambulant, deaf/blind/partially sighted and behaviour problems. Thus a more detailed and accurate picture of clients and service they required could be realised with data being easily accessible.

In a follow up visit in 1985 the team praised the planned Special Care Units but felt that further consideration would also have to be given to the needs of people with profound learning disabilities, particularly those with challenging behaviour.

ii. Education

Since the 1st April 1971 when the Department of Education and Science assumed responsibility for the education of children with learning disabilities, no child, however severely handicapped is regarded as 'ineducable' or 'unsuitable for education' in school. Thirty thousand children (Mittler 1979) who had previously been the responsibility of local and hospital health authorities were transferred into the education system as it was felt it was no longer justifiable to cut them off from mainstream education. With no similar community/mainstream provision for adults, school leavers with profound learning disabilities or severe learning disabilities and challenging behaviour whose needs could not be met at an Adult Training Centre had to take the retrograde step of returning to a hospital setting or staying at home.

West Sussex Social Services department were very aware of this anomaly. - The Principal Officer Mental Handicap in a memo to Divisional Directors (March 1984) stated that 25% (87) of special school attenders in West Sussex suffered from profound learning disabilities and the Social Services department had no provision for them outside of hospital settings.

iii. "Services for Mentally Handicapped People"

This report, presented to the West Sussex Social Services Committee on 20th January 1984, was commissioned by the

Director of Social Services shortly after his appointment to West Sussex. It was the first of several reports covering each of the major client groups for which the Social Services Committee was responsible.

Its aim was to specify the existing facilities/resources for people with severe learning disabilities and to make recommendations as to the philosophy and development of the Service. Under the heading Day and Domiciliary Care Services it stated:-

> "The County Council does not provide any 'special' day care for those who are hyperactive or who have multiple handicaps." (p. 16)

To correct this imbalance the following proposal was made:-

> "Special Care Units of 10 - 12 places each to cater for the severely handicapped should be developed at an Adult Training Centre in each Division.....They should cater first for those who are or can be at home with parents, and then for those in residential care....These units will cost about £100,000 each, with staffing etc. costs about £50,000 per annum. They would not be operational before 1986/7" (p. 17).

<u>The Evolution of Special Care Units</u>

Almost immediately this proposal was put into effect, with the first Special Care Unit being planned for Chichester. It was to be linked to the existing Adult Training centre. In order to produce the best possible design the Principal Officer, Learning Disability, and various Centre Managers visited similar units in other counties familiarising themselves with as many different designs and approaches to

units catering for people with profound learning disabilities or severe learning disabilities and challenging behaviour. They also contacted various national bodies such as DHSS., Mencap etc. to request advice and guidance on national recommendations and developments. Finally, using a needs led approach, they assessed twelve children with profound learning disabilities who attended a special school in Chichester to see what resources they would need when they, eventually, left school.

The funding for this project and the later Special Care Units was; a percentage of money raised from the sale of Forest Hospital (£2.25 million) plus 'dowry' money (£10,250 p.a. per client, inflation linked for life) that each health authority client transferring to Social Services would bring with them and 'new growth' money from the Social Services department.

After several financial and architectural revisions to the original plans the design of the Unit was accepted and building began.

It was established that the Special Care Units would cater for 12 people daily, who lived in the community and who were defined in the National Development Team's category 4;

> "...severe double incontinence, multiple physical handicaps, severe epilepsy, extreme hyperkinetic behaviour, aggression to self and others." (appendix 1 page 251).

The County's overall guidelines for the Unit were grounded in Wolfensberger's (1972) principle of Normalisation, with the Centre Manager being responsible for more comprehensive and specific aims and objectives. The staffing provision was decided as follows:-

1 - Assistant Manager, 3 - Instructors, 1 - Driver/Care Assistant, 1 - part time Cleaner. (The Manager of the Centre having overall responsibility for the running of the Unit.)

The programme available to Users would be geared to individual needs identified through use of assessment, covering areas such as:- independence in feeding, dressing, toileting and mobility, recreational, social and leisure activities.

The Special Care Unit at Chichester took its first clients in March 1987. West Sussex Social Services department has since built another three Units; one in Horsham (1988), one in Rustington (1989) and the most recent in Durrington, opened in 1990. In each case the same design has been used, making only minor modifications when necessary.

Summary

There were four major influences which contributed to West Sussex Social Services providing day care for people with

profound learning disabilities or severe learning disabilities and challenging behaviour;

1. The closure of Forest Hospital
2. The National Development Team's recommendations on organisation of services for people with learning disabilities in West Sussex
3. Education for children with profound learning disabilities or severe learning disabilities and challenging behaviour in community settings.
4. West Sussex Social Services report "Services for Mentally Handicapped People"

In only three years (1984-1987) there had been a shift from large institutions to Special Care Units, from Health Authority to Social Services, from diagnosis and prognosis to individuality and status improvement. The implications of these new resources were manifold;

- children leaving school did not need to return to a hospital setting for their day care.
- individual needs could increasingly be met.
- quality of life for the Service User was enhanced.
- the range of appropriate activities was increased.

However this initial policy was predominantly service led, i.e. it looked at a building that was capable of meeting the the needs of a group of people rather than looking at individual needs, and it did not appear, from admission criteria or policy documents, to recognise the differing

needs of people with severe learning disabilities and challenging behaviour.

2. SOCIAL SERVICES DAY CARE FOR PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR IN WEST SUSSEX - CURRENT PROVISION (1991/2).

Defining the Client Groups

The following definitions of the two client groups were produced by the author to facilitate the understanding and responses to a questionnaire designed to establish the number of people in West Sussex, with profound learning disabilities or severe learning disabilities and challenging behaviour, and the resources available to them.

a.) Profound Learning Disability

"A person in need of constant care and close supervision. Gross impairment of language, motor and sensory development. In addition many people will have other serious disabilities such as :- multiple physical disabilities
double incontinence
epilepsy
behavioural disturbances."

b.) Challenging Behaviour

"A person who has a severe learning disability and whose behaviour is such that it is difficult for them to be supported by the people who relate directly to them in the place where they live and spend time. Examples of their behaviour could be:- severe physical assault of others if regular or frequent

- occasional, unpredictable attacks where the trigger factor cannot be identified
- serious sexual attacks
- severe self injury if regular or frequent
- psychological problems e.g. depression

The use of the term challenging behaviour, rather than problem behaviour helps to:

> "focus attention on the challenges that must be faced by services if these people are to be offered high quality local support." (Blunden and Allen 1987, p. 7)

Sources consulted to obtain these two definitions were; World Health Organisation (1967), Norris (1975), DHSS. (1984), Sheffield Health Authority (1988), Grossman (1973).

Results of the Questionnaire

There was a 100% response.

In total nine establishments had positive returns and were consequently visited; - five (55.6%) were purpose built day centres for people with severe learning disabilities, two (22.2%) were multi-purpose day centres, one (11.1%) was a day centre for the elderly mentally infirm and one (11.1%) was a day centre for the mentally ill.

a.) People With Profound Learning Disabilities

-Thirty six people with profound learning disabilities receive Social Services day care in nine Centres in West Sussex (Table 1).
-That is 20 men and 16 women.
-Thirty one (86.1%) of these people receive their day care in 5 units catering specifically for people with learning disabilities, i.e. Adult Training Centres. Of those 31 people, 29 (93.5%) have the facility of a Special Care Unit available to them.
-Three (8.3%) attend 2 multi- purpose Day Centres.
-One (2.8%) attends a Mental Health Day Centre
-One (2.8%) attends a day Centre for the elderly mentally infirm, (see Table 1).

The attendance pattern for this group is shown in Table 2.

Of the 36 people, 25 (69.4%) spend the majority of their time in Special Care Units built specifically for this

client group. Nine people (25%) use the range of resources/activities available within a Day Centre and 2 clients (5.6%) are in a "special needs" group within a Day Centre.

NAME OF CENTRE	TYPE OF ESTABL-ISHMENT	MAXIMUM PLACES PER DAY	MALES WITH PROFOUND LEARNING D/ULTIES	FEMALES WITH PROFOUND LEARNING D/ULTIES	TOTAL WITH PROFOUND LEARNING D/ULTIES
ALEFORD	A.T.C.+ S.C.U.	112	5	5	10
COPSDALE	A.T.C.	110	1	1	2
ELMHURST	A.T.C.+ S.C.U.	112	4	2	6
PEBBLES	A.T.C.+ S.C.U.	62	3	2	5
OAKWOOD	A.T.C.+ S.C.U.	115	3	5	8
STREAMTON	MULTI-PURPOSE CENTRE	100	1	1	2
CLANDON	MULTI-PURPOSE CENTRE	50	1	-	1
RANGELY	E.M.I. DAY CENTRE	25	-	1	1
FORDHAM	MENTAL HEALTH DAY CENTRE	30	(DID NOT SPECIFY)		1

Table 1: Numbers of people with profound learning disabilities who receive Social Services day care.

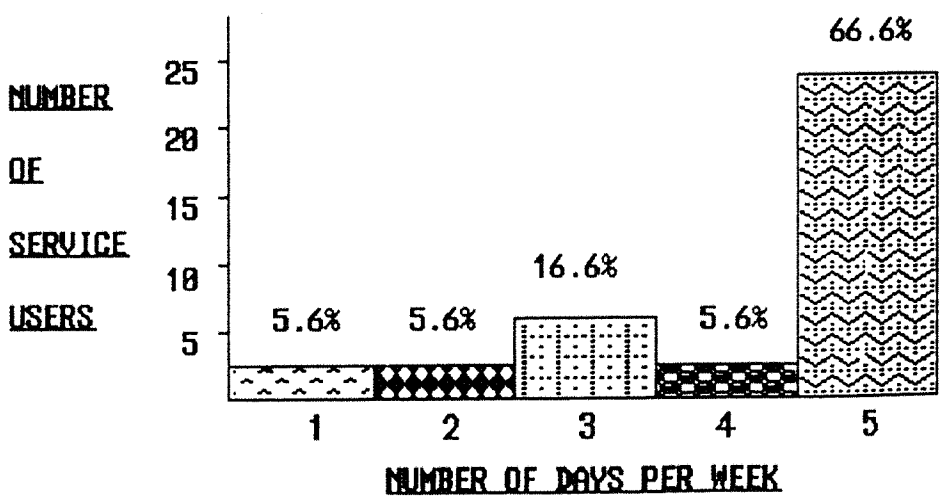


Table 2: Attendance pattern for people with profound learning disabilities who receive Social Services day care.

Written aims and objectives for this client group are available at just under half of the 9 Centres (44.4%). However two thirds of the Centres (66.7%) provide Service Users with individual programmes.

Where the clients were based in a Special Care Unit the average Instructor/Client ratio was 1 : 4. However there was insufficient information to work out the staff/client ratio where clients took part in the range of activities in a Day Centre. Additional out of Centre "specialist" staff, listed by the respondents who work with this group is summarised in Table 3.

(X = SERVICE IS USED)

SPECIALIST	A	B	C	D	E	F	G	H	I	TOTAL CENTRES	%
SPEECH THERAPIST	X		X	X	X					4	44.4%
MUSIC THERAPIST					X					1	11.1%
ADULT EDUCATION TUTOR	X				X					2	22.2%
COMMUNITY MENTAL HANDICAP TEAM	X		X		X					3	33.3%
PHYSIO THERAPIST			X		X					2	22.2%
BEHAVIOURAL THERAPIST					X					1	11.1%
OCCUPATIONAL THERAPIST	X		X		X					3	33.3%
PSYCHOLOGIST					X					1	11.1%
AROMATHERAPIST			X							1	11.1%
OWN CARE ASSISTANT							X			1	11.1%

A=ALEFORD: B=COPSDALE: C=ELMHURST: D=PEBBLES:
E=OAKWWOD: F=STREAMTON: G=CLANDON: H=RAMGELY:
I=FORDHAM:

Table 3: Specialist staff working with people with profound learning disabilities who receive Social Services day care.

b.) People With Severe Learning Disabilities and Challenging Behaviour.

From the 19 day Centres circulated, only 5 (26.3%) had people who, according to the author's definition, exhibit challenging behaviour. These 5 were all Adult Training Centres, i.e. day Centres catering specifically for people with learning disabilities.

In total there were 39 clients, 21 men and 18 women. This is illustrated in Table 4.

NAME OF CENTRE	TYPE OF ESTABL-ISHMENT	MAXIMUM PLACES PER DAY	MALES WITH CHALLE/ NGING B'AVIOUR	FEMALES WITH CHALLE/ NGING B'AVIOUR	TOTAL WITH CHALLE/ NGING B'AVIOUR
ALEFORD	A.T.C.+ S.C.U.	112	0	2	2
COPSDALE	A.T.C.	110	6	4	10
ELMHURST	A.T.C.+ S.C.U.	112	3	4	7
PEBBLES	A.T.C.+ S.C.U.	62	2	2	4
OAKWOOD	A.T.C.+ S.C.U.	115	10	6	16

Table 4: Numbers of people with severe learning disabilities and challenging behaviour who receive Social Services day care.

Apart from two people (5.1%), the rest of the clients (94.9%) spend the majority of their time based in the main day Centre, there being no specialised units available for them.

The attendance pattern for this client group is illustrated in Table 5.

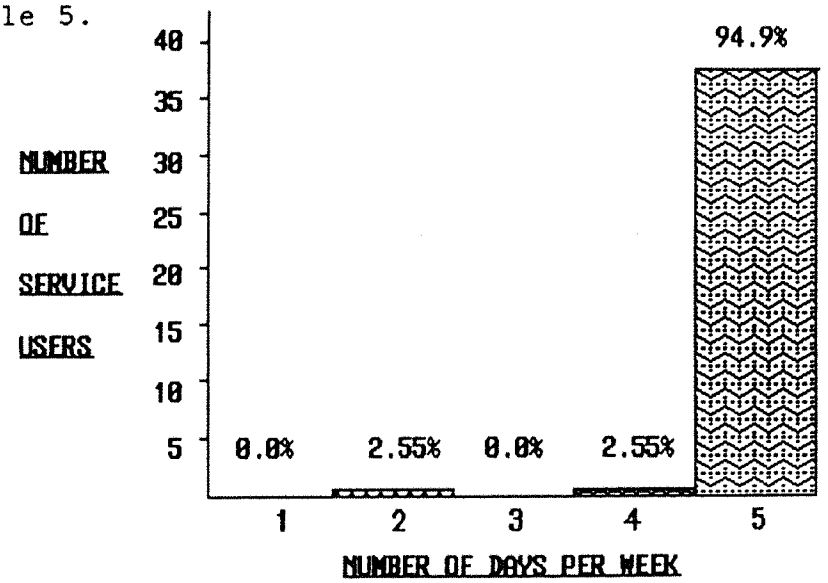


Table 5: Attendance pattern for people with severe learning disabilities and challenging behaviour who receive Social Services day care.

Three Centres (60%) have written aims and objectives for work with this client group and all 5 (100%) provide their clients with individual programmes.

It was hard to specify the staff/client ratio, as the majority of people are included in the main Centres activities, however these ratios are shown in Table 6. (NB. the ratio for 'Oakwood' may be inaccurate as they do not differentiate between staff for the main Centre and the Special Care Unit.)

In addition out of Centre "specialist" staff are also used and are summarised in Table 7.

NAME OF CENTRE	STAFF/CLIENT RATIO
ALEFORD	1 : 9
COPSDALE	1 : 12
ELMHURST	1 : 12
PEBBLES	1 : 10
OAKWOOD	1 : 8

Table 6: Staff/client ratios for people with severe learning disabilities and challenging behaviour who receive Social Services day care.

(X = SERVICE IS USED)

SPECIALIST	A	B	C	D	E	TOTAL CENTRES	%
SPEECH THERAPIST	X		X	X	X	4	80%
MUSIC THERAPIST			X		X	2	40%
ADULT EDUCATION TUTOR	X		X		X	3	60%
COMMUNITY MENTAL HANDICAP TEAM	X		X		X	3	60%
PHYSIO THERAPIST			X	X	X	3	60%
BEHAVIOURAL THERAPIST				X	X	2	40%
OCCUPATIONAL THERAPIST	X		X	X	X	4	80%
PSYCHOLOGIST					X	1	20%
ART THERAPIST			X			1	20%
SOCIAL WORKER	X					1	20%

A=ALEFORD: B=COPSDALE: C=ELMHURST:
D=PEBBLES: E=OAKWOOD:

Table 7: Specialist staff working with people with severe learning disabilities and challenging behaviour who receive Social Services day care.

Summary

The questionnaire was successful in achieving its objective. However it must be acknowledged that although it would seem to be a very thorough overview using explicit definitions, the results must still be considered relatively subjective as they are based on an individual's, or a small staff group's, definition of the service user. Many professionals found completing the questionnaire a very difficult task, particularly in identifying people with profound learning disabilities. The problem the author had envisaged, that service users may be identified by the building they received day care in, rather than by their individual characteristics, did on occasions prove to be true. For example, in one Special Care Unit the Assistant Manager recorded 'x' number of people with profound learning disabilities (i.e. the number of people who attended the Unit), observations by the author led her to believe this was not the case, and once encouraged to assess each person individually the total dropped by half.

By studying and comparing the results of both client groups the following points emerge as significant:-

- All 39 people (100%) with challenging behaviour use day centres specifically for people with learning disabilities. However apart from one Centre which has a 'special needs'

unit there are no specialist facilities within these Centres for them.

- The attendance pattern for the two client groups differs significantly. Only two thirds (66.6%) of the clients with profound learning disabilities attend Centres 5 days a week, whereas the majority (94.9%) of people with challenging behaviour attend full time.

- Individual programmes are available for all Service Users who attend Centres for people with learning disabilities. However where clients attend non specialised Centres no individual programmes are provided.

- In purpose built units for people with profound learning disabilities the staff/client ratio was 1:4, in the remaining Centres the ratio was, on average, 1:10.

- In addition to this emerging picture of clients and resources it has also been possible to compare the provisions for the two different client groups. What has become apparent is that the larger of the two client groups, those with challenging behaviour, have less specialised resources and a lower staff/client ratio even though they have the higher attendance rate.

3. DAY CARE IN THE NORTH EAST DIVISION

The Questionnaire provided the author with a profile of the numbers of people with profound learning disabilities or severe learning disabilities and challenging behaviour and the resources available to them in West Sussex. The next objective was to first look, in greater depth, at one of the divisions of West Sussex - North East, and then examine the services, for people with profound learning disabilities or severe learning disabilities and challenging behaviour, provided by one of the Day Centres in that area.

Location

The Social Services department in West Sussex is divided into three operational divisions, one of which is the North East division (appendix 3, p. 256). This, in turn is divided into four areas. The divisional boundaries are co-terminous with the District Health Authority. The population being 284,000 (May 1992, JD105).

Day and Residential Care

There are 26 establishments in the Division:-

- 9 Homes for Elderly People
- 3 Children's Homes
- 2 Homes for Children with Learning Disabilities

- 5 Hostels for Adults with Learning Disabilities
- 2 Day Centres for Adults with Learning Disabilities
- 1 Day Centre for People with Physical Disabilities
- 2 Multiple Use Centres
- 2 Family Centres

There are also a number of establishments in the Voluntary Sector used by the Division, e.g. National Children's Homes, Ifield Hall, Mencap.

Fieldwork Services

There are 10 teams managed on an Area basis which comprise of Social Workers, Volunteer Co-ordinators, Home Care, etc.

Day Care for People with Profound Learning Disabilities or Severe Learning Disabilities and Challenging Behaviour

The afore-mentioned questionnaire identified only three Centres in the North East division (Table 1, page 78 and Table 4, page 80) which provide a service for people with profound learning disabilities or severe learning disabilities and challenging behaviour:- Copsdale, Elmhurst and Clandon. Further visits to each establishment confirmed that these findings were, indeed, correct in the case of Copsdale and Elmhurst but not in the case of Clandon. The man identified at Clandon was brain damaged as a result of a

road traffic accident in adult life, he did not have profound learning disabilities. For this reason neither he nor the Centre will be included in this study.

It was anticipated that out of the 5 Day Centres in the North East division only Copsdale and Elmhurst would give a positive response - they being the only Centres providing a service exclusively for the client group that was being targeted.

The author's original intention had been to study, in great depth, both these Centres and build up a more detailed picture of the services offered to these two client groups. However during the preparatory work for this research project there was a major change in the management of the two Centres. This necessitated the author focusing her work on just one of the Centres, rather than both of them. The original plan had been to study responses to a different therapy at each Centre. The new approach was to maintain the two therapies, Yoga and Aromatherapy, but to use one base - Elmhurst.

Using Elmhurst Centre as the focus of this study did not change the research rationale as it was not the author's intention to compare the results at the two Centres. In addition Elmhurst Centre has a tradition of teaching Yoga, the therapy that was formerly to be studied at Copsdale, and

the new Manager is not only familiar with this activity but actually knows the Yoga Instructor.

ELMHURST CENTRE - GASLEIGH

Elmhurst is situated in Gasleigh, a growing town which is now completing a period of renaissance with new shops, roads and an accompanying infrastructure being provided. However it still retains the atmosphere of an old market town with the stability and community spirit bred over the years. The surrounding district is rural but includes a number of small towns, villages and hamlets. In recent years there has been a significant increase in the number of people living in the northern part of the area, with its proximity to an airport and access to London by road and rail.

The Centre can be found at the extreme edge of an industrial estate on the north eastern side of Gasleigh. After initially passing large company premises and finally turning into a close of small brightly coloured "lock-up" units, Elmhurst Centre becomes visible. It comprises a large fairly modern single storey, flat roofed building linked by an enclosed glass passageway to a smaller, but conspicuous by its raised red roof, new unit. The Centre stands in approximately two acres of ground. Half an acre, at the back is cultivated for the commercial production of fruit, flower

and vegetables, with green houses, a poly tunnel and various sheds breaking up the landscape. The rest of the ground is laid to grass with neatly kept flower beds, shrubs, garden furniture and paths.

On entering through a door in the link corridor one can turn left into the newer and smaller building - the special Care Unit or right into the main and original Centre built in 1976.

ELMHURST CENTRE - PHILOSOPHY

- To affirm and enhance the dignity, self respect and individuality of people with learning disabilities.
- To make available patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society.
- To minimize the differences in both appearance and behaviour of people with learning disabilities and the environment in which they live and learn.
- To increase the range of skills and experiences and to give choice and opportunity.
- To work with people rather than compensate for them.

ELMHURST CENTRE - STAFFING

1 Manager

2 Assistant Managers

8 Instructors (based in Main Centre) responsible for:-

Art and Craft	Woodwork
Workshop	Extra Support
Community Development	Community Activities
Independent Living Skills	Horticulture

3 Instructors (based in Special Care Unit)

2 Driver/Care Assistants

1 Caretaker

1 Cook

1 Kitchen Assistant

1 Clerical Assistant (part time)

THE MAIN CENTRE.

a.) Building and Environment.

This SCOLA designed building, popular for local authority buildings in the 1960s is typically of part prefabricated, and part brick construction with suspended ceilings and large sliding windows. It comprises of a Foyer/Reception area, containing two offices, staff room and toilets. Comfortable chairs, carpeting, plants and displays of art and craft work take away any preconceived ideas that a visitor may have of entering an 'institution for the disabled'

From this area one can go directly into a large dining room/hall with adjacent kitchen or along a long brightly decorated corridor containing cloakrooms, a domestic science teaching kitchen known at the Centre as the Independent Living Skills unit, a 'communications' room housing computers, typewriters, work stations etc. and a first aid room. At the end of the corridor through a well used door, one enters a large high ceilinged workshop. Although its windows are of fan light type at roof level the overall impression is of a light and airy work place. Passing through the workshop to the right is a woodwork shop full of machinery and stacked high with completed and semi-completed small wooden items.

b.) The Client Group.

People with severe learning disabilities i.e. National Development Team categories I - III (appendix 1 page 251) who live, in the Elmhurst Centre catchment area (appendix 3 page 256) either at home, in Social Services accommodation, or Social Services funded housing . In addition residents of one Social Services hostel in Crawley may also attend Elmhurst Centre.

There are 100 places available. At present there are 69 people on the register, three of whom are part time i.e. attend 3 or less days per week.

The age of the clients range from 18yr. 3mn. to 66yr. 8mn., with the mean being 35yr. 8mn.

The seven people with challenging behaviour, identified in the questionnaire (table 4, page 80) are based in the main Centre and take part in the whole range of activities on offer (page 93/94), they have no separate base area and like all the Trainees have an individual programme drawn up to meet their needs. In some cases, however, their programme may be limited as their behaviour makes it impossible to partake in certain activities. Examples of these behaviours include unpredictable aggressive attacks on any one who may be in the vicinity, abusive and offensive language and uncontrollable self injury, e.g. a man who will lie down on the pavement and bang his head continuously on the ground, attacking anyone who tries to prevent him injuring himself. Very recently an instructor has been given the responsibility of giving extra input to both the clients and staff who work with this group, in all areas of their programmes.

c.) Keyworking and Individual Programme Planning

In order to minimise the institutional nature of the Day Centre each Trainee is allocated a Keyworker. The aim of the keyworker, as stated in Elmhurst Centre's own policy document, is to:-

"...form a partnership between a Trainee and a member of Staff. Together they build up a relationship of mutual trust and respect. The Instructor works with the Trainee on a regular basis to ascertain and monitor the Trainee's individual programme, work out future needs and advocate and liaise with Centre Staff, Carers and other Agencies as necessary."

d.) Activities Provided in the Main Centre.

Each Trainee is based in a work area i.e. light industrial workshop, woodwork shop, horticulture unit, main kitchen and working with the Caretaker. In this way they learn not only work skills but the social skills and responsibilities needed in a working environment.

From these bases each Trainee follows her/his own programme made up of sessional activities selected from three core areas:- independent living skills, further education and leisure/recreational activities. Sessions can last from twenty minutes to all day, according to the activity and the client's need. On completion of the period the Trainee returns to his/her work base.

Activities include; swimming, judo, drama, adult education classes, work experience voluntary work, cooking, budgeting, art and craft, music and rock climbing.
Wherever feasible the activities take place in the local community, this is in line with the Centres commitment to the philosophy of Social Role Valorisation. For example

drama takes place in Gasleigh Arts Centre and further education classes at the local adult education Centre. In all approximately 33% of the Trainees time is spent on activities in the local community.

In addition to Centre instructors organising these activities, sessional tutors are hired where required e.g. judo coach, music teacher, and a vast range of therapists and other professionals work with clients and advise staff, e.g. occupational therapists, Community Team for People with Learning Disabilities.

SPECIAL CARE UNIT

a.) Aims

- To discover the Trainees strengths and needs.
- To provide a way of developing their abilities.
- To teach them through their senses and experiences using social, leisure and educational activities.
- Whilst Trainees are in the unit to provide for their physical needs.

b.) Building and Environment

On entering this four year old unit one is bombarded with the feelings of warmth, intimacy and yet spaciousness. This

is perhaps due to high but sloping ceilings containing soft lighting, carpeting practically throughout and soft background music playing.

The building contains an assortment of rooms radiating from a mainly glass office/workstation in the centre. There are two lounges, one containing more functional items such as tables, chairs, book shelves and educational equipment, the other with a leaf chair, swinging gently, coloured mattresses for relaxation and a vibro-massage bed. Both these lounges open on to a patio and the garden. Following round from the lounges is a small room, named the noise/quiet room, which is used for sensory stimulation, individual work etc. In contrast to these rooms the wet area/changing rooms are functional and clinical, they contain a spa bath, and the most upto date aids for looking after client's personal hygiene.

c.) The Client Group

This unit caters for 12 people daily who -

> "...are profoundly and severely mentally handicapped adults who may have additional physical disabilities or behavioural disorders" (West Sussex County Council 1987).

At present there are 10 people on the register - 5 women and 5 men - three of whom attend part time, i.e. 3 days or less a week. Seven clients live at home, two are the

responsibility of the health authority and one lives in a social services hostel.
The mean age is 29yr. 10mn. with the oldest person being 49yr. 10mn. and the youngest 20yr. 3mn.

Using the author's definition there are eight people with profound learning disabilities based in the Special Care Unit.

d.) Keyworking and Individual Programme Planning

As c.) (page 92)

e.) Activities provided by the Special Care Unit.

Each Trainee has an individual programme aimed at meeting their individual needs. To this end each Trainee is assessed using a variety of methods which include observation, checklists, likes/dislikes and personal histories. Centre staff, parents/carers and other professionals all contribute, but because of the severity of the clients disabilities they have very little involvement in this process.

Activities on each person's programme tend to fall into three main categories; (i) self help skills e.g. feeding and mobility training, (ii) cognitive development e.g. sensory

stimulation, communication, (iii) recreation and leisure e.g. horse riding, trampolining etc.

THE DEVELOPMENT OF NEW ACTIVITIES/SERVICES FOR PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR

With the closure of Forest hospital, a large 'mental handicap' institution in Gasleigh, in the late 1980s/early 1990s many people with profound learning disabilities or severe learning disabilities and challenging behaviour were transferred to Elmhurst Centre for their Day Care.

This necessitated the Management team at Elmhurst looking for additional activities and projects, e.g. intensive support workers, communication workshops, to meet needs not previously encountered within the Centre.

One of the projects being explored by the Centre Staff was the use of Complementary Therapies e.g. music therapy, relaxation, hydrotherapy and aromatherapy and massage. It was felt that these activities were beneficial as an addition to the traditional skills/task orientated ethos of the Day Centre. They were chosen for the following reasons:-

- to produce feelings of calmness and provide relief from tension.

- their holistic nature closely paralleled the Centre's philosophy.
- to increase feelings of self awareness and self esteem.

Initially the therapies were introduced to people based in the Special Care Unit. However in a relatively short time people with severe learning disabilities and challenging behaviour were also included in the programmes.

It was in this context that the author developed a project to explore how four people, two with profound learning disabilities and two with severe learning disabilities and challenging behaviour, responded to complementary therapies. The project, divided into a preliminary study and a main study, evaluated service users responses to a new area of Day Care development.

The benefits of the two complementary therapies chosen, Aromatherapy and Massage and Yoga, have been discussed at length previously (pages 3, 42, 54-55) however their inclusion in the project, as opposed to other complementary therapies in use at Elmhurst, e.g. hydrotherapy, was a pragmatic decision made jointly by the author and the Centre Manager. The only criteria used was that they were already established within the Day Centre.

The nature of the research - i.e. that it was not a

contrived situation, rather, part of a persons individual programme, necessitated that the staff group should select the participants from the group previously identified as having either profound learning disabilities or severe learning disabilities and challenging behaviour. The criteria being that the Service User would benefit from the complementary therapy as part of their total individual programme.

Singling out individuals to participate in the project was an example of one of the 'ethical dilemmas', referred to at the beginning of this chapter, that the author was constantly considering. Campbell and Kimmel (1985) suggest that those receiving a 'treatment' are ascertained as the most needy. It is a method that on the one hand eliminates the need for a comparison group who would consequently be disadvantaged by not being 'treated', but on the other hand it must be recognised that it is likely there may be other clients who would benefit from the intervention if more resources were available.

Summary

The study of Elmhurst Centre provided a detailed analysis of one resource which supported people with profound learning disabilities or severe learning disabilities and challenging behaviour in West Sussex. In addition it concluded Phase I

of the research aims by examining the Centre in the divisional context, and 'set the scene' in which the practical intervention took place. Phase II, the introduction of yoga or aromatherapy and massage sessions to four service users is described in the following chapters.

CHAPTER 3

PRACTICAL INTERVENTION - METHODOLOGY

The methodology for introducing the four participants to either yoga or aromatherapy is described in this chapter. Firstly the theoretical basis will be examined and then an outline of the design and the personnel will be given. The objectives and the procedure for collecting and analysing the data will then be explained.

INTRODUCTION

The methodology for Phase II (page 5) was predominantly qualitative, using the case study as the principal approach. A case study has been described (Yin, 1989) as a real life enquiry that investigates a contemporary phenomenon within its real life context.

Using this definition the aim of the intervention can be analysed thus:-

real life enquiry that investigates a contemporary phenomenon -----> exploring how people with profound learning disabilities or challenging behaviour respond to complementary therapies

within its real life context. ----->within a Day Care setting.

This method of enquiry is particularly useful, writes Yin (1989), when the researcher has little control over events. It allows an investigation to retain the holistic characteristics of every day life. This attribute is decidedly important when working with people who have profound learning disabilities or severe learning disabilities and challenging behaviour in a Day Centre. Outside variables such as home life or medication are forever changing without the researcher always being aware. The holistic nature of a case study is also in keeping with the principle of Normalisation (Wolfensberger, 1972) and the ethos of the research project.

Case studies, says Yin (1989), are useful in situations in which the intervention being evaluated has no clear single set of outcomes. In the case of a new therapy, for example aromatherapy, being introduced into a person's already highly structured programme it was impossible to predict what the outcome would be.

In order to introduce the four participants, two of whom had profound learning disabilities and two had severe learning disabilities and challenging behaviour, to the complementary therapies it was necessary to divide this case study into

modules - a preliminary study and a main study. The preliminary study involved preparatory work and gaining baseline information whilst the main study concentrated on recording and evaluating the participant's responses to the therapies.

THE DESIGN

The structure of the two studies consciously adopted a common design. This was to enable the participants, during the preliminary study, to become familiar with the model that was to be used when the therapies were introduced (main study) and to give baseline information, in similar conditions, which could be used for comparative purposes.

During the course of each study, participants took part in two consecutive 15 minute sessions (fig. 1, p. 104) each week. The first session during the preliminary study was a traditional, constructive activity, e.g. learning a new skill. This session was consequently substituted for the therapy during the main study. The second session remained constant throughout both studies - a social/leisure activity, e.g. having a cup of tea and a chat.

fig. 1.

	Preliminary Study	Main Study
Session 1 (15 mins)	Constructive Activity	Therapy
Session 2 (15 mins)	Social/Leisure Activity	Social/Leisure Activity

All activities were chosen by the participant (if able) and the appropriate Keyworker as relevant to the participant's individual programme. The nature of the activity will be discussed, in relation to each participant, in Chapter 4 and 5.

In order to give maximum protection to the participants during the sessions the following safeguards were built in:-

a) The sessions were held in a familiar setting in order to reduce any anxiety or distress.

b) The timing of the sessions was kept short (max. 15mins.) in order that participants did not lose concentration, were not bored or tired.

c) By devising an individualised assessment (page 113-115) it would immediately become apparent if a participant was unhappy, anxious or distressed. In addition the involvement of the keyworker who knew the client well ensured that no physical or mental harm was unintentionally incurred.

d) As the Centre was already using the chosen therapies they had obviously already decided that it was beneficial and a positive asset to their programme. In the same way the

therapists had already been selected and approved by the Manager.

e) If at any time the Centre staff, the therapists, service user or carer felt that to continue the research project would have been detrimental or had a negative effect on the client it would have been stopped immediately.

f) Information concerning the research project was readily available and communicated to all participants, centre staff and significant others.

These safeguards were in line with the Social Research Association Ethical Guidelines:-

> "The social researcher should try to minimise disturbances both to the subjects themselves and to the subjects' relationships with their environment. Social Researchers should help subjects protect their own interests by giving them prior information about the consequences of participating." (p. 91)

PERSONNEL

1. Clients

The two participants, chosen by the staff, with profound learning disabilities were Melanie and Luke. Marcus and Ann were the participants selected from people who had severe learning disabilities and challenging behaviour. Profiles of each client were drawn up using:-

-the researcher's own observations during the course of the study,

-information from clients, keyworkers and staff,

-information contained in participant's personal file.

One participant from each client group took part in each therapy, i.e. Melanie and Marcus - yoga, Luke and Ann - aromatherapy.

The four people chosen were intellectually unable to give informed consent. To obtain consent from a person who cannot grasp the entire situation would be mere tokenism. The British Psychological Society suggest:-

> "Where real consent cannot be obtained from adults with impairments in understanding or communicating, wherever possible the investigator should consult a person well placed to appreciate the participants reaction, such as a member of the person's family, and must obtain the disinterested approval of the research from independent advisors." (The Psychologist, 1990, p. 270)

This, therefore, put an added responsibility on the researcher, so in addition to the Centre's consent she approached each person's carers, firstly by letter, followed up by a home visit to, not only, get this additional consent but also to explain the objectives of the project. When asking for consent the researcher also checked whether any areas such as religion or culture would be affronted by participation in the project. In addition other professionals/therapists were consulted to establish any

pre-existing medical conditions which might make this intervention harmful.

2. Observer (the author).

By observing the majority of the sessions herself the following outcomes were achieved:-

i. The author was be able to get to know the client in depth and thus be able to become part of "his/her world"

ii. When the research on the therapies began, being a familiar person, the observer's presence did not effect the participants responses. This may not have been necessary as Murphy cited in Hogg and Raynes (1987, p. 202) states:-

> "...what is less likely is that people who are profoundly or severely handicapped will alter their own behaviour in any predictable way, as a result of an observer's presence."

iii. There was a measure of consistency in the work with all four clients, particularly as the Keyworkers were different for each client.

iv. The Keyworkers, therapists and the author were able to get to know and trust each other; they were also able to practice their recording and observation skills together.

The initial plan was for the observer to be present at all sessions. This did not, in fact, transpire. The Aromatherapist requested that the observer, after having set up the video camera, left, returning at the end of the

session. In the therapist's experience she had found that an onlooker distracted the client and put a strain on the relationship between the client and therapist. Similarly one of the keyworkers felt that the observer's presence may inhibit and distress the participant during the Social/Leisure activity.

Recognising the importance of respecting the participants' feelings the observer was only too happy to accede to these requests. The observer, in these two cases, witnessed the sessions vicariously - i.e. through video recordings.

In small scale research such as this study, the researcher is the main instrument of the research process and it is therefore essential that the researcher's own actions activities and influences, as well as those of the people participating, are understood. The researcher needs to develop the skills of self-awareness and self-criticism and become alive to the influence that professional experience has, in any statements s/he may make.

3. Keyworkers

Each participant had a designated keyworker (for role of keyworker see page 92) who worked with them during the constructive activity (preliminary study) and the social/leisure activity (preliminary and main studies).

Only two participants' keyworkers remained constant throughout the course of the practical intervention, changes being made due to staff leaving and staff being redeployed within the Centre.

4. Therapists

The Yoga Instructor, Ruth, works part-time at another Social Services Day Centre for people with learning disabilities in the North East division of West Sussex, where she specialises in teaching language and communication skills as well as running Yoga classes. Ruth is a slim, fair haired Scots woman who is sincere and forthright in what she says and has boundless energy. She has attended the YOU & ME yoga (page 122) training course run by Maria Gunstone and has taught this method for two years. Ruth also belongs to a Yoga group in her home town, exercising once a week with friends.

Sandy, the Aromatherapist, always appeared calm and quietly self-assured, she greeted everyone warmly and enthusiastically, appearing always to be in a good humour. She dressed in leggings and loose T-shirts, for ease of movement, and, at the commencement of a session, always kicked off her shoes.

Sandy has been practising Aromatherapy and Massage for ten

years having obtained the ITEC Diploma in Aromatherapy and the Raworth Diploma in Holistic Aromatherapy.

PRELIMINARY STUDY

The Constructive Activity and Social/leisure Activity sessions during the Preliminary Study had the following objectives:-

- To record and monitor the participants' communication patterns, in order to gain an understanding of their responses in terms of positive and negative emotions.
- To establish baseline recordings of each persons most common expressions and actions.
- To obtain data that could be used for comparison within the Preliminary Study, between the Preliminary and Main Study and between both Studies and the person's normal activities.
- To counteract any argument that what might be being observed in the main study is a placebo effect, i.e. if people with profound learning disabilities or severe learning disabilities and challenging behaviour were given 1 to 1 attention, whatever the activity, there would be improvements.

The starting point of the preliminary study was to consider

methods of recording, assessing and measuring strengths, needs, achievements and changes.

Traditional Assessment Practices.

In the past much research with people who have profound learning disabilities or severe learning disabilities and challenging behaviour has taken a scientific approach to answering the questions - Was there a change in behaviour? and Was our intervention responsible for the change? One of the ways this was done was by Assessment, i.e. monitoring and measuring behaviour and achievements. Hogg and Raynes (1987) identified four broad classes of assessment.

- 1. Norm Referenced Tests - their main function being to discover how well an individual performs in relation to other people drawn from the same class of individual, i.e. a global score for major domains of development, e.g. IQ. tests.

- 2. Assessment of Adaptive Behaviour - a measurement of social competence or functional classification, covering such areas as self feeding or personal hygiene e.g. Copewell.

- 3. Criterion Referenced Assessments - items to be scored represent achievements which are of importance in the

individual's adjustment to his or her environment or which reflect the outcome of teaching or training. It does not compare individuals but is sequential - one step is achieved before moving on to the next, e.g. Portage.

- 4. Behavioural Observation - this method records and monitors behaviour in everyday settings. Consequently it goes beyond checklists and is an essentially novel assessment. It generally involves counting and recording the frequency and/or duration of defined behaviours.

The first three of these four models emphasise a clinical approach, looking at how a particular part of a person functions, or how one person's development compares to another. The tendency is to be analytical, mechanical and skills orientated, which has the advantage of standardisation and scientific accuracy. Behavioural Observation deviates from this, being needs led, although traditionally such assessments have concentrated on specific behaviours rather than the whole person.

The Need For A New Approach

The author felt that the above models were not adequate or appropriate to the nature of the practical intervention. Firstly, because scientific assessment inadvertently perpetuates the power imbalance between researcher and

participant, not only are deviant groups in a 'no win' situation being a group generally devalued by society but in addition they are 'subjects' for research. This disparity also goes against one of the aims of the principle of Normalisation (Wolfensberger 1972), whereby the dignity of the individual is enhanced and any negative attributes diminished.

Secondly, the author wanted to adopt an approach of looking at the whole person - their physical, emotional, intellectual and spiritual make up. It was important to emphasise each client's individuality, their strengths, needs, likes and dislikes. The author hoped to become part of 'their world' and this required a much broader perspective than the limited design of standardised checklists.

Therefore before starting any practical work with the participants it was necessary to devise a range of approaches that would record the required data effectively, i.e. an individualised assessment.

- Forms

After consulting the speech and language therapist who visits the Centre and looking at relevant communication assessments the author developed two forms to record the participants' responses.

Form A (fig 2) had significant parts of the body as headings (Coupe et al. 1987), with space for notes to be written beside each. Its purpose being to record individually distinctive movements or expressions e.g. blowing 'raspberries', pushing glasses into position or legs crossed.

Form B (fig 3) was designed to record responses or reactions that express feelings or emotions. Eighteen emotions were identified, set out in pairs of opposites, e.g. like/dislike, excited/apathetic, with spaces beside each for the observers comments.

- Notes from Keyworkers and Observer

Forms which, apart from the participant's name and session number, were otherwise blank, were produced by the author. The information she required to be filled in was explained to the Keyworkers as:-

- Significant events for the participant prior to the session.
- Comments on "how the session went"
- Observations on the participant's mood/frame of mind.
- Notes on the participant's views of the session.

- Video Camera

The author borrowed a camera and tripod on which to record

each session. The Participant and Keyworker were asked whether they wanted the observer present and except for one 'social activity' she was invited to all sessions. From the research project point of view this was most beneficial as the observer was able to see the activities at first hand and identify with the whole environment and atmosphere. Additionally she could also reposition the camera as necessary.

fig. 2. - Form A.

NAME: _____ SESSION: _____

HEAD

FACE

MOUTH

EYES

HANDS

ARMS

LEGS

BODY

VOCALISATION

fig. 3.- Form B.

NAME: _____ SESSION: _____

LIKE	DISLIKE
AMUSEMENT	BOREDOM
ALERT	LISTLESS
EXCITED	APATHETIC
CALM	DISTRESSED
RELAXED	TENSE
HAPPY	SAD
ENJOYMENT	DISPLEASURE
CERTAIN/SURE	PUZZLED

Data Collection

Over the course of six months (May 1992 - November 1992) the four participants took part in the weekly sessions. In total 53 sessions were documented.

Data was collected from:-

i. Video recordings of each session. (The participants were given the opportunity of viewing their own sessions each week.)

ii. Written reports completed after each session by the keyworker using some or all of the criteria (page 114) agreed prior to the intervention commencing. Inevitably, due to pressures of work the keyworker did not always have time to do this, resulting in each session not consistently having all types of data.

iii. Written report completed after each session by the observer.

iv. Parents, Carers and members of the Staff team were asked, at regular intervals, for their comments and observations.

The observer had intended writing notes during the sessions but after a very short while realised that she missed too much when concentrating on recording. On reflection she also felt that note taking may have inhibited either, or both, the Service User and keyworker/therapist. Ann frequently

included the observer in the conversation and process of the session which confirmed the observer's decision not to write during the activity.

Analysis of Data

Bearing in mind the qualitative nature of this research, the analysis of the data collected deliberately endorsed an approach that mirrors the holistic nature of the intervention.

Each participant's responses to all the sessions were reviewed systematically in the following manner:

a) Individual sessions

- The video was evaluated a session at a time. By using the remote control pause facility the tape was stopped at regular intervals, e.g. every 10 secs. or if something of significance was seen or heard, to record, in note form, the responses and content of each session,

- The video evaluation notes and the keyworker's and observer's reports containing observations and comments were recorded onto form A and form B.

(Appendix 4, p. 257) contains an example of how this data

was collected for an individual session)

b) On completion of the Preliminary Study

- Using the video evaluation notes and the therapist's and keyworker's reports a chart (fig. 4.) was drawn up to show the most frequent physical (including verbal/vocal) responses. Each action or expression had to occur more than once or for a substantial amount of time (approx. 10 secs) for it to be included.

fig. 4. -

Response	Sessions								
	1a	1b	2a	2b	3a	3b	4a	4b	--->
Scratches ear, nose	x	x	x		x	x	x		
Smiles, laughs	x	x	x	x	x	x	x	x	
Falls asleep			x				x		

The percentages of occurrence of each response, during the preliminary study, were worked out and the most common expressions and actions were listed, e.g. Luke scratched his ear, nose or eye in 13 out of 15 sessions = 86.6%.

- Additional/significant findings were noted, e.g.

> "The ferocity of Luke's rocking during the social/leisure activity did not always correspond to the tempo of the music."

(These responses are detailed for each participant on the following pages, Ann p. 135 - 138, Luke p. 160 - 162, Marcus p. 182 - 185, Melanie p. 210 - 212).

- All form B's for each person were summarised onto one sheet, (Appendix 5, p. 268 contains an example of how this information on all sessions was collated for one individual participant)

MAIN STUDY

The aim of this part of the project was to engage the participants in the two therapies - Yoga and Aromatherapy and Massage. By recording and analysing their responses the author was able to note changes, both positive and negative, within the actual session and compare these with each person's responses in other activities. There was no intention to look at lasting, overall change but rather to ascertain the advantages and disadvantages of the two therapies as new activities on offer, to people with profound learning disabilities or severe learning disabilities and challenging behaviour, at Elmhurst.

Yoga

The word yoga is from the Sanskrit for 'union', and has the same root as the English 'yoke'. It is based on the theory of union of the self with higher consciousness (Inglis and West, 1983).

There are many types of yoga e.g. Bhakti yoga which is for the religious devotee, Raja yoga, the yoga of the mind, which aims at controlling negative feelings such as doubt anger and fear. However most common in the Western world and the method used in this research project is Hatha yoga, (in Sanskrit 'ha' means sun and 'tha' moon, suggesting the uniting of two opposites), which is a physical activity. It is primarily the performance of asanas - physical postures - which produce "profound relaxation and tranquillity of mind" (Martin, 1989).

The yoga used in this research project is a system using sound, colour and 'Whole Body Movement' named YOU & ME devised by Maria Gunstone for people with learning disabilities. Its aim is to tone and relax the whole of the body, improve self-awareness and develop particular areas that need to be strengthened. This is achieved by introducing the participants to different postures and breathing techniques (Gunstone, 1992).

Aromatherapy

> "Aromatherapy is the use of essential plant oils from a single botanical source. These are mainly used through massage, inhalation and baths to promote health and relaxation." (Chappell 1991, p.20)

The medicinal properties of plant oils have been recognised for thousands of years. The ancient Greeks, Persians and

Egyptians all employed them. It is, however, only recently that health professionals have begun to take their potential seriously (Tattam, 1992, Burns and Blaney, 1994, Armstrong, 1991).

The most popular way of applying oils, and the method used in this research project, is through massage. Massage is a form of non-verbal communication. It assists people to become aware of themselves and others. Massage is known to have emotionally releasing effects on people who have difficulty opening up (The S.E.E.D. Institute 1992).

The main aims of Aromatherapy and Massage at Elmhurst are to relieve tension, provide appropriate physical contact and give a person the feeling of complete relaxation.

As each therapy was currently practised in the Centre the ethical issues had already been considered and therefore no further consideration was considered necessary by the author. She was not implementing a contemporary method but researching a fairly new initiative already in practice and therefore considered beneficial, by the Centre, to the Service Users.

Data Collection

Over the course of five months (January 1993 - May 1993) the participants took part in the weekly sessions. In total 50 sessions were documented.

Data was collected from:-

i. Video recordings of each session. (The participants were given the opportunity of viewing their own sessions each week.)

ii. Written reports completed after each session by the therapist and keyworker using some or all of the criteria (page 114) agreed prior to the intervention commencing. Inevitably, due to pressures of work the keyworker did not always have time to do this, resulting in each session not consistently having all types of data.

iii. Written report completed after each session by the observer.

iv. Parents, Carers and members of the Staff team were asked, at regular intervals, for their comments and observations.

The observer did not write notes during the sessions for reasons explained previously (preliminary study - data collection, p. 118)

Analysis of Data

Each participant's responses were reviewed individually and are presented in tabular and descriptive formats in chapters four and five.

- At the end of the Main Study the author evaluated the video recordings a session at a time using the method outlined in Preliminary Study (page 119). Appendix 6, p. 269 gives an example of a video analysis of one typical session.

The summaries of the participants' characteristically distinctive behaviours, from the Preliminary study (Appendix 5, p. 268) were used to decode much of the non-verbal communication and vocalisation/speech contained in the video notes. However whilst recognising the importance of the summaries for interpreting and understanding participant's responses the author was conscious that using only the summaries would be clinical and limiting. They had to be used as a tool in conjunction with other qualitative data.

- Using the therapist's and keyworker's reports and the video analysis notes a chart (fig. 4, p. 120) was drawn up to show the most frequent physical (including verbal/vocal) responses. Each action or expression had to occur more than once or for a substantial amount of time (approx. 10secs)

for it to be included. (Appendix 6, p. 269 gives an example of the above mentioned data.)

- The percentages of occurrence of each response during the main study, were worked out and the most common expressions and actions were listed and interpreted (main text, chapters 4 and 5) using the information gleaned during the preliminary study.

- The video notes, reports from the keyworkers and therapists, information on the environment and observations of participants behaviour prior to the session (appendix 6, p. 269) were used to produce;
  - a qualitative vignette of each session with a summary of key points (one session for each participant is produced as an example in the main text)
  - a summary and discussion of the most common expressions and actions of each participant which were compared with the Preliminary study and the person's behaviour within the Centre.
  - a summary and discussion of participants' progress in the therapy sessions

(p. 142-154, 165-177, 190-204, 215-229)

SUMMARY

The methodology outlined in this chapter was created to introduce the participants to the complementary therapies. It described a model consisting of two studies;
- a preliminary study which developed methods to gather baseline recordings of the participants' most common expressions, actions, and responses
- a Main study structured to record the participants' responses to the intervention.

In order to achieve this, new and untried methods were devised. This approach could be described as a 'developing methodology', with each phase giving construction to the next. In this way the exploration gradually unfolded to elucidate the participants' responses to yoga or aromatherapy.

It was essentially a qualitative design which was relatively unorthodox in that it took the unusual stance, for work with people who have learning disabilities, of being non-behaviourist, i.e. the people were central to the process not their behaviour. This attitude/philosophy determined the methodology and shaped it accordingly.

Using this methodology the participants' responses were recorded over a period of eleven months (six months -

preliminary study, five months - main study). A total of 103 sessions were recorded and evaluated. The findings, based on an analysis of this data as outlined in this chapter, are detailed in the following two chapters.

CHAPTER 4

AROMATHERAPY INTERVENTION - FINDINGS

Ann's and Luke's individual responses to Aromatherapy are detailed in this chapter (chapter 5 describes Marcus' and Melanie's responses to Yoga) under the following headings:

- Personal Profile
- The Preliminary Study
- The Main Study.

The personal profile gives an overview of the participant's background, physical characteristics, abilities and disabilities and present life style. The Preliminary Study describes the activities chosen, the keyworker and the setting before presenting the findings in tabular form. Finally any significant findings are discussed. The Main Study describes the process of each session and illustrates each participant's response with :-

- a vignette of one session
- tables to show, compare and interpret the most common expressions and actions of each participant and discussion of the key findings.
- a summary of progress in the therapy sessions

ANN

PERSONAL PROFILE

Ann is 33 years old (D.O.B. 24-6-60), about five foot in height and has a mass of dark unruly hair. She always wears trousers with either ankle boots or trainers and whatever the weather has a thick jumper with her. Her handbag is also an essential part of Ann's attire, being worn diagonally across her body, and very rarely being removed even if its position is causing her discomfort or inconvenience. Watching Ann walk from room to room reveals her making rude gestures or swearing under her breath at any one she passes and then quietly laughing to herself.

As well as a severe learning disability Ann has challenging behaviour which is characterised by unpredictable bouts of swearing, spitting and extreme methods of gaining attention. For example, on one occasion, she threw stones through the window of the Manager's office when she felt that someone else was getting too much attention.

Ann's parents became aware of her disability when she was two years old. This heightened the already tense situation at home, caused by her mother finding it harder to cope after the birth of each successive child (Ann has 4 sisters and 2 brothers). These problems necessitated the involvement of the NSPCC. in

the supervision of the family. Eventually, when Ann was 5 years old her father left the family home.

In 1968 Ann, aged 8 years, was admitted to a large 'mental handicap' institution on the outskirts of Gasleigh. Whilst resident, there were periods when her mother only visited her on the annual 'fete' day and other times of quite intense and concentrated family interaction. Staff felt these extremes were caused by Ann's mother being unable to balance her love for Ann with her guilt and dislike of Ann living in such a large and awesome hospital. Little is recorded of Ann's progress, until the closure of the hospital, when Ann was transferred to the responsibility of West Sussex County Council's Social Services department.

At this time (1990) Ann moved to Canford, a purpose built hostel for 24 adults of all ages who have learning disabilities. From there Ann went daily to Elmhurst for her Day Care. With input from her keyworkers, Centre and Hostel staff, a speech therapist and an art therapist a clearer picture of Ann's strengths, needs, likes and dislikes began to emerge. A speech and language therapist assessed Ann's level of comprehension at a level of 3 words (Derbyshire language scheme) and her expressive language as fair; this she complements with natural gesture e.g. when Ann is talking about her dislike of one of her peers she will shake her fist and mime wringing their neck. Ann's eye contact is good initially,

but she constantly needs her attention refocussing. Her speech is typified by constant questioning and periods of silence/thought. When chatting with Ann her preferred topics of conversation are the pop group "Abba", her most recent episodes of conflict, imaginary outings with a favourite member of staff or her experiences at Judo.

Ann enjoys the majority of physical activities, having tried and liked Judo, rock climbing, swimming, keepfit, trampolining and Yoga. With much encouragement and individual attention Ann will take part in more sedentary occupations: art, simple contract work, basic cooking etc. However Ann can be stubborn and disruptive doing these activities, banging the table loudly with her fist, spitting and swearing, if not closely supervised.

Ann refers to a select few, both men and women, as her "boyfriends", these are however often one sided relationships with her appearing not to have any close companions. Within the Day Care setting Ann seems always to have an infatuation with a member of staff who she constantly talks about, calling them "a monkey" and fantasising about trips she imagines they have been on together. In addition this person is also the most frequent recipient of Ann's challenging behaviour.

At home (the hostel) Ann makes no attempt to personalise her room. There is nothing on her chests of drawers, table etc., no

pictures or posters on the walls, and plants and ornaments that have been given to her, as presents, are either discarded or put away in cupboards. In addition when Ann goes to bed at night she is very reluctant to change into night attire, keeps her handbag under her pillow and refuses to shut her bedroom door. Her Keyworker is sure this behaviour pattern is a reflection of her life in hospital where people were not encouraged to express their individuality, their personal belongings were regularly stolen or defaced and there was a constant fear of being harmed by other patients.

THE PRELIMINARY STUDY

Constructive Activity

The activity chosen for the first session was to match and name colours and shapes. The reason for this was twofold, firstly to help Ann with the contract work in the workshop which involves sorting and colour identification of components and secondly to enable Ann to identify and choose the clothes she wears and buys.

After the fifth session Ann's keyworker, Jackie, decided that Ann was not interested enough in the activity and changed its focus to looking at time - identifying times of the day when various activities took place.

Social/Leisure Activity

The second part of the session was for Ann to make and have a drink with Jackie. This would be seen by Ann as a special treat as she would be receiving individual attention that time constraints would not normally allow.

The Keyworker

Ann's keyworker at the day centre - Jackie - was excited by the project and hoped it would give her a greater insight into 'Ann's world'. Ann sees Jackie in two different roles. Firstly as a Keyworker (for role of Keyworker see page 92) and secondly as the Instructor who arranges her leisure activities in the Community, e.g. Judo, swimming.

In her Keyworking role Jackie is treated by Ann as a very special person. Ann displays a wide range of emotions/responses to Jackie which very few other staff experience. For example Ann will alternatively spit at Jackie or want to go out with her socially. She will appear embarrassed in Jackie's company or 'hide' from her.

Setting

It was decided to use the staff room, which is frequently used for small group or individual work, for the first activity and

the Independent Living Skill's (ILS's) kitchen for the second. However only the first two sessions took place in the staff room with Session 4 taking place in the Art room and the remaining sessions being held in the dining area of the ILS's kitchen. This final change of venue was at the Manager's request as the staff room was needed for another group activity, all involved were happy to comply with this request.

Results

On completion of the eight sessions the data was summarised to produce tables, to show Ann's most common expressions and actions (Table 8, below) and a summary of Ann's responses or reactions that express feelings or emotions - form B (Table 9 page 136).
The two activities each week i.e. constructive activity session and social/leisure activity are counted separately, therefore during eight weeks there will be 16 sessions recorded - (this will apply to each participant's results).

Session 4 is not included in these tables as it was taken by a different member of staff

Table 8. Ann's Most Common Expressions and Actions

In 12 out of 14 sessions - 85.7%

- Hand covers face.
- Smiles/Grins.
- Elbows on table, head resting on hands.

In 8 out of 14 sessions - 57.1%

- Talks about pains, parts of the body that "hurt".
- Keeps handbag across shoulders.
- Talks about 'banging', swearing, hitting etc.

In 7 out of 14 sessions - 50%

- Bangs chest in imitation of Tarzan.
- Initiates conversations.
- Is unable to accept praise.
- Relaxed posture.

Table 9. Summary of Ann's Responses or Reactions that Express Feelings or Emotions (form B)

Like Expresses verbally Tarzan imitation	Dislike Expresses verbally Emphatic shake of head
Amusement Small smile, chuckle	Boredom Walks out of room Talks about aches and pains Changes subject Looks away
Alert Eye contact Concentrates on task Looks up at external noises	Listless
Excited Tarzan imitation Raises voice Uses gestures to emphasise words	Apathetic
Calm Body posture relaxed	Distressed Sucks thumb Rubs body part that hurts Changes the subject Covers face with hands
Relaxed Body relaxed Leans back in chair Arms unfold Puts handbag down	Tense Arms folded Won't let go of handbag Touches possessions frequently

Doesn't mention aches and pains
Enjoys small amount of physical contact

Happy
Smiles/laughs
Rubs hands together

Enjoyment
Expresses verbally
Initiates conversation

Certain/Sure
Points to self or object to emphasise speech
Works with confidence e.g. puts pieces of puzzle in correct spaces firmly and quickly

Sad
Talks about aches and pains
Shoulders hunched, head down

Displeasure
Expresses verbally
Bangs table with elbow or hands
Shake her fist
Sticks two fingers up and swears
Covers face with hands

Puzzled/Embarrassed
Shrugs shoulders
Hands cover face
No reaction to praise?

Additional Findings

a.) There was no clear progression of achievement in consecutive constructive activity sessions.

b.) The two activities showed contrasting responses. In the constructive activity session Ann regularly appeared bored or distressed - e.g. talked about aches and pains, whilst in the second session she was relaxed - e.g. body posture relaxed.

c.) Although Ann consistently talked about 'banging' and swearing (57.1%) there was no occurrence of challenging behaviour during the sessions.

d.) Session 4 was taken by Janet, another Instructor well known to Ann. The responses in this session were very different - Ann

did not talk about her aches and pains, she didn't hold her head and she didn't talk about 'banging' and swearing, i.e. some of the most common expressions in all the other sessions. It was felt by Jackie and Janet that this was probably due to Ann's unfamiliarity with Janet, i.e. She did not feel secure enough to express feelings, emotions etc.

e.) In all the constructive activity sessions Ann was unable to accept praise. She either covered her face in embarrassment or took no notice.

f.) Ann was unable to say what made her happy or sad. She could however be certain to what or who she liked or disliked.

g.) Two expressions/actions were not common to both activity sessions but scored highly within that activity - Changes the subject, 50%, (constructive activity) - Relaxed posture, 85.7%, (social/leisure activity).

THE MAIN STUDY

a.) Therapeutic Intervention - Aromatherapy

Ann had started having sessions with Sandy for three weeks prior to the main study commencing, in order for them to get to know each other and for Ann to be able to make an informed choice as to whether she wanted to participate in the research project. Her enjoyment and assent were obvious by her actions

after the first session - she ran to Sandy on seeing her arrive the following week and said "Me today".

Ann's arrival at the session was always strident, she could normally be heard shouting and swearing at people she passed on the way to the session. She hurriedly came in the room talking to Sandy and the observer while at the same time removing her handbag, boots, socks, jumper and bra. These she positioned tidily on the bench before lying down ready for Sandy to cover her with a towel. She then dismissed the observer saying "see you later" and turned her attention to Sandy.

The observer positioned, focused and started the camera once Ann had laid down, this was in order to preserve Ann's dignity when she was undressing. The video analysis therefore starts at this point, however the therapist's and observer's reports detail any significant points prior to the massage beginning.

Sandy warmed the oil in her hands before applying it and knelt beside Ann to begin the massage. Sandy told Ann which part of her body she intended treating and asked if she was in agreement. As a rule Ann consented with the proviso "do my back later".

Moving round the body quietly, sensing Ann's mood Sandy either, talked softly asking questions about the effectiveness of the massage or about every day things, or kept quiet if she

suspected Ann was falling asleep. She was more than happy to accept, either verbally or by understanding non-verbal signals, Ann's preferences and wishes regarding the treatment. On finishing one part of the body Sandy wrapped it in a clean towel in order to maintain the feeling of warmth and comfort.

The Setting

The room allocated to these sessions was in the Special Care Unit and was identified as the "noise/quiet" room. It was carpeted and curtained and had fitted benches, covered with red vinyl cushions, along two facing sides of the room. Apart from this there was no furniture in the room as most activities take place on the carpet which has under floor heating. On to the carpet was positioned a cushioned mat which was covered with a towel and a pillow. The curtains were partially closed hoping to create a warm environment and at the same time give enough light for the video camera to work effectively. To complete the tranquil ambiance necessary for this therapy, relaxation music was played through speakers positioned at ceiling height. Unfortunately the room was not sound proofed and everyday noises from the unit could always be heard.

For Ann it was an absolute contrast to the areas in which her programme usually took place. Her environment generally being large, functional, noisy and distracting.

b.) Social Leisure Activity

The social/leisure activities and the accompanying methodology, i.e. for Ann to make and have a drink with her key worker, was the same as that chosen for the Preliminary Study. However the Keyworker and the setting changed.

The Setting

This activity took place in the Portakabin. The room was a short distance from the main building and was normally used for art and craft work in one half, and as a staff work room in the other. It was carpeted, curtained and always warm but had a 'cluttered appearance' with every available surface being covered with craft materials or books. A formica topped table and plastic moulded chairs were used, with the tea being brought over prior to the session starting. Ann was well acquainted with the venue.

The Keyworker

Rebecca, a mature, long standing member of staff had taken over from Jackie as Ann's keyworker. Although very different in age and personality it was clear that Ann respected Rebecca and would seek her out if she felt the need for comfort or help in organising her programme. Ann also enjoys cooking which she has always done with Rebecca. To help the transition, particularly

for this project, Rebecca had joined Ann and Jackie during the last two social/leisure sessions of the preliminary study.

ANN'S RESPONSES

Vignette of Session 11

Aromatherapy;
As soon as Ann came into the room she asked Sandy if she would massage her face and neck - this Sandy willingly agreed to. Ann sat on the mat and shuffled down it until Sandy had enough room to sit at her head. Ann leant forward and picked up the towel that was covering her feet and wrapped it around her knees which were bent up. Before Sandy had a chance to start Ann requested her back be massaged. Promising to do that next Sandy started the treatment, concentrating on Ann's neck and shoulders.

Ann initiated the conversation by asking Sandy if she was married and continued to listen or alternatively ask questions as Sandy quietly talked about her family. Ann admitted she had a boyfriend but gave no further details. During the course of this conversation Ann lifted her arm up and 'tweaked' Sandy's nose several times. On one occasion Sandy reciprocated the gesture to Ann's amusement. As the treatment progressed to Ann's face she became quieter, her hands/arms were resting

loosely on her ribs, her body was totally still and she was smiling.

At Sandy's request Ann turned to lay on her stomach, resting her head on her arms. Neither Ann nor Sandy spoke and apart from occasionally repositioning her head Ann was completely still and relaxed. After a few minutes Ann fell asleep and only awoke when the observer came in at the end of the session.

Tea with Rebecca;
Ann was happy to come to the session and showed no signs of sleepiness. She sat with her legs crossed under the chair and her bag firmly across her body. She would not take the bag off.

The session was very short Ann not wanting to chat. On two occasions she pulled faces at Rebecca and she also attempted to kick her, she immediately said sorry but was laughing as she drank her tea. Ann drank her tea extremely fast considering it was very hot and handed the observer her mug, she then folded her arms and burped loudly. Ann put her thumb in her mouth and then got up quickly announcing that she wanted to look at the video. She did not spend long looking before she announced she was going back to the workshop.

Summary of key points;
- Ann immediately asked if she could have her face and neck massaged

- Ann held a very sensible conversation with Sandy about Sandy's family
- Ann and Sandy enjoyed the light hearted exchange of 'tweaking' noses
- There was no talk about spitting banging etc.
- Ann gradually relaxed and became quieter before eventually falling asleep
- Ann did not want to talk with Rebecca or the observer, consequently it was a very short session.
- Ann kicked and made rude gestures to Rebecca
- Ann wanted to watch the recording of the session.

Ann's Most Common Expressions and Actions

Table 10 - Therapy sessions

	Main Study	Preliminary Study	Interpretation
Asks for specific massage	100%	00%	Likes/certain
Vocally quiet	90%	00%	Relaxed/ contented
Relaxed	80%	14%	Relaxed
Initiates conversation	60%	43%	Enjoyment
Completely still	60%	00%	Relaxed
No response to questions	60%	00%	Sleepy/ listless
Talks about Alison	60%	00%	Infatuation
Alert/watching therapist	50%	14%	Alert
Talks about 'banging'	50%	63%	Distressed
Smiles/laughs	50%	100%	Happy/amused
Hand covers face	00%	100%	Embarrassed/ displeasure
No response to praise	00%	100%	Embarrassed
Shoulders hunched, head down	00%	86%	Sad

(After session 11 Ann was transferred to a Health Authority Unit for observation and assessment due to a considerable deterioration in her behaviour. Session 4 was not included in tabular data because of a malfunction of the video camera.)

A summary of the therapist's feelings about the eleven sessions.

"I feel Annie has gained a tremendous amount from these sessions. When I first treated Annie she was extremely wary of me, never taking her eyes off me for a second, she also kept all her clothes and shoes within arms reach and regularly checked that they were all still there.

I feel she has learnt trust and friendship from these sessions and besides the relaxation in mind and body that she acquired, I feel that touch was very important. I don't know how often Annie gets to be treated as an individual on a one to one basis, which enables her to feel special and loved and to gain pleasure. I think this is where touching is so important, especially with an aggressive person (as apparently Annie has often been).

I think aromatherapy made Annie feel special and I found her a pleasure to treat."

Discussion

- Table 10 shows that 9 out of the top 10 expressions and actions (main study) were positive and demonstrated Ann's predilection for, and ability to relax during, aromatherapy and massage.

- Ann conversed with Sandy on an equal footing, initiating conversation and directing her to preferred parts of the body for massage. This type of communication and relationship is rarely seen within the Day Centre or Hostel, normally Ann takes the role of 'child' which encourages others to act in a parental manner (Berne 1968). The observer felt that these appropriate interactions were the result of Sandy respecting Ann as a client receiving a treatment and not making judgements

or being influenced by reports of incidents of challenging behaviour. It could be argued therefore that an 'outsider' who respects a person with learning disabilities and has no preconceived ideas or knowledge of them can bring about a change in that person's feelings of self worth and corresponding behaviours.

- Ann became relaxed in 9 out of the 11 sessions, the two sessions (9 and 10) where she did not relax she was calm and sociable. This is a major contrast to Ann's typical behaviour and differs drastically from the pre-intervention study where the setting and staffing were similar. This data confirms that aromatherapy and massage produce feelings of relaxation and peacefulness in Ann. This finding is even more significant given that over the course of the eleven weeks, outside of the main study sessions, Ann's behaviour was rapidly deteriorating to the extent that the Centre staff felt that Ann needed specialist help that they could not offer.

- There is only one expression/response that is similar in the preliminary study and the main study:- 'talks about banging', this refers to Ann describing previous incidents of challenging behaviour. As these episodes happened throughout each day they appeared to be constantly on Ann's mind. The content of the sessions i.e. learning to recognise colours or the time or aromatherapy or Ann's state of relaxation did not make any difference to the prevalence of this response.

- Many of the differences in actions/reactions between the two studies can be explained by the disparity in the content of the sessions. However there are some anomalies;

i.) the negative emotions displayed in the Preliminary study and absent in the main study again confirm Ann's preference for aromatherapy and massage.

ii.) there were more incidents of Ann being alert during the aromatherapy and massage sessions than in the constructive activity sessions. This was contrary to the author's expectations but can be explained by Ann's liking for the therapy and her good interaction with the therapist, i.e. Ann was interested and well motivated.

iii.) Ann smiled and laughed more in the constructive activity session. This finding appears to contradict other findings which suggest Ann preferred/enjoyed the aromatherapy and massage sessions. One possible explanation may be that as she relaxed Ann smiled/interacted less. This also could account for Ann's reluctance, at times, to answer Sandy's questions - she was quiet and contented and did not want to make the effort required to respond.

Table 11 - Social/leisure activity

	Main Study	Preliminary Study	Interpretation
Thumb in mouth	72%	29%	Relaxed
Kicking/rude gestures	72%	00%	Displeasure/ attention seeking
Initiates conversation	64%	57%	Enjoyment
No response to questions	54%	00%	Sleepy/ listless
Won't let go of handbag	45%	50%	Tense
Talks about Alison	45%	00%	Infatuation
Looks at video	45%	00%	Interested
Talks about Jackie	45%	00%	Infatuation
Relaxed	36%	86%	Relaxed
Shoulders hunched, head down	00%	86%	Sad

(After session 11 Ann was transferred to a Health Authority Unit for observation and assessment due to a considerable deterioration in her behaviour.)

Discussion

- The positive indicators during the main study social/leisure activity were; Ann's willingness to come to and stay at to the sessions, her interest in the video camera, initiating conversation and reminding Rebecca each Thursday that the sessions were going to take place. It can therefore be assumed that Ann was a willing participant.

- There were a wide range of expressions and actions recorded in the main study social/leisure sessions which depict the

turbulence Ann was experiencing, in her life, at this time, e.g. relaxation versus displeasure or attention seeking behaviour. There was constant talk about Alison and Jackie with whom Ann seemed infatuated and although the kicking of Rebecca and the observer did not appear to be malicious it was a new behaviour. Whilst Ann's feelings of wretchedness were forgotten or eradicated during the aromatherapy and massage sessions they were always present during the social/leisure sessions. There are many explanations for this;

i.) Although there was a one to one staff ratio Ann may have thought of the session as a mainstream activity and exhibited many of her normal challenging behaviours.

ii.) There was no structured approach to help Ann relax.

iii.) The staffing and setting of the session.

However Ann's responses during these sessions were still much better than during normal Centre activities.

- Although the content of the main and preliminary study social/leisure sessions were the same, many of the differences in responses can be explained by the change in keyworker and the increase in Ann's challenging behaviours. The observer could ascertain no other changes in Ann's lifestyle and therefore suggests that Ann's regression could have been caused by her keyworker, Jackie, leaving. This would also explain Ann's new infatuation with Alison - a replacement for Jackie. However it could be argued that the differing responses in the social/leisure activities were due to the differing nature of

the session preceding it. The focus of the preliminary study first session was interactive and demanding whereas during the main study it was relaxing and passive.

Table 12 - Overall responses

The responses shown are a combination of two activities, i.e. aromatherapy and massage or learning colours or time and tea and a chat, and therefore give a global picture of Ann's reactions.

	Main Study	Preliminary Study	Interpretation
Initiates conversation	62%	50%	Enjoyment
Vocally quiet	57%	00%	Relaxed/ contented
Relaxed	57%	50%	Relaxed
Thumb in mouth	57%	21%	Relaxed
No response to questions	57%	00%	Sleepy/ listless
Asks for specific massage	48%	00%	Likes/certain
Smiles/laughs	48%	86%	Happy/amused
Talks about 'banging'	43%	57%	Distressed
Kicking/rude gestures	43%	00%	Displeasure/ attention seeking
Shoulders hunched, head down	00%	86%	Sad
Hand covers face	00%	86%	Embarrassed/ displeasure

Discussion

- During the main study (therapy and social leisure sessions) 7 of the 9 (78%) most frequently recorded expressions and actions show that Ann enjoyed the activities and was relaxed and happy. Ann, the therapist, her keyworker and the observer confirm that this was indeed the case.

- The negative, e.g. tense, attention seeking, behaviours recorded in Table 11 (social/leisure) are less prominent in Table 12 due to high incidence of positive responses recorded during the aromatherapy and massage sessions.

- Many differences in the responses to the two studies can be explained by the differing nature of the first sessions, i.e. therapy and constructive activity. For example; a.) the higher incidence of relaxation in the main study, b.) the embarrassment during the preliminary study caused by Ann being confused/distressed when giving a wrong answer, c.) The vast difference in occasions when Ann smiles/laughs - main study 48% : 86% preliminary study (suggested explanation p. 148).

- The overall responses given by Ann during the course of the total intervention were very different than her normal behaviour. The reactions were much more positive and optimistic and any negative behaviours were restrained and calm. Apart from the benefits, discussed earlier, of aromatherapy and massage, individual, specialised work with Ann appears to have a beneficial, therapeutic effect.

SUMMARY

The personal profile indicates Ann is an active person, enjoying physical pursuits. Sedentary activities can be

enjoyable, but difficult behaviour ensues when Ann is not interested, becomes bored or does not receive the attention she desires. This was illustrated at certain points during the preliminary study e.g. boredom was expressed by talking about her aches and pains or changing the subject.

In the wider context of Ann's deteriorating behaviour over the period covered by the main study, aromatherapy as a sessional intervention appears to have been enjoyed and had positive benefits, e.g. Ann was actively engaged during the sessions and was relating to the therapist. Aromatherapy enabled Ann to relax fully in 8 out of the ten recorded sessions. Ann's participation in social/leisure sessions during this same period showed some increase in difficult behaviours, although this was not as marked as in other activities within the day centre.

Together these sessions show unprecedented results particularly given their sedentary nature and are even more remarkable in the context of Ann's increasingly challenging behaviour.

LUKE

PERSONAL PROFILE

Luke is 27 years old and lives at home with his mother and two brothers in a small village approximately 8 miles from the nearest town. As his mother doesn't drive they live a fairly isolated life. Luke's father left home when he was twelve.

At the age of six months Luke suffered from, what his mother called "seizures" but it was not until nine months later that he was diagnosed as having Tuberous Sclerosis Epiloia with Epilepsy. This condition is typified by growths on the brain which calcify with age and become hard or sclerotic. The face is covered in a rash of small 'bumps' across the cheeks and nose and 1 in 2 people affected will have a learning disability. Luke's epilepsy is now reasonably well controlled by medication, having approximately one grand mal seizure once each week usually at night, whilst sleeping.

Luke did not receive any formal education until the age of 7 years when he began at a large 'mental handicap' hospital. He later transferred to a new purpose built school for children with severe learning disabilities. There he stayed until he was 19 years old. The next 18 months Luke spent at home, the alternative being to return to the Hospital for Day Care which his mother did not want. However very reluctantly, she

eventually agreed that they both needed a break from each other and so Luke returned to the Hospital until the opening of the Special Care Unit at Elmhurst in 1988.

Today Luke presents as a quiet, lethargic and unresponsive man. He has very dark short hair and is clean shaven apart from long black sideburns. His face is covered in a red, raised rash which is a characteristic of his condition. Luke rarely smiles or looks up, his head moves continually from side to side. Luke's hands rest on his lap and appear elegant and could even be described as artistic, the fingers being long, slender and beautifully formed, they too move constantly, stroking one another.

Luke can walk unaided but his stiff legs and collapsed arches make him slow and uncertain of stairs and uneven surfaces.

Luke does not speak but communicates by making sounds or movements. Luke's understanding of vocalisation and speech is limited, he can respond to his own name but is unable to follow very simple commands without a lot of physical prompting.

Luke is completely dependent on others for all his basic needs i.e. toileting, dressing and undressing, personal hygiene, safety and food preparation. If food is positioned in just the right place Luke will sometimes feed himself using his fingers, if however a spoon is needed Luke requires assistance. However

he does incline to be lazy and would much rather sit and wait for someone to feed him. Luke can, and does, drink by himself using one or both hands.

Luke finds social interaction quite difficult, he is very attached to his mother and appears happiest when he is aware she is in the vicinity. With Centre staff or other carers it takes Luke a long while to build up relationships but once familiar he will respond, by touching or hugging, if approached. However he will not or cannot initiate any such advance. To strangers and his peers Luke shows a passive rejection, he will make no move to look or communicate with them.

Luke has been in the Special Care Unit for four years now. His day starts with a taxi ride from home arriving at the Centre by 9.30am. His programme includes music, trampolining, trips out to the local community, sensory stimulation, massage, spa baths and hydro-therapy. During these sessions Luke frequently stares into space and rarely interacts with the Instructor, he will only join in with others in the group if prompted, generally he remains passive.

THE PRELIMINARY STUDY

Constructive Activity

The first activity for Luke was to encourage him to eat independently, using his fingers. He had been known, occasionally, to feed himself but staff believed that he was so used to being fed he now never thought to feed himself. It was thought that meal times were often too busy and noisy to work individually with Luke so a short session in the afternoon would be an ideal opportunity. The food chosen was crisps, as Luke prefers savoury food to sweet items.

Social/Leisure Activity

Luke's Keyworker thought he would like to listen to music, a well established favourite activity. His keyworker chose different types of music firstly to introduce Luke to a wider range of styles and secondly to further ascertain his taste in music.

The Keyworker

Luke had had the same keyworker, Mal, for the past sixteen months. Mal is a very quiet, thoughtful man who works in the Special Care Unit where Luke is based. Mal, along with other

Unit staff, looks after Luke's personal care needs and work with him in activity sessions.

After the first session Mal informed the author that he had been offered another job and would be leaving before the end of the initial stage of the research project. It had been decided by the Centre Manager that Elsie, a part time member of staff, would take over the Thursday sessions but would not necessarily become Luke's Keyworker. Elsie is a relatively new member of staff who is also based in the Special Care Unit. Over the eight sessions Mal participated in sessions 1, 2 and 4, with Elsie being involved in the remainder.

Setting

The two activities took place in the dining area of the Independent Living Skills kitchen. This resembled a domestic dining room with a dining table and chairs, a side board and many homely objects. For both sessions Luke sat on a dining room chair which was moved away from the table for the music session

Results

On completion of the eight sessions the data was summarised as described on page 120 and the following expressions/actions were found to be characteristically distinctive of Luke.

Table 13. Luke's Most Common Expressions and Actions

(The two activities each week, i.e. constructive activity and social/leisure activity, are counted separately. Session 3b - Social/leisure activity is not included as Luke was asleep, therefore total of sessions recorded = 15)

In 13 out of 15 Activity sessions - 86.6%

- Patting hands.
- Scratches ear, nose or eye.
- Completely still.

In 12 out of 15 Activity Sessions - 80%

- Head moves from side to side.

In 11 out of 15 Activity Sessions - 73.3%

- Smiles.
- Gentle rocking.

In 10 out of 15 Activity Sessions - 66.6%

- Hands resting on top of each other.

In 9 out of 15 Activity Sessions - 60%

- Leans forward to concentrate.

In 8 out of 15 Activity Sessions - 53.3%

- Claps hands.
- Blank expression, staring.

Table 14. Summary of Luke's Responses or Reactions that Express Feelings or Emotions (form B)

Like Finger and thumb in mouth Makes noises	**Dislike** Will not co-operate Looks away
Amusement Smile	**Boredom**
Alert Opens eyes Leans towards person or object	**Listless** Falls asleep Doesn't participate Lazy No expression, staring
Excited Rocking energetically Loud noises Claps	**Apathetic** Eyes not focused? Relies on staff Does not respond
Calm Hands still, in lap	**Distressed** Head moving from side to side?
Relaxed Body posture Gentle rocking Pats hand in lap Scratches ear, nose and eye	**Tense** Body posture
Happy Smiles Finger and thumb in mouth Noises	**Sad**
Enjoyment (as Happy and Like)	**Displeasure**

Additional Findings

a.) Little real progress seemed evident in Luke's finger feeding skills until sessions 5 and 6 when he repeatedly reached into the bag to help himself. However this did not continue in the last two sessions where Luke lacked motivation.

This did not appear to be due to any physical problem as he was alert and lively in the following music sessions.

b.) Luke showed a positive response to the social/leisure activity - e.g. clapping, rocking, making noises - in contrast to the constructive activity and normal activities within the Unit where he is passive - e.g. staring, still, turning away from activity.

c.) The observer had to liaise with the keyworker for interpretation of many of the responses. This had not been the case with the participants who had some language skills.

d.) The periods of stillness during the social/leisure activity appeared to the observer as periods of contentedness or relaxation. However in the constructive activity these periods gave the observer the feeling that Luke was being uncooperative. These observations highlight some of the difficulties in interpreting behaviours, e.g. stillness in one context equates to relaxation, while in another can be interpreted as uncooperative.

e.) The ferocity of Luke's rocking during the social/leisure activity did not always correspond to the tempo of the music.

f.) Smiling did not appear to be a response to an external stimulus or an interaction between anyone or anything.

g.) The observer was unable to notice any signs that Luke was upset by his Keyworker leaving.

THE MAIN STUDY

(The setting and process of the sessions are similar to those described previously for Ann,(pages 139-140), therefore only additional information relating directly to Luke will be recorded.)

a.) Therapeutic Intervention - Aromatherapy

Previous to this intervention Luke had been attending aromatherapy sessions, intermittently over the course of the previous three months, and the staff team felt that he enjoyed and benefited from the sessions.

The sessions were organised on an individual basis and lasted for between 15 and 20 minutes. Luke was allocated the first session and on arrival the observer and Sandy firstly welcomed Luke and then talked with the member of staff who had brought him. Together they would then help him lie down on the mat and whilst Sandy continued talking to Luke and stroking his face the observer took off his boots and socks. Because of this initial involvement the observer did not start the video camera until Luke was lying down, however the therapist's and observer's reports detail any significant points prior to the massage beginning.

The process of the session was very similar to that described previously, however with Luke, Sandy generally began treating

his feet unless he showed displeasure or pulled a foot away, in which case she would try an alternative part of his body.

The Setting

The sessions took place in the Noise/Quiet room of the Special Care Unit. Luke was familiar with this setting, using it for sessions of sensory stimulation and relaxation each week.

b.) Social/Leisure Activity

The social/leisure activity and the accompanying methodology, i.e. for Luke to listen to music with his keyworker, was the same as that chosen for the Preliminary Study.

The Setting

The Portakabin (p. 141) was the venue for these sessions. As Luke was not familiar with the room or its location his keyworker took him there each day prior to the sessions beginning.

The Keyworker

Luke had a new keyworker, Colin, who wanted to take part, with Luke, in this part of the project. Although new to the role of Instructor in the Special Care Unit, Colin was familiar with

the Centre as he had previously been the Caretaker. Colin is a quiet, caring man who is conscientious and reliable. He felt he was gradually getting to know Luke but was only too willing to consult his colleagues for help and advice. Luke appeared to be at ease in Colin's company and willingly accompanied him to various activities.

LUKE'S RESPONSES

Vignette of Session 13

Aromatherapy;
There had been a two week gap without any sessions due to first Sandy being away and then the observer. Luke was delighted to see Sandy again and gave her a hug as he walked into the room.

Luke lay down on his back with his knees bent upwards and his hands resting loosely on his chest. He was still smiling as Sandy knelt down beside him. Luke tried to sit up stretching one hand out towards Sandy as she prepared to start massaging his hands, and then lay back alternatively putting his fingers in his mouth and waving them in the air.
Once again Luke lifted his upper body right off the mat and stretched his arms towards Sandy, putting his left arm around her neck and curling his legs and lower body to one side. Sandy stayed in this position and at the same time rubbed Luke's back

through his jumper, Luke frequently looked up at Sandy and smiled. To no avail Sandy tried to persuade Luke to lie back down, he kept one arm round her neck and with the other hand played with Sandy's hair.

Sandy again attempted to settle Luke back onto the mat this time successfully. She then proceeded to treat his feet and lower legs. Luke became relaxed with his hands clasped together on his chest and his head occasionally moving from side to side. Luke pulled his foot away but was happy for Sandy to massage the other foot which he eventually pulled away as well. Luke did not want to turn over for a back massage consequently Sandy massaged his neck and face. Luke was relaxed and still during the latter part of the session.

Music;
Colin and Luke walked together to the Portakabin, with Colin pointing out the flowers and shrubs as they passed them.

Luke sat very still with his legs crossed under the chair and his hands in his lap. He was constantly looking around the room, moving his head to get a better view.

Luke really looked as if he was enjoying the music, sometimes he smiled and sometimes he looked as if he was going to start rocking but he remained relatively still. The second piece of music was much more lively and Luke reacted by gently rocking,

tapping his hands together and smiling. The final record saw him responding in a similar manner with one short burst of more energetic rocking. Luke was happy to leave the session and went with Colin for a drink.

Summary of key points;

- Luke was in a very responsive mood wanting to touch and be held.
- Sandy did not complete many of the massages due to Luke holding on to her.
- Luke smiled throughout the session.
- Luke pulled his feet away when he had had enough.
- Towards the end of the session Luke became sleepy/relaxed and became still.
- Luke was alert throughout the music session, he enjoyed the music, smiling and quietly rocking.

Luke's Most Common Expressions and Actions

Table 15 - Therapy sessions

	Main Study	Preliminary Study	Interpretation
Completely still/relaxed	- 100%	- 88%	Relaxed
Head moves from side to side	- 92%	- 75%	Habit
Vocal noises	- 62%	- 25%	Like/excited
Smiles	- 62%	- 63%	Happy/amused
Scratches head/face	- 54%	- 75%	Relaxed
Lifts head/body up	- 54%	- 00%	Likes/alert
Laughs	- 54%	- 00%	Happy/excited
Curls up on side	- 54%	- 00%	Relaxed
Grinding teeth	- 54%	- 00%	??
No expression/staring	- 00%	- 88%	Listless
Patting hands	- 00%	- 88%	Relaxed
Gentle rocking	- 38%	- 75%	Relaxed
No response	- 00%	- 63%	Listless

A summary of the therapist's feelings about the thirteen sessions

"He certainly got a lot of pleasure on many occasions as he would often smile and he seemed to like being cuddled and giving cuddles. I got the impression he came from a loving and caring family. On the days he came in and was visibly distraught, the relaxation music seemed to have a great calming effect on him and then a back massage really calmed him. I am quite convinced that Luke likes to be touched and I think he is a very loving person."

Discussion

- Using the Summary of Responses (Table 14, p. 161) it is possible to establish that Luke enjoyed the Aromatherapy and Massage sessions, i.e. he smiled, laughed, made noises, relaxed and co-operated.

- Many of Luke's responses during the aromatherapy and massage sessions were completely out of character. He was totally relaxed during the therapy sessions yet was able to exhibit positive, active responses, e.g. sitting up and reaching for therapist, waving arms, moving to indicate a part of the body he wanted massaged. This combination is not normally seen within the Unit, Luke is either passive and listless or, when listening to music, energetic. As these reactions do not occur normally and were not recorded in the preliminary study or in the social/leisure activity it must be concluded that they were the result of the therapy or the therapist or a combination of both. Having already ascertained that Luke has difficulty with social interaction the most probable cause for his change in behaviour was the aromatherapy and massage intervention.

- The most consistently recorded response to the aromatherapy and massage was, not surprisingly, 'completely still/ relaxed'. What ever mood or physical disposition Luke was in at the beginning of the session he could always achieve a state of relaxation by the end of the treatment. The music, ambience of

the room, the massage and Sandy's presence were the contributing factors to this. Whilst Luke is normally prone to falling asleep, due either to listlessness or disturbed nights through having fits, he rarely manages to sleep when restless and fretful as he did during some of the aromatherapy sessions. It is reasonable to assume therefore that aromatherapy and massage is beneficial in helping Luke relax when he is in an agitated state.

- When comparing the responses to the two studies the following points emerge:-

a.) During both the constructive activity sessions and the aromatherapy and massage sessions there was always recorded periods when Luke was completely relaxed and still. However the 'stillness' appeared to signify differing reactions; in the constructive activity sessions it was sometimes a negative response, i.e. when Luke would not participate in the finger feeding sessions he would sit, virtually still staring ahead, whereas in the aromatherapy and massage sessions the 'stillness' was a tranquil, contented state.

b.) Although both studies show many positive responses, there were high incidents of listless, uncooperative behaviour in the preliminary study which although common during daily activities were not recorded in the main study. Additionally vocal noises and laughing, which the observer and the therapist interpreted as communicating contentedness and excitement, were recorded in over half the aromatherapy sessions as compared to a quarter of

the Constructive activity sessions. This data confirms the observer's view that Luke enjoyed and responded well to aromatherapy and massage sessions.

c.) In Table 15 only four of the top actions/expressions in the Preliminary Study are listed in the top actions expressions in the Main Study. This can be explained, to a certain extent, by the difference in the activities in the two studies. However laughing, and vocal noises (likes, happy, excited) were not dependent on the content of the session so could have been expected to be equally prevalent in both studies. This again provides further evidence of Luke's pleasure during the main study sessions.

d.) The inherent dangers of interpreting only physical responses without looking at the wider context of the situation, e.g. when Luke is still he could be either relaxed or uncooperative/listless.

Table 16 - Social/leisure Activity

	Main Study	Preliminary Study	Interpretation
Gentle rocking	- 83%	- 71%	Relaxed
Smiles	- 75%	- 86%	Happy/amused
Completely still/relaxed	- 58%	- 86%	Relaxed
Patting hands	- 50%	- 86%	Relaxed
Claps hands	- 50%	- 71%	Excited
Violent rocking	- 50%	- 57%	Excited
Vocal noises	- 08%	- 57%	Like/excited
Head moves from side to side	- 17%	- 86%	Habit
Scratches head/face	- 42%	- 100%	Relaxed
Leans forward to concentrate	- 33%	- 71%	Alert

(There were only twelve recorded sessions as Luke could not wake up after falling asleep in session 2 of the Aromatherapy.)

Discussion

- Luke's most noticeable expressions/actions during the social/leisure activity (main study), showed that he was relaxed and happy.

- Both the preliminary and main study recorded activities/expressions conveying happiness, relaxation and varying degrees of excitement, confirming the premise that Luke enjoys and responds positively to music.

- Whilst there was a higher incidence of stillness/relaxation during the Preliminary study, during the main study there were less responses showing excited behaviour. Overall Luke was quieter and more relaxed during main study music sessions, i.e.

in eight sessions (67%) Luke appeared sleepy and relaxed throughout. This behaviour was not always a direct result of the aromatherapy session e.g.;

Session 1 - aromatherapy and massage = very relaxed,
music = sleepy and relaxed.

Session 12 - aromatherapy and massage = totally relaxed, peaceful,
music = lively, responsive.

However there was, over the period of 13 weeks, evidence to show that Luke was generally more relaxed during the main study music sessions than he was either during normal activities or during the preliminary study.

- The observer and the keyworker could find no explanation for the dramatic decrease in 'head moves from side to side' unless it was another indication of Luke's relaxed state.

- Luke's responses to the music, during the main study, were different from those in the Preliminary study where Luke was much more excited and alert in between short periods of stillness. In contrast during the majority of sessions in the main study there were only very short bursts of energetic behaviour and frequent occasions when Luke looked as if he might become excited but chose to remain quiet and relaxed. These responses were not what his keyworker would have expected, e.g. in response to an Elvis record Luke occasionally rocked gently and clapped, instead of becoming excited and

lively. It can be concluded therefore that when a music session is preceded by an aromatherapy and massage session Luke's responses are more reserved and restful.

- As with the discussion of Ann's responses (p. 153) it is important to acknowledge that having the social/leisure activity after a therapy session, as opposed to after a constructive activity session, may well create a different experience for the participant with correspondingly different responses.

Table 17 - Overall responses

The responses shown are a combination of two activities, i.e. aromatherapy and massage or eating crisps and music, and therefore give a global picture of Luke's reactions.

	Main Study	Preliminary Study	Interpretation
Very Still	- 80%	- 87%	Relaxed
Smiles	- 68%	- 73%	Happy/amused
Gentle rocking	- 60%	- 73%	Relaxed
Head moves from side to side	- 56%	- 80%	Habit
Scratches head/face	- 48%	- 87%	Relaxed
Claps hands	- 44%	- 53%	Excited
Patting hands	- 24%	- 87%	Relaxed

Discussion

- The responses shown in the main study, and the absence of any negative reactions, confirm that Luke found the combination of aromatherapy and music sessions relaxing and enjoyable.

- This table shows that five out of the top six actions/expressions in the Main Study were also most prevalent in the Preliminary Study. However in the main study they occurred less frequently. From these responses it can be assumed that Luke was contented and at ease with all the sessions. The negative responses recorded in the preliminary study (constructive activity) became less apparent when the two sessions were viewed collectively.

- The one noticeable difference between the two studies was the infrequency of 'patting hands' during the main study. This can be explained by the nature of the activity, i.e. Luke was lying down, his hands were being massaged or resting at his side.

- The expressions and actions recorded in the two studies are more positive than those observed during the course of Luke's normal activities.

Summary

The data relating to Luke's personal profile suggests he is a quiet, unresponsive man with a profound learning disability who finds personal relationships difficult.

The preliminary study showed some spasmodic progress with finger feeding which could have been hindered by changes in staffing. Luke participated in the music sessions and appeared to enjoy them.

Luke's responses to the aromatherapy sessions indicated that he took tremendous pleasure in this activity and was quickly able to relax and build a relationship with the therapist. Even when he was relaxed Luke was able to exhibit positive, active responses. This was a great contrast to his disposition in day to day activities in the centre.

Luke enjoyed the main study music sessions although he appeared less excited than in the preliminary study.

One to one attention seemed to benefit Luke. However there were more signs of positive responses during the aromatherapy sessions.

CONCLUSION

Whilst recognising the individuality and differing disabilities of the two participants, there were some common themes relating to their responses to the aromatherapy intervention. Both Ann and Luke appeared to:-

- find the sessions enjoyable and relaxing
- behave in a qualitatively better way than in conventional day centre activities
- exhibit more positive social and interactive skills than normal

In contrast to these positive outcomes there was:-

- little evidence to suggest that the benefits were continued after the sessions ended.
- difficulty in interpreting some responses/reactions which might make some observations somewhat speculative.

CHAPTER 5

YOGA INTERVENTION - FINDINGS

This chapter focuses on a further two case studies where yoga was introduced to the participants as a specific intervention. The findings are presented using a similar structure to the previous chapter, i.e. under the headings - personal profile, the preliminary study and the main study.

MARCUS

PERSONAL PROFILE

Marcus was born at his parent's home in London in 1969. It was a difficult and complicated birth and entailed the family General Practitioner pulling Marcus out by hand. His mother recalls that Marcus was very cyanosed when born and took a while to begin breathing. At 3 weeks his mother was informed that Marcus had Down's Syndrome. Marcus could crawl at 12 months and walk at 18 months of age.

In 1970 the family moved to Scotland, where at the age of 4 Marcus attended a mainstream playgroup, followed by a Nursery

School before starting at a Special School. At the age of 8 years the family once again moved and Marcus attended a Rudolf Steiner School as a weekly boarder. During 1979 the family moved to Sussex and Marcus was placed at school for children with learning disabilities and lived at home. He settled well and school reports suggest he made good progress.

Since leaving school Marcus's days are spent working in the Horticulture Unit at Elmhurst. From this base he takes part in a number of activities including music therapy, rock climbing, swimming and adult basic education. Marcus will work, at times, on his own initiative but on other occasions he will go off on his own and refuse to co-operate. His unsettled and occasional aggressive behaviour appeared to stem from the time his parents withdrew Marcus from Elmhurst, where he was happy and well settled, deciding that he should try living away from home again. A place was found in an establishment in Wakefield that provided both residential and day care. This move proved to be unsuccessful, Marcus did not settle missing both the staff and friends at Elmhurst and family life. Consequently he returned home and rejoined his peers at Elmhurst three months later.

Marcus now lives at home with his mother and father, their home being on the campus of a fee paying school, steeped in ancient traditions, where his father is employed. Marcus's brother who lives in London, is very important to him. He frequently talks as if he is his brother describing things he has done and

places he has visited. Possibly due to the fact that there are few other relatives the family has a very sharing and close relationship with one another.

Marcus is above average height for a young man with Down's Syndrome, he is overweight and wears thick lens glasses to correct short sightedness. Marcus is a man of great contrasts; he can sometimes be found "charging around" full of aggressive energy shouting at real or imaginary people, whilst at other times he is quietly withdrawn and will sit outside, whatever the weather, talking to himself.

Outbursts of challenging behaviour occur at least daily. Examples during one typical week (January 1993) include smashing a tray of glasses, shouting aggressively whilst alone in the dining room, refusing to talk to staff, crying, taking another service user's wheelchair, swearing loudly and excessively. Marcus has got a sense of humour and will enjoy a joke and the company of his peers and staff, however for no obvious reason his mood can suddenly change and he will become very distressed, eventually shouting and rushing away.

Marcus has a great many self help and academic skills. He has good expressive language, using pronouns and adjectives and can comprehend 4 - 5 information words in a sentence.

THE PRELIMINARY STUDY

Constructive Activity

As Marcus had recently opted to help the caretaker clean the main dining room it was thought fitting for his keyworker, Graham, to teach Marcus how to sweep up. The timing of the session was appropriate as it was immediately after lunch. Graham's aim was to help Marcus be more systematic in his approach.

Social/Leisure Activity

The second activity, jointly agreed between Graham and Marcus, was to have a drink and a chat. Marcus enjoys socialising and Graham was pleased to have time to be with Marcus on an individual basis. Graham requested that the author, in her role of observer, was not present at this session. He felt it would inhibit him and may distress Marcus. However they both agreed to leave the video camera running throughout.

The Keyworker

When Keyworking was introduced at Elmhurst, in 1989, Graham had asked to be Marcus's keyworker and had continued throughout the following three years. Marcus is based in the Horticulture Unit which Graham runs and has consequently built up a strong

relationship of trust with Graham. Graham is in regular contact with Marcus's parents who have many concerns regarding Marcus's challenging behaviour.

Setting

The main dining room, with a capacity for seating 80 people, was the setting for both parts of the session. Prior to learning how to sweep up Marcus stacked all the chairs and tables. This was already part of his routine. On completion of the first activity Graham and Marcus got themselves a table and chairs, collected drinks from the vending machine and sat in the dining room to have their chat.

Results

On completion of seven sessions (Marcus did not want to attend session 3) the data was summarised as described on page 120 and the following expressions/actions were found to be characteristically distinctive of Marcus.

(The two activities each week, i.e. constructive activity and social/leisure activity, are counted separately. Therefore a total of of 14 sessions were recorded)

Table 18. Marcus's Most Common Expressions and Actions

In 11 out of 14 Activity Sessions - 78.6%

- Sighs
- Smiles
- Rubs eyes, forehead, face

In 10 out of 14 Activity Sessions - 71.4%

- Talks to self.

In 9 out of 14 Activity Sessions - 64.3%

- Plays with his glasses

In 7 out of 14 Activity Sessions - 50%

- Repeats instruction or question.

Table 19. Summary of Marcus's Responses or Reactions that Express Feelings or Emotions (form B).

Like	Dislike
Expresses verbally	Expresses verbally in aggressive tone
Rubs hands together	Turns away
Smiles	Argues
Amusement	Boredom
Laughs	Sighs
'Fools around'	
Alert	Listless
Follows instructions	
Good eye contact	
Looks around at external distractions	
Excited	Apathetic
Shouts	
Talks animatedly	
Uses hands when talking	
Calm	Distressed
Works uninterruptedly	Shouts
Sits back in chair	Covers head with hands
Good communication skills	Rests head against wall
	Turns away from people
	Talks, aggressively, to self
Relaxed	Tense
Body posture relaxed	Body hunched
Talks about family holidays	
Takes glasses off	
Sighs	
Happy	Sad
Face 'lights up'	Withdraws into self
Smiles and rubs hands	Sighs
Enjoyment	Displeasure
Smiles to self	Becomes agitated/rushes around
Hurries to what he wants to do	Points
	Shouts
Certain/Sure	Puzzled
Uses gestures to emphasise speech	Rubs face with hands
	Repeats question/instruction
	Hand covers mouth

Additional Findings

a.) During the course of the seven sessions Marcus was able to learn to sweep the floor proficiently and moved on to learn how to mop. By the last session he was only needing occasional prompts to remind him of parts he had missed. Graham felt that Marcus had really enjoyed the sessions and the accompanying feelings of achievement.

b.) Marcus constantly fiddled with his glasses, touching them, pushing them into place and rubbed his eyes, forehead and face. This appeared to be a subconscious/nervous habit akin to biting nails or sucking thumb, rather than a physical problem or a response to a situation or person.

c.) During both activities Marcus would not have stayed in the room if he had not have wanted to be there. However, particularly during the social/leisure activity his body posture indicated he was not relaxed, e.g. he sat hunched over the table, during three of the sessions he had his back to Graham.

d.) Graham frequently noted that it was hard to follow Marcus's train of thought, the subject often changing and going off at a tangent.

e.) Although there had been episodes of challenging behaviour prior to most of the sessions, during the activities there was no occurrence of it.

THE MAIN STUDY

a.) Therapeutic Intervention - Yoga

After having met Marcus, and talked with his Keyworker and Instructors to ascertain his abilities, needs and preferred methods of working Ruth chose and adapted seven postures (exercises) and breathing exercises for Marcus (fig. 5, p. 187).

The Session

Marcus had a session of Yoga on a Monday afternoon lasting approximately 15 minutes. There was a yoga mat for each participant and one for Ruth. Marcus's session was structured, sequential and attended by two other Service Users, Kathy and Patricia. Including additional members in the session had been done following advice from the staff at the Centre. They felt Marcus may find the 'one to one' teaching too intensive and threatening especially as Ruth was relatively unknown to him. He would feel under great pressure to 'succeed' if he was the sole focus of attention. Much care was taken to choose the right people. They needed to be compatible with Marcus, preferably female as he related more easily with women and they should need minimal support from Ruth. Kathy and Patricia met these criteria and in addition had participated in Yoga activities before and were keen to join a new group.

fig. 5. -

1st POSTURE

BREATHE IN

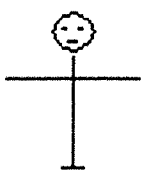
BREATHE OUT

2nd POSTURE

BREATHE IN

BREATHE OUT

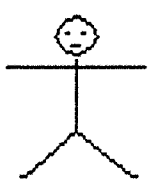
3rd POSTURE



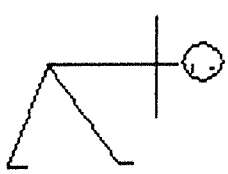
BREATHE IN

BREATHE OUT

4th POSTURE

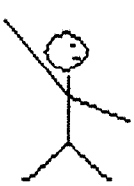


BREATHE IN



BREATHE OUT

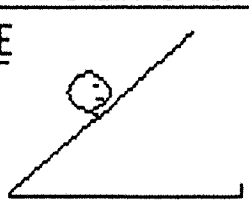
5th POSTURE



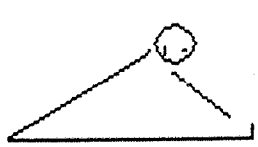
BREATHE IN

BREATHE OUT

6th POSTURE

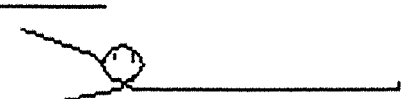


BREATHE IN



BREATHE OUT

7th POSTURE



BREATHE IN

BREATHE OUT

Loose clothing was worn by everyone and on arrival the participants took of their shoes and glasses and jewellery, if wearing them. Marcus's session followed a regular routine, which the participants soon learnt, warm up exercises followed by practising each of the seven postures and accompanying breathing exercises. Ruth took on the role of Instructor demonstrating each posture and then assisting the participants with their technique.

On completion of the yoga postures, Marcus's sessions ended with a few minutes of relaxation to the accompaniment of music

The Setting

The setting for the yoga sessions changed over the course of the 15 weeks. The first room allocated by the Manager had, in the past, been used for communication and study sessions but due to staff shortages was no longer in regular use. In order to make enough space Ruth removed many things from the room. The resulting environment was a fairly bare room with a few chairs around the edge, a table with a plant and a cassette/ radio on it, a flip chat on its stand and the video camera and tripod. Onto the lino covered floor yoga mats were placed. One session was spent in a Portakabin, one end of which was normally used for craft work and had boxes of dried flowers, pots of paints and photo albums on every available surface, the

other end had been adapted to be a staff work area containing desks, bookcases etc.

The last move for the yoga sessions was to the staff room. This room leads off the reception area and is frequently the venue for small group work. It is furnished with low comfortable chairs, and is spacious and light, one wall of the room having windows along its length. Prior to the session Ruth and the author cleared and tidied the room to make it more befitting to the session.

b.) Social/Leisure Activity

The social/leisure activity and the accompanying methodology chosen for the Preliminary Study, i.e. a cup of tea and a chat, remained the same. Marcus's original Keyworker, Graham, continued to work alongside him during this part of the study. However rather than use the dining room, Marcus rearranged some chairs in whichever room the Yoga session had taken place and Graham joined him, bringing the tea with him.

MARCUS'S RESPONSES

Vignette of Session 8

Yoga;
Marcus was waiting for Melanie to finish so he could prepare the room for his session. Before beginning the exercises Ruth reassured Marcus that there was no need to get up immediately relaxation had finished, she was happy for him to take his own time.

1st. posture; Although Marcus sat in anticipation of the session starting he was reluctant to move into the correct posture for this exercise. He was slightly aggrieved with Patricia and could be heard whispering "don't be silly". A prompt from Ruth brought the response "I'm OK." but it needed a further prompt before Marcus was ready. He then actively participated, looking most proficient.

2nd. posture: Before taking up the correct stance Marcus looked around, almost as if he needed reassurance he was going to take up the proper position. Apart from being distracted momentarily by noise outside the room Marcus exercised well.

3rd. posture; Marcus scratched his head each time he raised his arms but this did not effect the success of the exercise.

4th. posture; Marcus responded positively extending his arms and breathing well. At one point he rubbed his face and said in what sounded like a despairing tone "Oh Christ".

5th. posture; Marcus was generally quiet whilst tying and untying the ribbons, he welcomed Ruth's help and at the end collected the ribbons from everybody. Ruth's instruction to start work on the posture was met with "Yes right" and from that point Marcus exercised proficiently.

6th. posture; Marcus positioned himself correctly and needed no prompts to start exercising.

Relaxation; Without looking around or hesitating Marcus lay down straight away and was immediately still. After a short time there were several body movements and yawns but Marcus still looked relaxed. He took Ruth at her word and didn't get up and stretch when the session ended but rolled into the now familiar position of lying sideways with his back towards everyone, head slightly raised and body curled. Marcus remained, even though the room was packed up around him, and began talking to himself in a loud angry voice e.g. - "why do you do it?" and "I want to know who did it".

Tea with Graham;
Marcus remained in the room until Graham arrived with the tea. He sat, until prompted, with his back to Graham. Marcus looked

sad, he sighed and had his hands covering his face. Very little conversation took place for the majority of the time. After answering any of Graham's questions briefly, Marcus spent time shouting and gesticulating with his glasses. Examples of the conversation are as follows:- "How dare you" and "Don't ever do that again".

Summary:-

- Marcus, on his own initiative, prepared the room.
- Apart from initial encouragement Marcus completed all the postures without prompts or assistance.
- Marcus's posture was accurate and he exercised energetically.
- Although Marcus was quiet and his sense of humour and fun was not present he still interacted positively with the group.
- Marcus quickly took up the relaxation position (this was the first time this had happened.).
- At the end of the Yoga session and during tea Marcus was very disturbed and appeared to be telling himself off.
- Marcus arrived at the Centre that morning in a distressed state - he was unable to tell any one what was wrong.
- During the course of the morning Marcus had smashed a tray of glasses.
- Considering the above two points Marcus's achievements during the yoga session were remarkable.

Marcus's Most Common Expressions and Actions

Table 20 - Therapy sessions

	Main Study	Preliminary Study	Interpretation
Follows instructions	- 100%	- 100%	Alert
Relaxes	- 100%	- 00%	Relaxed
Rubs/scratches head, face	- 100%	- 100%	Puzzled
Sighs	- 85%	- 86%	Bored/sad/ relaxed?
Smiles	- 77%	- 71%	Like/happy
Yawns	- 77%	- 00%	Relaxed
Finger and thumb tap nose	- 69%*	- 00%*	Relaxed
Talks to self	- 69%	- 86%	Distressed
Positive interaction with group members	- 62%	- 00%	Happy/calm
Negative Interaction with group members	- 54%	- 00%	Dislike/ distressed
Touches/plays with glasses	- 00%*	- 71%*	Relaxed
Repeats Instructions	- 07%	- 57%	Puzzled

Discussion

- The expressions and actions documented in Table 20 (main study) imply that Marcus was willing and very able to participate in all the sessions. This was evident, not by a display of positive emotional responses, but by the lack of negative reactions, i.e. there were no instances of extreme distress, anger and unco-operativeness which are regularly demonstrated by Marcus during Centre activities.

- During the Yoga sessions there were several instances of Marcus skylarking and joking. This behaviour was not evident in

the constructive activity or social/leisure sessions. Two explanations for this are possible; i.) It was an expression of enjoyment/relaxation. ii.) Marcus enjoyed and reacted to having his peers working alongside him (the other sessions only comprised Marcus and a member of staff).
The first explanation is the most likely as the Centre staff confirmed that all Marcus's past behaviour points to him preferring the company of staff to service users.

- During the constructive activity Marcus frequently (57% of sessions) repeated instructions, this only happened once (14%) in the Yoga sessions where instructions were just as prevalent. He also talked to himself more often (86% : 69%) during the constructive activity. Again there are two possible reasons;
i.) Marcus did not need/like to echo or talk to himself when his peers were present.
ii.) Repeating instructions and talking to self were signs of boredom/loneliness which did not occur when Marcus was absorbed in the yoga sessions.
Marcus's keyworker thought it was the latter reason - yoga was a new and stimulating activity, whereas cleaning was a routine task that Marcus normally carried out alone.

- Other disparities in responses in the two studies are explained thus;

a.) Differing instances of relaxation in the main study and the preliminary study are due to the differing nature of the constructive activity i.e. sweeping and mopping a floor.

b.) Yawning occurred in Yoga sessions whilst preparing and taking part in relaxation. There was no similar circumstance during the constructive activity session

* c.) Finger and thumb tapping nose took place in between Yoga postures, or while Ruth was helping the other participants. It can be compared to similar actions in the constructive activity when Marcus would touch/play with his glasses, (Marcus was not wearing glasses during the Yoga sessions) an action which appeared to be a subconscious or nervous habit.

d.) The Yoga sessions differed from the constructive activity in that it had other service users present. This produced differing responses e.g. Positive and Negative Interaction.

- Marcus's responses to the Yoga sessions were not predetermined by his state of mind prior to the session. On all but one occasion disturbed/challenging behaviour preceded the session.

Table 21 - Social/leisure activity

	Main Study	Preliminary Study	Interpretation
Sighs	- 100%	- 57%	Bored/sad/ relaxed?
Talks to self	- 86%	- 57%	Distressed
Rubs head, eyes face	- 86%	- 71%	Puzzled
Takes glasses off	- 86%	- 57%	Relaxed
Relaxes in chair	- 71%	- 43%	Relaxed
Good eye contact	- 71%	- 57%	Alert
Smiles/laughs	- 57%	- 86%	Happy/likes
Hunched shoulders/body	- 43%	- 86%	Tense
Turns back to Graham	- 43%	- 43%	Distress/ dislike

(There were only 7 sessions in the main study due to Marcus's keyworker being on leave)

Discussion

- Table 21 gives a good indication of the pattern of the social/leisure sessions during the main study, i.e. both positive and negative responses being of equal prevalence. There were three sessions (43%) where Marcus could be described as being relaxed, convivial and calm, two (28.5%) when he was withdrawn and distressed and two (28.5%) where Marcus started the session tense and uncommunicative but gradually became relaxed and talkative.

- There appears to be a direct connection between Marcus's reactions in these sessions and his achievement and demeanour in the yoga sessions. As Marcus progressed and became relaxed within the yoga group the negative responses in the

social/leisure activity decreased. Another example to illustrate this point is evident in Session 8 although participating in the yoga Marcus was quiet, got annoyed and talked to himself. His subsequent mood during the social/leisure activity was described as:-

"sad, uncommunicative and distraught".

- By comparing the responses to the two studies it can be seen that although Marcus relaxed more within the main study sessions overall, there were more negative expressions than positive. The furniture used in the two studies was different and probably explains the differing response to relaxation, i.e. in the main study Marcus sat on an easy chair whereas in the Preliminary Study he sat, shoulders hunched, at a table, frequently resting his elbows or arms on it. Explanations for an increase in other negative responses are harder to determine other than the differing nature of the preceding activity and Marcus's behaviour had regressed generally. In addition the author believed that Marcus's keyworker felt unequal to responding to Marcus's needs. This was borne out in one keyworker report (session 9) where Graham stated:-

"Maybe it is time for Marcus to have a change in keyworker; somebody with some new ideas."

- Even though Marcus did not show positive reactions to some sessions the fact that he came to the session and stayed there was confirmation of his wish to participate. A typical response

if Marcus did not want to co-operate would be running out the room, banging the door behind him.

Table 22 - Overall responses

The responses shown are a combination of two activities, i.e. the therapy session (yoga) and the social/leisure session (tea and a chat with Graham) and therefore give a global picture of Marcus's reactions

	Main Study	Preliminary Study	Interpretation
Rubs/scratches head/face	- 95%	- 86%	Puzzled
Relaxes	- 90%	- 21%	Relaxed
Sighs	- 90%	- 79%	Bored/sad/ relaxed?
Talks to self	- 75%	- 71%	Distressed
Smiles or laughs	- 70%	- 79%	Happy/Likes
Follows instructions	- 65%	- 50%	Alert
Repeats instruction	- 10%	- 50%	Puzzled
Plays with glasses	- 05%	- 50%	Relaxed

Discussion

When studying the combined responses to the sessions the positive outcomes highlighted during the therapy sessions are less evident and there appears to be very little differences between Marcus' responses to three very differing responses, i.e. sweeping, yoga and tea and a chat.

- The responses that differ greatly between the two studies

have been discussed previously (p. 194/5, 197)

- An important outcome from these studies is the frequency of actions expressing relaxation. In all yoga sessions and 5 out of 7 social/leisure sessions Marcus spent a significant time in a relaxed state. For someone who is often distressed and tense this is a remarkable achievement. The higher incidence within yoga is significant. Whilst acknowledging the nature of the exercise induces relaxation it must be recognised that in normal activities having other service users present is often a precursor to Marcus's challenging behaviour. It would appear therefore that yoga directly aids Marcus in relaxation and additionally that this disposition is carried over to a successive activity (page 196).

Marcus's Progress in Yoga

Marcus had attended Yoga classes when he was at school and has the ability to understand and follow instructions. Therefore it was only necessary for Ruth to demonstrate a posture, give physical and verbal prompts and Marcus would become reasonably proficient. Consequently the aim of these sessions was not primarily to teach the Yoga postures but to encourage participation and relaxation.

It was not necessary to measure the length of time spent exercising as Marcus participated for the whole 15 minutes. Ruth devised a method of recording Marcus's progress and achievements during the sessions (Table 23.)

Table 23 - Marcus's Progress and Achievement in Yoga

	Session
a. Passivity	
1. Body lacks muscular tension	
2. No eye contact	1, 2, 3, 4, 5,
3. Dependent on physical support	
b. Interest	
1. Notices what is going on	1
2. Eyes alert	
3. Holds body more upright, may require physical prompt.	
c. Recognition	
1. Recognises and responds to activity	2 - 13
2. Recognises and responds to music	2 - 13
d. Expectation	
1. As c., but may prepare room etc.	8 - 13

2. Refers to therapist with anticipation e.g. eye contact

e. Co-operation

1. Actively participates in postures	1 - 13
2. Uses own strength, some physical prompt may still be needed	2 - 13
3. Takes turns and interacts with group.	7 - 13

f. Initiative

1. Participates and is able to take initiative	5, 11 - 13

Additional achievements noted by Ruth were;

- Marcus's posture improved
- Marcus's self confidence improved.

Discussion

- Marcus's achievements in Yoga showed a consistent and steady pattern with a gradual increase in his performance levels. The three week gap at the end of March made no difference to Marcus's progress. This was in direct contrast to Marcus's

behaviour within the Centre which over the same period of time was becoming more challenging.

- Marcus's relationship with Ruth, the therapist, was hard to ascertain. There was some friction at the start before Ruth realised that Marcus hated being the centre of attention. By adjusting her approach Marcus became much more relaxed although occasionally he appeared to resent physical prompts and reminders. Typical responses on such occasions would be "For God's sake" or "stop fussing". Other occasions saw Ruth and Marcus sharing a joke and Marcus always made a point of helping Ruth prepare and clear away.

- During the yoga sessions Marcus's confidence grew to such an extent that he took the lead in the sessions.

- Marcus was able to join in and become fully relaxed during the last part of each session, when the group laid down and relaxed to music. However he became agitated (Sessions 2, 3, 5 and 7) when Ruth asked the group to finish relaxing and slowly stretch. To counteract this problem Ruth tried turning the music off at the end of the session and letting the participants leave in their own time. Marcus reacted well to this change but still seemed withdrawn and uncommunicative. He was unable to explain his feelings but Ruth, the observer and Marcus's keyworker felt that Marcus did not want the session to

finish - he was relaxed and enjoying the music and perhaps did not want to return to his normal routine.

- One of the aims of the yoga sessions had been to encourage Marcus to participate, not only did he participate in the exercises but also, from session 7 onwards, Marcus began to interact/participate with other members of the group. Yoga had therefore been a successful medium to enable Marcus to achieve this goal.

Summary

The picture drawn of Marcus at the start of the chapter shows him as a man of ever changing moods, behaviours and reactions. He generally has difficulty relating to his peers and his frequent episodes of challenging behaviour are a source of concern to all at Elmhurst.

During the Preliminary Study Marcus seemed to respond well to, and enjoy, the constructive activity - sweeping. However he was not always relaxed or easy in the succeeding session.

Marcus took to the Yoga sessions well, following the instructions and coping with, and sometimes enjoying the company of the other service users. His sense of humour and ability to initiate postures and preparatory activities were frequently present.

The main study social/leisure activity found Marcus to be less settled in comparison to the preliminary study but much better than in general day to day centre activities where there was an increase in challenging behaviour.

Marcus was more at ease and less distressed/angry while engaged in structured individual or small group sessions, i.e. sweeping and yoga.

MELANIE

PERSONAL PROFILE

Melanie is 22 years old, she is tall (5ft. 5ins.), well built and has short fair hair. On first meeting her one immediately notices her happy smile, affectionate manner and her ability to demolish anything in sight! Although fully mobile, Melanie is clumsy and uncoordinated, falling and bumping into things due to either her frequent petit mal fits or her innate enthusiasm and boisterousness. Melanie has very little recognisable speech but nevertheless is fairly communicative and can be very vocal to communicate emotions or seek attention.

Melanie has a profound learning disability (Stanford Binet Intelligence Scale, form L M, - Mental Age = No Score) with global retardation/epilepsy. There appears to be no apparent cause for her disability but it is possible it is the result of a whooping cough vaccine at the age of 20 months.

Melanie lives at home with her Mother and an older and younger brother who not only look after her but also show great love for her. Her maternal grandmother is also a key figure in the family. Melanie's father is separated from her mother and is not allowed access to her. Due to the constant attention, support and energy it requires to look after her, Melanie has respite care every weekend and at holiday periods in a Health

Authority residential home. During the week days she attends the Special Care Unit at Elmhurst Centre full time.

Melanie will rarely make speech noises when spoken to but is continually vocalising using squeaks and open vowel sounds. She does, however, employ some informal communicative behaviours, in particular she will use whole body action. Melanie will gesture by reaching out to be lifted or hugged, and will clap her hands if she is happy or wants something. She will also watch people with interest and responds to familiar people differently from strangers. Melanie always looks at the person talking to her and will show awareness of sounds, voices, music and different tones of voice. She can wave goodbye and will hold her bottom if she wants to go to the toilet.

Melanie has very limited verbal comprehension skills, but is able to respond to her own name and appears to understand the word "No". She will sometimes respond to simple spoken requests and follow simple directions. Melanie kisses and hugs people as a sign of affection and may hit out if frustrated. She will also smile when she wants something. Melanie has no visual problems, and can recognise staff, family, food etc.

Within the Day Centre Melanie responds best when she is involved in a highly structured programme. This is necessary as she needs to know her boundaries - she will run around the Unit, eat or destroy items of equipment and knock people or

things over if she is not supervised continually. She will actively co-operate in some activities, and will also, at times, sit and refuse to move or co-operate.

Melanie particularly likes physical activities, e.g. trampolining, walks, football and keepfit. However her fine motor skills are poor and consequently she is not interested in any "table top" activities. During relaxation and massage sessions Melanie usually manages to rest and occasionally her eyes start to close. If able, she will fight this, always wanting to be part of anything that may happen. Melanie loves going out and mixing in the community. However her behaviour is not socially acceptable. She will take items from shops and eat them, push people out of the way and knock displays over.

Socially, Melanie appears to prefer the company of people who are more able than her peer group. She responds very well to the staff in the Special Care Unit, but does not yet have the skills to form friendships amongst the other clients.

THE PRELIMINARY STUDY

Constructive Activity

Any quiet, constructive activity is usually a challenge for

Melanie who has an incredibly small concentration span and finds it virtually impossible to sit still for more than a few seconds. Bearing this in mind the staff team decided that watching a series of slides would increase Melanie's concentration and help her focus her attention - the constantly changing, magnified pictures would hopefully achieve this aim. After three sessions the activity was changed due to Melanie breaking the slide projector and Janet, the keyworker, was asked to assist Melanie pick up a piece of replica food from her left hand side, hold it and then put it in a box on her right. The objective was firstly to see if Melanie showed any signs of recognising the food, secondly to increase her concentration and thirdly to introduce Melanie to a sequential task.

Social/Leisure Activity

Melanie had recently been introduced to, and shown great enjoyment of, relaxation activities, this coupled with her love of water made a session using the footspa an obvious choice for the second activity.

The Keyworker

Melanie's Keyworker was on maternity leave and the role had, for the purpose of this project, been temporarily assigned to Janet who had recently left Elmhurst but had asked if she could

be involved in this research programme. Previous to leaving the Centre Janet had worked in the Main Centre and had taken a special interest in Melanie.

To overcome any difficulties Janet arrived well before the sessions were about to commence so she could meet up with Melanie and get up to date information from the staff in the Special Care Unit. The impact of Melanie's primary keyworker not being there and the other staff changes were being felt by Melanie who expressed her confusion in mildly challenging behaviour - e.g. even lower concentration span, hyperactivity.

Setting

The first two week's sessions took place within the Special Care Unit, the first activity in the noise/quiet room and the footspa session in one of the lounges. After this, because of timetabling difficulties, the participants were asked to use the staff room. Although having initial reservations regarding this venue it subsequently turned out to be most beneficial as there were less people and things to distract Melanie. A description of this environment has been described on page 189.

Results

On completion of five sessions (Melanie was ill on two occasions and the Keyworker had one weeks holiday) the data was summarised as described on page 120 and the following expressions/actions were found to be characteristically distinctive of Melanie.

Table 24 Melanie's Most Common Expressions and Actions

In 8 out of 10 Activity Sessions - 80%

- Laughs, mouth open, face animated.
- Clapping

In 6 out of 10 Sessions - 60%

- Holds, touches and cuddles Janet,
- Hits, slaps and kicks Janet.

In 5 out of 10 Sessions - 50%

- Rubs nose.
- Dribbles
- Rocking

Table 25 Summary of Melanie's Responses or Reactions that Express Feelings and Emotions (form B)

Like	Dislike
Cuddles and touches person	Won't move
Claps hands	Won't co-operate
Hugs and kisses person	Squealing noise
Co-operates	
Takes person's hand	
Amusement	**Boredom**
	Disrupts activity
	Yawns?
	Walks away
Alert	**Listless**
Eyes focused	Quiet, very little movement
Looks up at external noises	Blank expression
Aware of surroundings	
Excited	**Apathetic**
Clapping, Rocking	
Waving Arms	
Laughing, Dribbling	
Jumping up and down in seat	
Blowing 'raspberries'	
Relaxed	**Tense**
Eyes flickering shut	Won't let herself fall asleep
Body still	
Mouth open	
Arms/hands limp	
Happy	**Sad**
Laughing and dribbling	
Big smile	
Enjoyment	**Displeasure**
Clapping	
Smiling	

Additional Findings

a.) Only having five sessions made it harder to identify consistent responses. A whole range of responses were observed

in four out of the ten sessions, some of which may have, over a longer time, become significant.

b.) Touch was found to be all important to Melanie. She never appeared to want to be on her own.

c.) The impact on the staff changes, within the Unit, was having a profound effect on Melanie.

d.) However boisterous and energetic Melanie was in the first part of the session, she was able, (except in session 6), to relax and calm down during the footspa session.

e.) The hitting, slapping and kicking was in no way malicious or a sign of distress. These behaviours were partly Melanie's desire to touch and be touched and partly the result of her high spirits and attention seeking.

f.) There was no apparent progress made in the constructive activity sessions. However this could not be expected in such a short space of time and especially as the activity was changed midway through the study. Melanie found it hard to concentrate, destroyed teaching aids and was very energetic.

g.) Melanie's behaviour was similar to that experienced in the Unit during comparable activities.

THE MAIN STUDY

(The setting and process of the sessions are similar to that described previously for Marcus (pages 188 -189), therefore only additional information relating directly to Melanie will be recorded.)

a.) Therapeutic Intervention

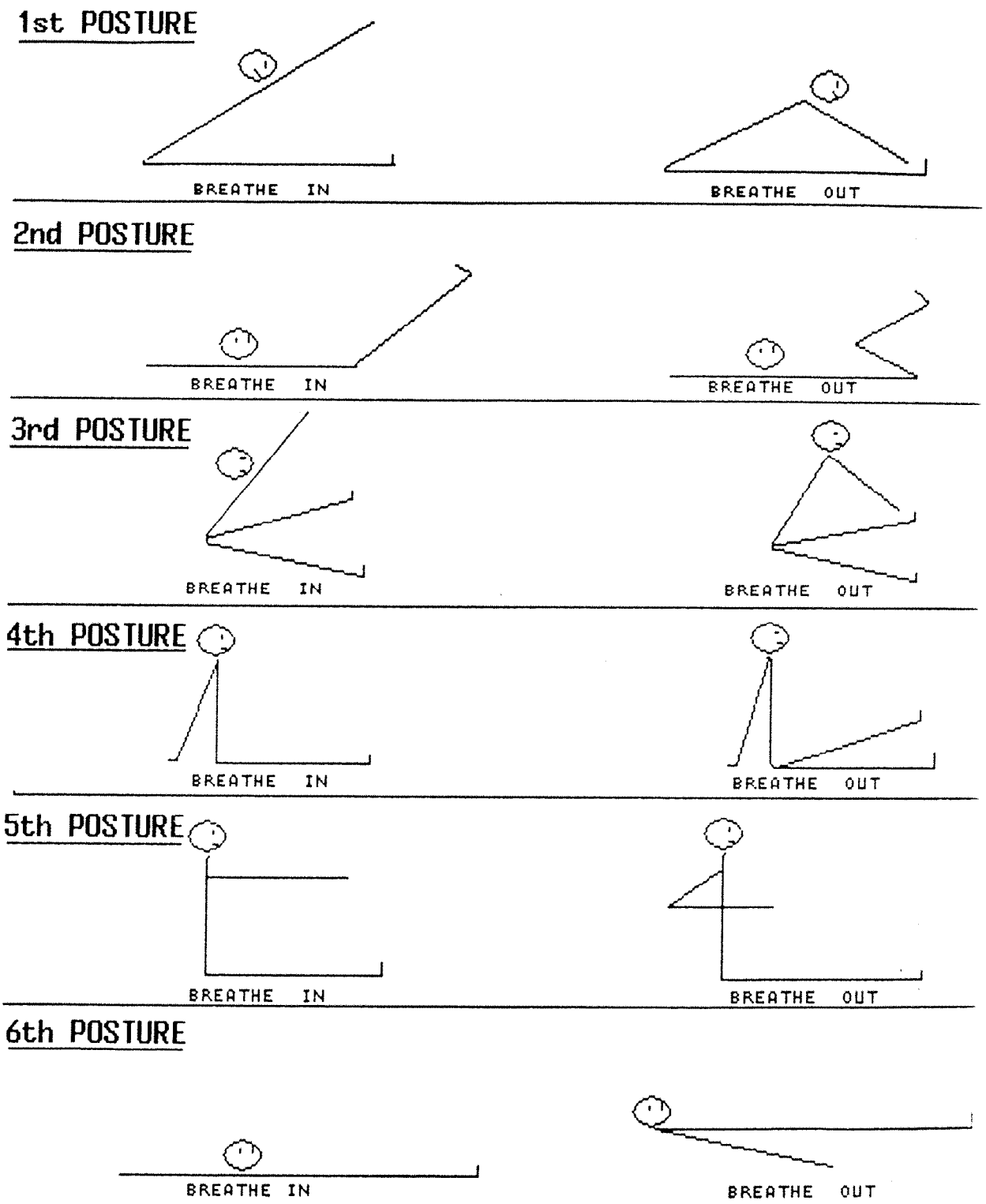
After having met Melanie and talked with her Keyworker and Instructors to ascertain Melanie's abilities, needs, and preferred methods of working, Ruth chose and adapted seven postures (exercises) and breathing exercises for Melanie (fig. 6, p. 214).

Melanie was allocated the first session and she and Ruth worked with only the observer present. Melanie's lack of comprehension and concentration coupled with her exuberant and impetuous personality made it necessary for the session to be very flexible, adaptable and needs led. For example if Melanie turned and lay on her stomach rather than lying on her back Ruth would adapt a posture and exercise with Melanie in that position. Had she attempted to encourage Melanie to turn over by physically prompting her Melanie would have taken the opportunity to play and something resembling all-in-wrestling would have occurred. Melanie needed Ruth to move each part of her body in order to practice the postures. However this quickly became a shared activity with Melanie co-operating. On completion of the yoga postures Melanie's sessions ended with a few minutes of relaxation to the accompaniment of music

The Setting

A variety of locations were used (page 188).

fig. 6.


1st POSTURE
BREATHE IN
BREATHE OUT
2nd POSTURE
BREATHE IN
BREATHE OUT
3rd POSTURE
BREATHE IN
BREATHE OUT
4th POSTURE
BREATHE IN
BREATHE OUT
5th POSTURE
BREATHE IN
BREATHE OUT
6th POSTURE
BREATHE IN
BREATHE OUT

b.) Social/Leisure Activity

The social/leisure activity and the accompanying methodology chosen for the Preliminary Study, i.e. a footspa session remained the same as did the setting and Melanie's keyworker, Janet.

MELANIE'S RESPONSES

Vignette of Session 3

Yoga:
Before beginning the session all the unnecessary furniture and equipment was cleared away thereby creating a similar environment to the previous week.

The author later learned that Melanie had watched Ruth arrive and was determined not to miss her session. Melanie could not therefore be persuaded to go to the toilet after her lunch and to ensure her intentions were understood she sat herself down in the corridor, refusing to go with any of the staff. She did however, get up, laughing and clapping (see checklist) when Ruth came out of the room to fetch her. After a cuddle and making loud laughing noises Melanie sat down heavily on the mat.

From her experiences of the last two sessions Ruth felt more could be achieved if she used Melanie's body position to determine the posture they would work on rather than have a pre-planned series of exercises. Accordingly, Melanie sat up with her legs out straight in front of her, well positioned for the 4th posture. Immediately Ruth lifted Melanie's leg she lay back and covered her face with her jumper, she was laughing but co-operated well with her legs (13 secs). Using both verbal and physical prompts Ruth suggested Melanie sat up and started the 3rd posture.

Although she was constantly looking around the room Melanie worked well (31 secs) only stopping when Ruth praised her, when she disengaged hands to clap herself. Melanie's excitement continued, she looked happy and started wriggling around the room towards the door. Eventually Melanie turned on to her side and Ruth manoeuvred herself to a suitable position and began posture 6. Melanie waved her legs in the air but let Ruth exercise her arms (42 secs). Together they move into the 1st posture (29 secs) before Melanie wanted to play - slapping Ruth and trying to catch her head between her legs.

This pattern was repeated with exercises interspersed with Melanie cuddling and playing (42 secs and 19 secs). Following this Melanie sat up straight on the mat with her legs crossed, body still, clapping her hands and looking around. She appeared relaxed/calm. However at Ruth's suggestion she was quite happy

to lie back and have her legs lifted in turn, i.e. 4th posture (21 secs). Ruth then knelt behind Melanie, her head resting on Ruth's knees and they started the 6th. posture. Although Melanie's legs were waving in the air she once again appeared calm and Ruth responded by talking much more quietly. Ruth lowered Melanie's head gently and moved away to put on a tape of relaxation music, Melanie remained in the same position until Ruth returned.

Here they stayed, Melanie giggling and waving her legs in the air (4 secs) and eventually becoming still (1 min. 26 secs). Both Ruth and the author felt 'moved' by the atmosphere - the music, Melanie's peace, and a sense of achievement. In contrast was the absurdness of Melanie's posture i.e. lying on her back, legs crossed in the air. Melanie ended the session by sitting up, getting herself to a kneeling position and signalling she wanted to go to the toilet.

Spa Bath:

Janet noticed that Melanie appeared relaxed at the start of her session. She sat with her legs slightly apart, her arms between her legs, mouth open and smiling. Even though Janet was in easy reach Melanie did not move towards her, hit her or attempt to cuddle her. However on one occasion Melanie reached out and took Janet's hand and put it on her own head, when Janet drew away Melanie tried again and kept on persisting until she had made Janet realise she wanted her head stroked. As the session

progressed Melanie's face became expressionless as she relaxed. She then returned to laughter and playing with the water.

Summary:-

- There had only been two other clients in the Unit that day and consequently the staff noted that the morning had been quiet, relaxing and enjoyable.
- Ruth believed the session had gone very well and felt Melanie was becoming more receptive.
- Melanie's responses are improving, she initiated most of the postures and gave very little resistance during the session.
- Melanie moved around the room less and appeared calmer.
- Melanie spent 3 min. 17 secs exercising and went into a relaxed position for the first time (1 min. 30 secs)

Melanie's Most Common Expressions and Actions

Table 26 - therapy session

	Main Study	Preliminary Study	Interpretation
Laughs, mouth open	- 100%	- 100%	Excited/happy
Claps	- 100%	- 100%	Likes
Holds, touches, cuddles	- 77%	- 60%	Likes
Covers face with jumper	- 69%	- 20%	Excited/plays
Relaxed	- 69%	- 40%	Relaxed
Rubs, eyes, nose, face	- 54%	- 20%	Relaxed
Hits, slaps, kicks	- 54%	- 60%	Excited
Dribbling	- 8%	- 80%	Bored?/ Excited?
Jumping on seat	- 15%	- 60%	Bored?/ Excited?
Rocking	- 15%	- 60%	Bored?/ Excited?

Discussion

- The therapy sessions were a very positive experience for Melanie. She liked the Instructor and held, touched and hugged her. Melanie appeared happy in the environment and was able to become relaxed even though there were periods in each session of great excitement. There were very few of the negative responses e.g. dribbling, experienced in the preliminary study. From this evidence it is possible to conclude that whereas the personnel and setting were liked by Melanie in both studies the content of the main study sessions, i.e. yoga, received more positive acclamation and less excited/destructive behaviour.

- There are only three common actions and expressions in the main study which had a comparable response in the preliminary study, i.e. laughs, claps and hits/slaps/kicks all of which indicate Melanie was excited by, and liked something or someone within both the therapy and the constructive activity sessions. The most probable conclusion, taking into account the above deduction is that these actions showed Melanie's enjoyment of Ruth and Janet's company.

- The diversity in responses was found in the following areas:-

a.) Covers face with Jumper - this response was most conspicuous during the therapy sessions. Ruth, at first thought it was a sign that Melanie was too hot. Over the course of time this did not prove to be the case, and on some occasions Melanie used the yoga mat instead of her jumper. There was no explanation for this response and its predominance during the therapy sessions other than Melanie's love of fun and Melanie's assumption that she and Ruth were playing together on the floor.

b.) Dribbling, rocking, jumping on seat - are almost eliminated once the therapy session took the place of the constructive activity. Initial findings concluded these actions could be construed as responses to excited behaviour. However in the light of findings from the main study, i.e. Yoga sessions which were often energetic and boisterous, the author suggests that dribbling and rocking may have indicated lack of interest or boredom.

c.) The therapy sessions produced more responses of relaxation and the accompanying rubbing of eyes than the constructive activity. From this the author concludes that in addition to some learning and progress being achieved (see progress in Yoga page 226) Melanie achieved a state of calmness.

Table 27 - Social/leisure activity

	Main Study	Preliminary Study	Interpretation
Very still, eyes closed	- 69%	- 80%	Relaxed
Relaxed	- 62%	- 40%	Relaxed
Hits, slaps, kicks	- 62%	- 60%	Excited
Laughs	- 54%	- 60%	Happy/Excited
Eyes glazed, staring	- 38%	- 20%	Relaxed?/ Listless?
Rubs, eyes, nose, face	- 31%	- 80%	Relaxed
Mouth open	- 38%	- 60%	Relaxed
Holds, touches cuddles	- 23%	- 60%	Likes

Discussion

- Melanie was able to become still and relaxed during nine out of the thirteen sessions of the main study. There was no link found between the length of time spent relaxing in the Yoga session and the success in relaxing in the social/leisure activity.

- By combining the responses 'very still, eyes closed' and

'relaxed' from both studies, the sessions when relaxation occurred are very similar. This was not unexpected as the main study design mirrored the preliminary study in every way. However the many responses that were not similar are hard to explain. There were fewer responses in the main study that were consistently recorded, Melanie did not need to touch/cuddle Janet in order to relax and before relaxing Melanie did not exhibit responses normally present e.g. rubbing eyes. It is possible that the previous session in the main study - yoga - had already put Melanie in a relaxed mood and she therefore did not 'unwind' or need Janet to help her relax. It appears therefore that the impact of the first session, i.e. constructive activity or therapy, may affect the outcome of the second activity i.e. social/leisure activity.

- It was noticeable that during the social/leisure activity in both studies there were fewer responses that expressed excitement e.g. clapping, 'blowing raspberries', than in the constructive activity or therapy sessions. It can therefore be concluded that Melanie was more relaxed and unexcited when using the spa bath.

Table 28 - Overall responses

The responses shown are a combination of two activities, i.e. the therapy session (yoga) and the social/leisure session (spa bath) and therefore give a global picture of Melanie's reactions.

	Main Study	Preliminary Study	Interpretation
Laughs, mouth open	- 76%	- 80%	Excited/happy
Claps	- 65%	- 80%	Likes
Relaxed	- 65%	- 40%	Relaxed
Hits, slaps, kicks	- 57%	- 60%	Excited
Holds, touches, cuddles	- 50%	- 60%	Likes
Very still, eyes closed	- 50%	- 40%	Relaxed
Covers face with jumper	- 50%	- 10%	Excited/playful
Rubs, eyes, nose, face	- 42%	- 50%	Relaxed
Dribbling	- 19%	- 50%	Bored?/Excited?
Rocking	- 19%	- 50%	Bored?/Excited?

Discussion

- Table 28 shows many similarities between the Preliminary and Main study. The four most common actions and expressions in the Preliminary study appear in the top five most common actions and expressions in the Main Study. It can therefore be concluded that although the first activities (constructive activity, Preliminary Study - therapy, Main Study) in the two studies differed, the most frequently observed responses were similar. All four actions are interpreted as showing excitement

and predilection which could well be the result of the individual attention Melanie received rather than the activities themselves.

- Four responses appear at variance to the Preliminary Study:-

1. Covering face with jumper - this was a new response, not observed before by Centre staff. From Melanie's demeanour and the context it can be concluded that this response is a sign of excitement and playfulness.

2. Dribbling and 3. Rocking - see notes on Table 26

4. Relaxed - the greater frequency of relaxation as a response can be explained by differences in the first sessions. During the constructive activity there was no opportunity for Melanie to formally relax whereas in the therapy sessions a time was set aside for relaxation prior to the session ending.

- Using the Summary of Responses or Reactions that Express Feelings and Emotions (Form B) it is apparent that Melanie enjoyed partaking in the therapy sessions and the social/leisure sessions, i.e. she smiled, laughed, touched, cuddled and co-operated. Similar responses were recorded in the constructive activity sessions. However boredom and destructive behaviours were also expressed.

- The observer and Melanie's keyworker confirmed that the responses recorded in Table 28 - Main Study are not typical of Melanie's daily behaviour within the Unit. There would be more

negative responses and less behaviours showing a relaxed state. The setting was similar, however the staffing ratio was higher, 1 : 1 as opposed to 1 : 3, and 3 out of 4 activities were concerned with relaxation. From this it can be concluded that in these studies both a higher staffing ratio and a relaxing activity produced positive responses and calmness in Melanie.

Melanie's Progress in Yoga and Social/Leisure Activities

From the data obtained from the sessions and Ruth's own notes and charts Table 29 was devised as a method of recording Melanie's progress and achievements during the yoga sessions.

- Column a shows times spent exercising
- Column b shows times spent relaxing
- Column c shows performance levels in Yoga on a scale of 1 - 6. 1 = Passivity, 2 = Interest, 3 = Recognition, 4 = Expectation, 5 = Co-operation, 6 = Initiative.
- Column d shows ability to relax during social/leisure activity on a scale of 1 - 4. 1 = totally unable to relax, throwing things, moving. 2 = calm, playing quietly whilst sitting still. 3 = relaxed, 4 = totally relaxed,

Table 29 - Melanie's Progress and Achievements in Yoga and Social/Leisure Activities

	A	B	C	D
Session 1	1m 36s	0m	1	4
Session 2	6m 05s	0m	2	1
Session 3	3m 17s	1m 30s	3	3
Session 4	2m 39s	5m 42s	3	3
Session 5	2m 20s	7m 01s	3	1
Session 6	6m 09s	4m 53s	4	4
Session 7	2m 29s	0m 32s	4 and 6	2
Session 8	2m 25s	2m 39s	5	2
Session 9	2m 59s	0m	5	1
Session 10*	1m 45s	2m 13s	1	-
Session 11	4m 17s	2m 29s	3	3
Session 12	3m 45s	2m 11s	3	1
Session 13	0m 49s	5m 22s	6	3

Discussion

*(session 10 - regular social/leisure activity did not take place due to Melanie's broken foot.)

- Melanie demonstrated she was able to learn, co-operate and initiate yoga postures. She worked out for herself how to take the yoga mat out of it's bag (session 6), took off her shoes and sat down when she entered the session and learnt how to switch on the spa bath (session 9). This evidence shows that given the correct medium i.e. a subject or activity that Melanie enjoys, both specific and related areas of skill can be learnt. This argument is supported in this study by the fact that Melanie did not show even the slightest improvement during the constructive activity where she expressed behaviour linked to boredom and dislike. In addition the ability shown is not commensurate with results of a previously taken IQ test (no score). Presumably Melanie was not interested in the activities involved in the test and therefore did not co-operate. The progress achieved in the Yoga sessions is very rarely seen in other parts of Melanie's programme.

- Between Session 9 and 10 there was a break of three weeks due to Ruth being on holiday and Melanie breaking her foot. Session 10 shows Melanie's performance in Yoga going right back to the start but quickly returning to previous levels.

- The time recorded for exercising can be misleading - on some occasions Melanie's efficiency and co-operation meant that she completed the exercises in a faster time (sessions 7, 8 and 9).

- Ruth concluded that as well as the yoga achievements shown on the table, Melanie had also extended her concentration level and had been able to lie still during relaxation.

- During session 13 Melanie excelled at Yoga despite staff being concerned about her health prior to the session. No reason was found for this disparity which highlights the problems of service users who have no recognisable form of communication.

- No consistent pattern of relaxation appeared in the social/leisure sessions, neither was there any correlation between Melanie's ability or lack of ability to relax in the Yoga session.

- During the period of the two studies there was no discernable change in Melanie's overall behaviour within the day centre.

Summary

The personal profile described Melanie as a vivacious, happy woman who despite her profound learning disability manages to relate and interact with staff and family. However Melanie's

boisterousness and impatience make it virtually impossible for her to take part in sedentary or community activities.

Melanie appeared to make no progress in the preliminary study constructive activity. In contrast during the therapy sessions Melanie cooperated, learnt new skills and extended her concentration levels. Her responses to the social/leisure activities in both the preliminary and main studies were similar, i.e. Melanie became still and relaxed.

CONCLUSION

Yoga as an intervention appears to have achieved more beneficial outcomes for the two participants than other activities on offer to them within the day centre. In addition there was a decrease in Marcus's and Melanie's unacceptable behaviours during the therapy sessions.

The intrinsic structure of the therapy met both participants needs for security and boundaries whilst at the same time providing them with a medium to relax.

CHAPTER 6

DISCUSSION OF FINDINGS

INTRODUCTION

The aim of this research project has been to look at the development of Social Services day care services for people with profound learning disabilities or severe learning disabilities and challenging behaviour. Having identified current policies/philosophies and services both nationally and in one local authority a relatively new response was outlined and studied.

This chapter will look, in more depth, at issues arising from the therapeutic intervention and then examine these findings in relation to service provision and organisation, i.e. in the wider context of the first phase of the study.

1. THERAPEUTIC INTERVENTION

Despite the fact that professionals working in the field of learning disability regularly discuss the use of complementary therapies in day and residential settings, the

literature review showed very little evidence of a systematic study of their benefits or indeed harmful effects.

The author, in her role as Assistant Manager in a Day Centre, was aware of this gap but still supported and encouraged the introduction of complementary therapies believing them to be holistic in nature and an aid to relaxation and calmness. In addition they appeared to be an appropriate response to the current philosophy of respecting each person as an individual in their own right. To examine this idea further and to look at the advantages of a non-behavioural approach, a systematic exploration in this area was conducted.

The findings from the research suggest that:-
1. During the therapy sessions all four participants' behaviour was qualitatively better from that normally exhibited during day to day activities; there was a decrease in negative responses and a considerable increase in positive behaviours.

All the participants' interactive and social skills improved dramatically in this context. This was characterised by Luke initiating interaction with the therapist, Melanie co-operating and learning additional skills, Ann communicating in an adult and relaxed manner and Marcus interacting with his peers and gaining confidence. Achievements of this type, whilst initially appearing relatively small and simple, are

quite remarkable for people with such severe disabilities as the four participants.

Confirmation that this was a result of the therapy can be further verified by comparing the data from the Preliminary study and the Main study. As mentioned previously (page 110) one of the objectives of conducting a preliminary study was to provide a comparison but at the same time eliminate the possible argument of the results showing a placebo effect, e.g. 1 - 1 attention or the personality of the worker. More positive responses were recorded to the therapy session than to the constructive activity session. Given that the process was virtually the same, e.g. similar settings and staffing ratios, it seems likely that it was the therapy that brought about the positive changes in behaviour.

2. For the two service users who had challenging behaviour there was a very high occurrence of relaxation within the therapy sessions (Marcus in every session, Ann in 80% of sessions). This was an unusual phenomenon. Firstly in that their normal programme within the Centre does not contain activities that induce relaxation, and secondly their personalities/disabilities show evidence of unrelenting tenseness and restlessness.

Further evidence of Marcus's and Ann's stability and progress during the therapy sessions is shown by comparing their

behaviour in these sessions to that in other activities. During the course of the research their behaviour within the day centre, was deteriorating rapidly, i.e. the frequency of episodes of challenging behaviour were escalating - this was not the case during the therapy sessions, in fact Marcus increased his levels of skill and confidence and Ann was relaxed and calm.

3. Luke and Melanie, the participants with profound learning disabilities, also responded better to the therapies than to activities in their individual programmes. Luke although often relaxing during regular activities demonstrated the ability to relax even when agitated prior to the session and showed an active interest and enjoyment in the session. Melanie, through the medium of yoga, enjoyed the structure and exercise provided by the sessions whilst at the same time being able to relax and learn new skills.

4. Whilst the two therapies had very different structures the participants were equally able to demonstrate the ability to relax and achieve a great sense of well being and contentment during the sessions. If in the future many more therapies are found to have the same results, the therapy most appropriate to a service users needs and wishes can be used. For example Yoga requires a minimum of physical contact, is structured and didactic whilst aromatherapy involves close proximity and contact, is quiet and inactive.

5. The introduction of complementary therapies widens the range of appropriate activities available to people with either profound learning disabilities or severe learning disabilities and challenging behaviour. In addition they encompass and emphasise the philosophy of Social Role Valorisation (Wolfensberger 1983). Therapies differ from traditional day centre activities which have been skills based, e.g. woodwork, further education, and service led. This has frequently disempowered service users by not acknowledging their needs and wishes and discouraging individuals' involvement in assessment and planning. In contrast yoga and aromatherapy are examples of holistic activities which are needs led yet produce similar, if not better results.

In the past some of the above mentioned outcomes could have been achieved by different methods, e.g. behaviour modification, but these tended to be predominantly controlling and occasionally punishment based (Brandon, 1989). The advantages of complementary therapies are that they give regard and respect to individuals and are age appropriate, gender neutral and enhance dignity.

Whilst acknowledging the benefits and many successful outcomes of the therapeutic intervention it is important to also consider the limitations of these positive outcomes.

Several questions arise which could form the basis of further study/research:-

- Did the intervention have any long term effects? It appeared from this study, although no evidence was collected, that the achievements recorded in the sessions were not transferred to other areas of the participants' programmes.
- Would more frequent, regular sessions produce long term, positive outcomes?
- Did the intervention inadvertently cause the participants, consciously or subconsciously, to feel dissatisfaction with their normal programme or were the sessions seen as a refreshing, invigorating interlude from the demands of everyday life?

2. ASSESSMENT

The findings from this study suggest that both therapies produced beneficial results regardless of whether the participant had a profound learning disability or challenging behaviour. What was important, in this evaluative study was the development and use of a specialised, unique assessment of need prior to holistic interventions being introduced - this will now be discussed further.

Traditionally assessment (page 111) was regarded as the administration of tests or measuring people with learning

disabilities to categorise them into sub groups, e.g. subnormality and severe subnormality. Another function of assessment, in the past, was to ascertain a person's level of functioning taking either a scientific or a behavioural approach. The prime rationale behind the testing was firstly to 'fit' a person with a learning disability into already existing services and, secondly, to determine the level on which instruction/teaching should commence.

Whilst acknowledging the validity and value of some of these models, when used independently of other information they deviate from the current philosophy of looking at, and respecting the whole person as an individual and meeting each person's unique needs.

In today's 'needs led' climate (page 29) it is essential to design and develop assessments that take account of a person's strengths, needs, likes, dislikes, significant life events, personality, sensory and health considerations and the wishes of the individual and his/her family or carer. This knowledge can then be used to tailor an individual package of care/service for each person. The approach developed in this study is one such way of gathering the information required, it also has wider applications for service provision (page 244).

The methodology, using new techniques e.g. close observation

to record emotions by video analysis, produces a more accurate understanding of a person in a relatively short time (under 8 hours per person). Although initially staff intensive, the obvious benefits of a worker having a detailed understanding of a persons communication pattern, e.g. how they express emotions, are immediately evident. An example of the effectiveness of the methodology is demonstrated by interpreting an action idiosyncratic to Ann - imitating Tarzan. Staff had first noticed this sign when Ann was rock climbing and interpreted it as her own sign for rock climbing. The analysis of the data demonstrated it to mean Ann liked something or someone. Prior to this finding, whenever Ann had made this sign people had always talked to her about rock climbing consequently not 'hearing' what she was trying to say.

Understanding how people with profound learning disabilities or severe learning disabilities and challenging behaviour express abstract concepts such as - like, happy, alert - is essential not only in giving a person a voice but also when teaching new skills. People with profound learning disabilities or severe learning disabilities and challenging behaviour are no different from other adult learners - i.e. they will quickly absorb new knowledge if they are interested and like the subject - staff therefore need to be able to ascertain what a person likes or is interested in. Melanie illustrated this by the skills she was able to acquire during

Yoga sessions (which she liked), whilst not learning similar skills during the constructive activity session. It can be concluded therefore that good individualised assessment leads to better, more appropriate teaching and learning.

The author's model of assessment can further be utilised in the assessment process in the context of the new Community Care legislation. Under section 47 of the 1990 National Health Service and Community Care Act, Social Services Departments are required to conduct an assessment -

> "...the Authority shall carry out an assessment of his (sic) need for these services'; and having regard to that assessment, decide whether his needs call for the provision by them of any such services." (p. 56)

In West Sussex the worker who first identifies a potential need for a community care service fills in an 'Initial Information Form' (SSP 420), social services staff then decide whether no action be taken or whether a simple assessment or complex assessment is required. Where a complex assessment of a person with learning disabilities is required staff working in Day Centres may well be asked to provide the 'specialist' element of the assessment as the majority of generic field workers do not have the necessary expertise or skills.

Formerly people were assessed purely on their requirements for a particular service. However community care legislation now requires that an overall assessment of need be made and a

package of care designed to meet those needs. Consequently new methods of assessment are needed to meet these requirements. The assessment technique developed for this study is one such method, designed specifically to meet the assessment needs of people with profound learning disabilities or severe learning disabilities and challenging behaviour. Service users needing this specialist assessment could attend a day centre for a time limited period. The resulting assessment could then be used by the Adult Assessment team in the preparation of a care plan.

Not only is this model relevant to community care but also to Individual Programme Plans (page 25/26) for people with profound learning disabilities or severe learning disabilities and challenging behaviour. After recently standardizing the IPP procedure, West Sussex has received initial feedback from keyworkers which has been generally positive. However concerns have been raised about the appropriateness of the designated forms for people with profound learning disabilities or people who have communication difficulties. Information recorded on strengths/needs lists has tended to list only skills based achievements or needs, e.g. Melanie can feed independently. However by incorporating the author's assessment techniques into IPP's and recording responses as 'strengths' on a strengths/needs list, e.g.; Luke pats his hands when he is relaxed or Melanie claps her hands when she is excited or

likes someone, a more accurate and practical document may well emerge.

Another key element to the provision of services, highlighted in the NHS. and Community Care Act (1990), is Advocacy, i.e. supporting and helping people speak for themselves and make realistic choices. For people with profound learning disabilities or severe learning disabilities and challenging behaviour it is essential to understand the verbal and physical clues they give in order to assist them in selecting their choices or preferences. The assessment procedure designed for this study can be utilised for this purpose, enabling any advocate to be well informed and aware of an individual's wishes.

3. THE ROLE OF THE DAY CENTRE WORKER

Whilst analysing the therapeutic intervention and the assessment procedure the author became aware of the wide diversity of roles played by the workers at the day centre.

It is only in recent years that these roles have changed and increased, due mainly to the introduction of Social Role Valorisation, the NHS and Community Care Act (1990) and the increasing number of people with profound learning disabilities or severe learning disabilities and challenging

behaviour receiving their day care within traditional Day Centres. This has required staff to develop new skills and approaches to their work.

The shift towards flexible, individual programmes which reflect an individual's wishes and needs challenge the traditional role of the day centre worker. Formerly, day centre staff were employed to 'instruct' people with learning disabilities in specific areas e.g. woodwork, horticulture, art, hence their title - Instructor. This was in line with the service led concept, i.e. the day centre offered various activities into which the service user was 'timetabled'.

Today, staff are expected to carry out a number of different tasks, for example at Elmhurst they are:-

a.) skills based teaching sessions

b.) assessing for IPP's

c.) assessing for Community Care assessments.

d.) co-working with sessional workers

e.) making home visits to arrange outreach activities

f.) keyworking

g.) carrying out administrative tasks

h.) undertaking physical/personal care

The diverse and differing nature of these roles, and the skills needed to implement them, is immediately apparent. Day centre workers consulted felt that these duties fell into two categories - 1. teaching sessions (a, e, g,)

2. keyworking/field work (b, c, d, e, f, g, h,).

Their opinions were divided as to which a day centre worker should do. However, all were unanimous in their belief that ideally the two roles should not be combined as they were at present.

This multiple role currently expected of Day Centre Workers was frequently observed during the course of the practical intervention (12 months). A worker would be called away to meet a social worker or help with a keyperson's problem when she/he was 'timetabled' to work with one of the service users during a social/leisure session, leaving either a colleague to cover or abandoning the activity altogether. The workers appeared to be shifting continually from task to task, not only giving a fragmentary, disjointed service to the clients but having to bear the stresses of the role conflicts.

In contrast the therapist, coming in to work specifically with the participants had none of these internal pressures. They arrived prepared for a time limited session, focused on the activity and were not interrupted by other Centre matters. The resulting sessions were positive for the participants and the therapist because continuity ensured that the service user felt valued, and the structure gave security and enabled learning to take place.

A final observation made during the period of the practical intervention, challenged the traditional assumption that

there is more continuity in staffing at a day centre compared to shift work within a residential establishment. Staff leaving the establishment, sick leave, holidays and staff redeployment within the Centre all led to frequent disruption in Service Users' Individual Programmes.
Many points arise from this discussion of the changing and ambivalent roles of the Day Centre Worker. Firstly Service Managers need to recognise and acknowledge these multifarious roles which have been brought about by community care legislation, changes in philosophy and attitudes and the advent of IPP's.

Secondly, having accepted the impact of these changes the role of the day centre worker needs to be clarified and defined accordingly. The most probable/practical role that could be assigned to day centre workers is keyworker/field worker (p. 241). The justification for this lies in:-

- the worker's knowledge and experience in the learning disability field
- the worker's training which has tended to concentrate on social work skills rather than specialist skill areas, e.g. art and craft, horticulture, yoga.

Adopting this approach would necessitate the employment of sessional workers to provide teaching/facilitating in identified areas of activity. Whilst acknowledging this would increase staffing levels, the increase must be seen as an

essential precondition of a Social Services Department advocating individual programmes for service users. The advantages of sessional workers within day centres, in addition to those identified previously (page 242), are that they need only be 'contracted' when a demand has been identified and a greater variety of activities/courses can be introduced. The keyworker could, if necessary, work alongside sessional workers helping them understand the service users' communication patterns, advising them of significant life events and co-running sessions when required. In this way sessional workers would gain more expertise in the field of learning disabilities, service users would be supported and keyworkers would be able to maintain an overall picture of their clients strengths and needs.

This change in the role of day centre workers raises various issues concerning day care provision and the wider provision of services for people with profound learning disabilities or severe learning disabilities and challenging behaviour.

4. SERVICE PROVISION

Findings from this study confirm that West Sussex day care provision, for people with profound learning disabilities or severe learning disabilities and challenging behaviour, mirror the national picture. It was found that:-

i.) Day care was, initially, a service led response rather than a needs led approach. West Sussex looked at a building suitable for the majority of former hospital 'patients' rather than a range of services that would meet individual need. To this end they built Special Care Units, attaching them to pre-existing Adult Training Centres. This service led approach is further confirmed by the fact that all the units are of the same design. The starting point was the building not the person.

ii.) People with profound learning disabilities and people with severe learning disabilities and challenging behaviour are a minority group. However within this group the main focus of the services were primarily for people with profound learning disabilities. The specialist service required by people with severe learning disabilities and challenging behaviour did not appear to be addressed - they were absorbed into mainstream provision. Evidence suggests that because this group of service users did not need specialised equipment, e.g. hoists, their specialised needs were not specifically addressed.
(Since 1993 this issue has, to some extent, been addressed by West Sussex County Council, Social Services department, with limited funding for additional staffing and resources being made available.)

iii.) Until very recently the County had no overall policy,

aims and objectives for learning disability services. In addition the findings from this study suggest that there is a wide diversity of provision within the County. For example, a dissimilarity in staffing ratios in the main Adult Training Centres, Oakwood having a staff/client ratio of 1:8 whereas Copsdale was 1:12.

iv.) Reflecting this diversity of practice, service development was reactive rather than proactive, there were pockets of good innovative practice which was not communicated or transferred within the Social Services department and developments were piecemeal and frequently the result of an imaginative professional rather than planned policy.

A number of strategies can be used by Service Managers to redress these inconsistencies:-

1. A county wide review of services for people with learning disabilities provides the opportunity to:-

- consider existing services and resources.
- seek the views of users, carers and providers of services etc.
- develop a strategy
- develop and plan services (in the light of existing provision, gaps in provision and local needs).

The County review set up in West Sussex (March 1994), after the completion of this research project, is a relevant example. It was developed through a series of eight project groups, two of which addressed the specific needs of the clients groups in the study - challenging behaviour and mental health needs and people with special care needs, including those with other disabilities and related physical health needs. The project groups gathered information through individual and group discussions, interviews, surveys and examples of good practice. Using this approach a county wide policy began to emerge. Services for people who challenge became one of five key developmental areas but, most importantly, the stakeholders, e.g. service users, carers, purchasers and providers, were consulted and given the opportunity to voice their ideas, opinions and concerns.

2. A different, but equally valid, starting point for service providers/managers to develop and examine their service, in a needs led and valued way, is to use the five accomplishments (O'Brien and Tyne 1986),(page 19/20). In order to consider this further the accomplishments are listed below with examples of good practice specifically related to people with profound learning disabilities or people with severe learning disabilities and challenging behaviour.

Community presence: providing a range of different settings, e.g. non-segregated, small units, where

people can spend their time within the local community.

Choice: not only encouraging and extending choice but actively working to understand people's communication and providing independent advocates where necessary.

Competence: giving people valued, age appropriate opportunities to develop their skills and provide the support required to accomplish them, e.g. yoga and aromatherapy.

Respect: ensuring that service users are valued as individuals within the service and in the community, e.g. their strengths enhanced.

Participation: encouraging service users to mix with non-disabled people, particularly with those not involved in providing a service.

3. Changes to services can also be brought about on a smaller scale by motivated and inspired individuals. Pilot projects, research studies and new developments can all be introduced at a local level (Audit Commission 1986). It is essential however that the positive outcomes are disseminated so that similar practice can be replicated throughout the service.

Adopting and implementing these or similar strategies will not only focus on the disparity of services but will also address the issues of providing a needs led and valued service for people with profound learning disabilities or severe learning disabilities and challenging behaviour.

These strategies mirror several of the key elements to the provision of services highlighted in Guidance to the Act (NHS and Community Care Act 1990):

- The provision of a needs led service
- The participation of service users in the assessment and drawing up of care packages
- Day services being based on individual assessment and programmes
- Community Care plans to be developed annually which set out a range of services that will be delivered, including those for people with learning disabilities.

CONCLUDING REMARKS

This chapter has discussed the main findings of the research project. It has shown that a relatively small scale project can not only have significant outcomes for the participants but can also have an impact on professional practice and service delivery.

The study was clearly important for a number of reasons: It showed that a research methodology could be devised to mirror current social work practice and philosophy; it described an innovative assessment technique; it illustrated one intervention used by a day centre to respond to a change in its clientele and it raised issues of relevance to both purchasers and providers of services for people with learning disabilities.

Despite recognised, and previously discussed, limitations the approach, exploration and intervention demonstrated a holistic way forward that recognises service users' individuality, their unique needs and their right to socially valued and beneficial activities.

APPENDIX 1

NATIONAL DEVELOPMENT TEAM - CATEGORIES

Category 1

Criteria; Competent in all areas of self-help, ambulant, continent, no behavioural problems, not disruptive in any way.

Category 2

Criteria; Continent, ambulant, almost completely self-sufficient with mild problems of behaviour which could be corrected with a short period of treatment and self help training. A number could be considered for self-care training units.

Category 3

Criteria; Continent with lapses at night. Some are mildly over-active with occasional mild behaviour problems. All are said to be easily managed and would benefit from specific training.

Category 4

Criteria; Severe double incontinence, multiple physical handicaps, severe epilepsy, extreme hyperkinetic behaviour, aggression to self and others.

APPENDIX 2 - QUESTIONNAIRE

SURVEY ON SOCIAL SERVICES DAY CARE PROVISION FOR PEOPLE WITH PROFOUND LEARNING DISABILITIES OR SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR IN WEST SUSSEX.

NAME OF CENTRE:.....

STAFFING PROVISION: *(please indicate numbers)*

a. MAIN CENTRE:

Manager	[ ]
Assistant Manager	[ ]
Instructor	[ ]
Care Assistant	[ ]
Driver	[ ]
Caretaker	[ ]
Others.....	[ ]
.....	[ ]
.....	[ ]

Vacancies: *(please indicate below titles and numbers of vacant places)*

b. SPECIAL CARE UNIT

Assistant Manager	[ ]
Instructor	[ ]
Care Assistant	[ ]
Driver	[ ]
Cleaner	[ ]
Others.....	[ ]
.....	[ ]
.....	[ ]

Vacancies: *(please indicate below titles and numbers of vacant posts)*

NUMBER OF CLIENTS:

a. MAIN CENTRE:

Maximum Number of Places	[ ]
Number of People on Register	[ ]

b. SPECIAL CARE:

Maximum Number of Places	[ ]
Number of People on Register	[ ]

PEOPLE WITH PROFOUND LEARNING DISABILITIES:
(please see attached notes for definition of this client group)

	Male	Female
a. How many people attending the Centre have profound learning disabilities?	[ ]	[ ]

b. Attendance pattern *(please specify numbers)*

1 day per week	[ ]
2 days per week	[ ]
3 days per week	[ ]
4 days per week	[ ]
5 days per week	[ ]
Other	[ ]

c. Where do these people spend the majority of their day care time? *(please specify numbers)*

Special Care Unit	[ ]
Behavioural Unit	[ ]
Main Centre - special needs group	[ ]
Main Centre - normal range of activities	[ ]
Out of Centre activities	[ ]
Other.....	[ ]

d. Does the Centre have written aims and objectives for work with this client group?
(if yes please attach a copy) YES\NO

e. Do these clients have individual programmes?
(if yes please attach an example programme) YES\NO

f. Please list 'out of Centre' staff e.g. physiotherapist psychologist, dance teacher, and the approx. number of hours per week they work. ..... [ ]
..... [ ]
..... [ ]

PEOPLE WITH SEVERE LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR:
(please see attached notes for definition of this client group)

		Male	Female
a. How many people attending the Centre have challenging behaviour		[ ]	[ ]
b. Attendance pattern *(please specify numbers)*	1 day per week		[ ]
	2 days per week		[ ]
	3 days per week		[ ]
	4 days per week		[ ]
	5 days per week		[ ]
	Other.....		[ ]
c. Where do these people spend the majority of their day care time? *(please specify numbers)*	Special Care Unit		[ ]
	Behavioural Unit		[ ]
	Main Centre - special needs group		[ ]
	Main Centre - normal range of activities		[ ]
	Out of Centre activities		[ ]

d. Does the Centre have written aims and objectives for work with this client group?
(if yes please attach a copy) YES\NO

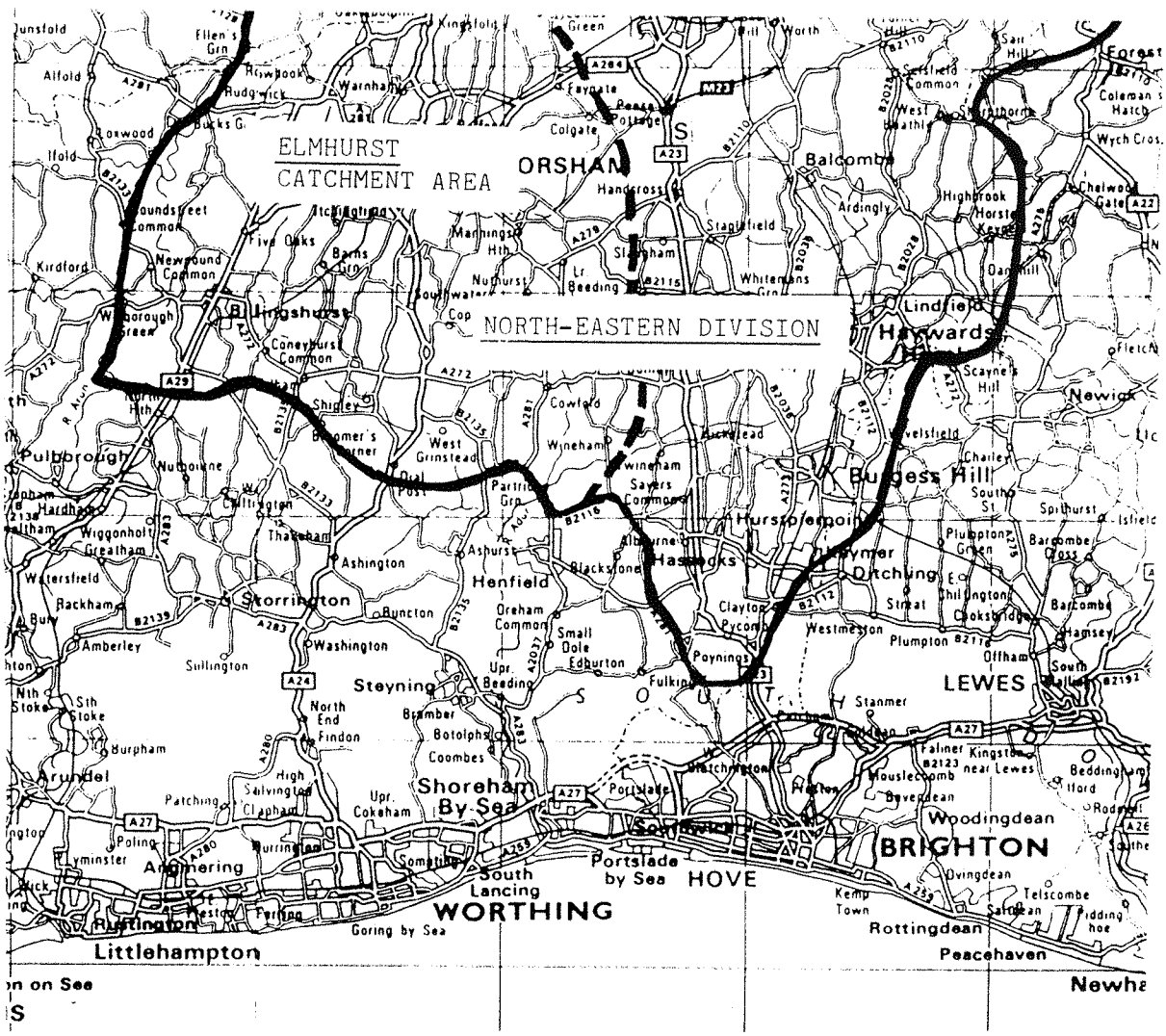
e. Do these clients have individual programmes?
(if yes please attach an example programme) YES\NO

f. Please list 'out of Centre' staff e.g. physiotherapist psychologist, dance teacher, that work with these clients and their weekly hours. ..... [ ]
..... [ ]
..... [ ]

ANY ADDITIONAL INFORMATION YOU THINK MAY BE RELEVANT.
(please attach separate sheet/s)

APPENDIX 3

THE NORTH EAST DIVISION OF WEST SUSSEX SOCIAL SERVICES DEPARTMENT



APPENDIX 4

EXAMPLE OF DATA PRODUCED FROM ONE PRELIMINARY STUDY SESSION

ANN - SESSION 6

1. OBSERVER'S REPORT.

It had been decided by the staff that the colour matching/ identifying was not right for Ann and so another of her needs was addressed - learning to tell the time.

Ann didn't look at the video or me at all until the very last few minutes of the constructive activity session.

After taking her watch off to use in the session and putting it on the table Ann constantly touched it.

Ann looked well and alert.

During the social/leisure activity Ann looked more relaxed than I had seen her before - She was not resting her arms on the table or appearing 'hunched up' and she hardly put her hands to her face.

Ann was able to positively assert her choice in music.

2. KEYWORKERS REPORT.

The activity was different this week. After discussion with Ann and other staff members it was felt Ann would benefit from work connected with time.

I showed Ann 'pictures' of a clock face showing different hourly times, e.g. 1 - 12 o'clock. Ann could identify 2 o'clock, although probably more through luck than judgement.

Then I asked Ann to choose 2 o'clock from two different clock faces showing 2 and 3 o'clock. Ann sometimes chose the correct time and sometimes chose incorrectly

I then asked Ann to draw 2 o'clock on a blank face, copying from the prepared drawing. Ann found this quite difficult - I put the prepared clock under the blank so she could trace over the top. Ann did this for 2 and 3 o'clock.
Throughout the activity Ann concentrated much longer than previous work with the colours. She was happy to remove her bag. She didn't become embarrassed or withdrawn. A couple of times she began irrelevant conversation but once acknowledged by me she concentrated again on her work.

She seems to have now understood that Mary (the author) has left Elmhurst. This was reinforced by a visit to Mary's new Centre that Ann and I made on Weds. 19th August.

During coffee Ann talked again of David - boyfriend etc., about me leaving, a photo of Scamp (my dog) and the video. Ann was relaxed and at ease throughout the session.

3. VIDEO EVALUATION NOTES

Constructive Activity

Ann immediately took her bag off when Jackie suggested it.
Arms folded loosely, resting on table, head forwards shoulders hunched, legs in sitting position, still.
Little laugh as Ann takes her watch off.
Arms unfolded but still resting on table.
Points to stomach - "Better now".
Jackie - "Good, that's right"
Ann intertwines fingers of hand and bends them back - this is a new response.
Folds arms on table.
Ann regularly touches her watch which is on the table beside her. (total number of times = 14)
Sighs, covers face with hands.
Talks about David.
Ann - "Tummy hurts"
Ann quickly points to the answer before Jackie has finished asking the question.

A response from Jackie sounds sarcastic, Ann puts both hands to her head/face, pushes her hair back, sighs and then continues with her head resting on the palms of her hands.
Hands/arms down when she starts the practical tasks again.
Concentrates, i.e. looks hard at watch while Jackie moves the hands - (could have been making sure Jackie wasn't going to take or damage her watch!!)
Ann smiles to herself when she answered correctly.
Quite happy/relaxed as Jackie holds her hand.
Jackie asks a question for the second time to try and elicit the answer - Ann puts her head right down on her arm which is resting on the table but quickly looks up and continues.
Ann thinks - puts her right hand to her head, elbow resting on table.
Pushes hair right back, rests chin on hand.
Jackie - "Do you think that's two o'clock?" - Ann puts her head on the table.
Big sigh.
Head on arms again as Jackie moves the hands of Ann's watch.
Looks up.
Ann gets the answer wrong - bangs table lightly with elbow, hand to head, doesn't look cross, smiles and rubs her head.
Jackie - "Brilliant" - Ann intertwined her fingers as before, raising her hands way above her head, almost a stretch.
Ann hits her chest twice with her fists, Jackie doesn't notice, Ann continues with task.

Arms folded.
Ann won't look at Jackie, when she finally does she puts her hand to her face, appearing embarrassed.
Ann gets the answer wrong again, short smile, hands to face.
Ann thinks the session is finished, picks up her watch, looks towards me and talks.
Jackie draws her attention back, Ann rests her chin in both palms of her hands and resumes concentration.
Jackie - "Count up to ten for me", Ann puts her hand to her face and pushes her hair back before she starts and does it again when she reaches eight.
Ann brings the session to the end by saying "Put watch on now?".

Social/Leisure Activity

Ann sits a little back from the table, left arm loosely resting on lap, right hand holding mug, legs in sitting position a little open. Ann's bag remains off.
Puts coffee down, right hand is placed loosely in lap.
Shrugs shoulders in response to question - "don't know".
Refuses shortbread - "No" and a shake of the head.
Ann - "Pardon Me".
Pats chest twice with open hand.
Talks about her visit to Mary's Centre, her awful behaviour on return to Elmhurst.

During these exchanges Ann's arms hands remain relaxed in her lap or alternatively she is drinking her coffee, her body is still and relaxed.

Ann describes incidents of bad behaviour, hands are clenched and shaking whilst still resting in her lap.

Ann looks at the video camera and says - "Why?".

When Jackie and I laugh as we attempt to explain Ann laughs too.

Jackie talks about her dog, Scamp, Ann says "yes" and smiles.

Ann points to the radio - "My favourite is Abba"

Ann starts many conversations e.g. "Liz is on holiday"

Ann puts her hand quickly to her mouth, almost slaps it and then puts it back.

When Jackie mentions Barry's name (a boyfriend) Ann puts her hand to her head with her elbows on the table (first time this session).

Ann rubs her face with her hand and rests her chin on her hands.

Ann - "It hurts here" - points to her stomach.

Ann talks about a member of staff hiding from her - "I hide" she laughs and rubs her face with her hand.

Arms loosely in lap, little laugh to herself.

Jackie - "Have you finished".

Ann immediately gets up and says goodbye, as she gets to the door she turns and sticks two fingers up at Jackie and me.

4. FORM A

HEAD

Resting on arms
Shakes to emphasis "No"

FACE

Very little expression
Small smiles

MOUTH

Sighs
Smiles

EYES

Expressionless
Eye contact with Jackie

HANDS

Covers/rubs face
Intertwines fingers and bends them back
Touch watch
Points to parts of the body
Rests chin on upturned palms
Hits chest lightly with clenched fists and open hand
Pushes hair back
Hold mug

ARMS

Folded loosely resting on table
Folded loosely in lap
Stretched above head
Elbows on table

LEGS

Sitting position
Always still

BODY

Shoulders hunched
Apart from arm and head movements always still
Pushes body back in chair as if to stretch
Shrugs shoulders

VOCALISATION

No problems, short phrases, normal tone

5. FORM B

LIKE	DISLIKE
	Shakes fist Vocalises Shakes head
AMUSEMENT Smile Laugh	**BOREDOM** Talks about aches and pains??
ALERT Concentrates, i.e. looks at task in hand, answers questions etc.	**LISTLESS**
EXCITED	**APATHETIC**
CALM	**DISTRESSED** Points to stomach - "It hurts" Sighs Covers face with hands??
RELAXED Handbag off Happy for Jackie to touch her hand Hands/arms loosely in lap Stretches	**TENSE** Touching watch constantly Fists clenched
HAPPY Smiles, laughs Intertwines fingers	**SAD**
ENJOYMENT Expresses verbally	**DISPLEASURE** Bangs elbows on table Expresses verbally

CERTAIN/SURE	PUZZLED/EMBARRASSED
Works confidently	Hands cover face Hand to mouth Looks away Pushes hair back??

6. CHART SHOWING MOST FREQUENT PHYSICAL (INCLUDING VERBAL/VOCAL) RESPONSES

Activity	Session						
	1	2	3	4	5	6	
						a	b
Hand covers face						x	
Smile, grin, laugh						x	x
Plays with watch						x	
Relaxed							x
Concentrating						x	
Removed bag						x	x
Arms folded						x	
Body hunched						x	
Talks about aches/pains						x	
Intertwines fingers						x	
Sighs						x	
Smiles/laughs						x	x
Pushes hair back						x	
Hands in lap							x
Talks about bad behaviour							x

(a= constructive activity, b= social/leisure activity)

APPENDIX 5

SUMMARY OF FORM Bs - MELANIE

LIKE	DISLIKE
Snuggles up to Janet - Claps hands - Hugs, kisses - Takes hand - Touches - Co-operates.	Won't move/co-operate Squeal noise
AMUSEMENT	**BOREDOM**
	Gets up from activity Yawns?
ALERT	**LISTLESS**
Eyes focused on activity/ person - Aware of movement outside- Aware of surroundings	Quiet Very little movement Blank expression
EXCITED	**APATHETIC**
Clapping - Rocking - Waving arms - Laughing - Dribbling - Jumping - Blowing raspberries	
CALM	**DISTRESSED**
RELAXED	**TENSE**
Eyes flickering shut - Still - Mouth open - Dribbling - Hands /arms loose between legs	Won't fall asleep completely
HAPPY	**SAD**
Laughing - Dribbling - Big smile	
ENJOYMENT	**DISPLEASURE**
Clapping - Smiling - Participating	
CERTAIN/SURE	**PUZZLED**

APPENDIX 6

EXAMPLE OF DATA FROM ONE MAIN STUDY SESSION

MELANIE - SESSION 1

1. THERAPIST'S REPORT

Melanie appeared to be curious about everything in the room, constantly touching windows, the drawings on the wall, which she tore, the chairs and the cassette radio. She was also aware of the activities which she could see through the window, in other parts of the building. She stuck her head out of the window at one point to gaze at faces she recognized outside.

Melanie's behaviour involved slapping, kicking, rubbing her eyes, pulling chairs and tables, moving around the room, pushing the mats, putting her sweater in her mouth and folding her arms.

Melanie's response to the activity was minimal at first with too many distractions but improved slightly when she was persuaded to sit down rather than stand. At one time she responded by bringing her hands up to touch mine.

2. KEYWORKER'S REPORT

Good session. Melanie was fairly still and quiet enjoying the peace. She looked around a fair bit not taking too much notice of visual distractions. An interruption in the session was taken very well, having little effect on Melanie's behaviour.

Several times she closed her eyes and appeared very sleepy.

Melanie was rubbing her right eye a great deal, whether this was through sleepiness or irritation I do not know.

When I asked if we should finish, Melanie responded a little bit later by taking her feet out of the footspa.

Staff reported that Melanie had been on a community activity this morning, which she prefers to being in the Centre. Therefore she was cheerful and bubbly.

3. VIDEO EVALUATION NOTES

Yoga

Melanie smiling, sitting clapping, banging legs, aware of camera.

Happy to get out of chair.

Let Ruth hold both her hands but jumped up and down. (13 secs.)

Pulls away, touches cassette, window.

Ruth asked Melanie to return to no avail.

Eventually returns smiling, clapping hands in front of her face.

First posture (9 secs.).

Goes towards window, waves at someone outside, takes Ruth over to look.

Wanders around the room playing with things.

Ruth demonstrates next posture, Melanie moves towards door and bangs it.

Opens door but stays in room, happy for Ruth to close it.

Jumps up and down, comes to see me at camera, ignores Ruth.

Goes towards door then window.

Jumping up and down frantically, laughing and dribbling.

Holds Ruth's hands for 5th. posture, pulls away, goes to flip chart, rips picture off wall.

Ruth calm, appears unfazed, uses same tone, firmly/positively encouraging, uses Melanie's name to gain attention.

Melanie returns to tape recorder, puts her head out of window.

Came away with Ruth, stood with her facing each other, Melanie clapping her hands and smiling.

Melanie lifts her T shirt up with her teeth.

Pays attention and works with Ruth (10 secs.)

Turns away to cassette recorder, Ruth asks if Melanie would like some music, stands quietly while Ruth puts a tape in.

Faces Ruth, hands together but jumping, won't participate unless Ruth is actually holding her hands, laughs.
Rips remaining pictures off the wall.
Melanie goes to the window, Ruth decides to continue doing the exercise talking it through even though Melanie isn't paying attention.
Twice Melanie goes to the door but is happy to return with Ruth.
Sit on mat together, Melanie clapping hands and smiling.
Ruth demonstrates 3rd posture but Melanie's eyes are focused on the window.
Ruth stands behind Melanie to lift her arms for the first posture.
Melanie at first pulls her hands away to clap and then grabs Ruth for a cuddle, laughs and smiles.
Ruth tries sitting legs out holding Melanie's hands and they 'see-saw' back and forth, most successful (1 min. 5 secs.)
Ruth changes the exercise to lie down flat - 2nd posture.
As Ruth demonstrates Melanie slaps her, Ruth puts Melanie into that position but Melanie thinks it a game and giggles, twists, kicks and turns.
Melanie pulls the bin over.
Melanie won't keep still, sits up, folds arms, hides head in jumper, rubs eyes.
Try 'see-saw' exercise again (18 secs.)
As she lies on the floor she pulls the legs of the flip chart.
Melanie sits on the floor rubbing her eyes and co-operates with

next posture (1 min. 2 secs.) however her eyes are looking around the room.

Finishes by doing exercises interspersed with playing (3 mins.)

The room looks like a battle zone.

Social/Leisure Activity

Sits on chair, arms hanging loosely by her side.

Rubs eyes.

Quiet.

Doesn't touch any objects within reach.

Hits Janet.

Puts one foot in the spa bath, needs a physical prompt to put other in.

** Very relaxed on chair.

Body still.

Smiles.

Follows Janet's movements with her eyes.

Gently moves feet in the bath.

Body still.

Mouth open, eyes flickering.

Smiles.

One hand is positioned between legs.

Still.

Watching out the window.

Mouth open, no expression.

Slight smile.

Body still, occasional head movements as Melanie looks around.

Rubs eyes.**

Apart from a slight distraction when the door of the room was opened, which brought smiles and laughter but no movement from Melanie, her responses for the rest of the session were as described above (** - **).

4. CHART SHOWING MOST FREQUENT PHYSICAL (INCLUDING VERBAL/VOCAL) RESPONSES

Activity	Session				
	1		2	3	4
	a	b			
Moves away from activity	x				
Smiling	x	x			
Slaps, kicks	x	x			
Relaxed		x			
Sweater in mouth	x				
Rubs eyes	x	x			
Clapping	x				
Jumps up and down	x				
Very Still		x			
Mouth open		x			
Laughs	x				
Touching things	x				
Hands between legs		x			
Puts head out of the window	x				

(a= therapy session, b= social/leisure activity)

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