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The forgotten people: The transition from school to post-school provision for young adults with profound physical and intellectual disabilities

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Abstract

Using a transactional model of disability as a tool of research, this study explores the transition period from school to post-school provision for young adults with profound physical and intellectual disabilities and their family carers from their perspective. The views of the young people themselves are indirectly obtained through their family carers as the young people have severe communication impairments.

The study adopts a case study approach and uses an emergent design. Data is gathered by interviewing the family carers individually in order to investigate their experiences of the Future Needs Assessment process, the transition period and the provision of post-school placements. This data is then used to devise an interview guide for a focus group discussion, consisting of the family carers and professionals involved with the transition stage, to explore ways of overcoming the difficulties encountered by the young people and their families. Finally, as the data suggested that there is little or no post-school placements and services for this group of young people, the study used the nominal group technique to suggest criteria for good quality provision and services. To set the study in context, national and local documents, concerned with learning disabilities and the transition period, are analysed. In addition, the underlying assumptions of both the family carers and the professionals involved in the study about the nature of impairment and disability are explored.

The study concludes that services are failing to meet the needs of these young adults and that they are being socially excluded from society, despite the philosophy of social inclusion espoused in recent legislation. It maintains that if change is to occur society needs to have a better understanding of people with profound physical and intellectual disabilities and the positive contribution they bring to society.

The Forgotten People

Imagine if you can
How it feels to be me
Trapped in a body without a voice
And longing to be free.

Forgotten by many in this world
Man has passed me by
Life has dealt me a cruel blow
But you won't hear me cry.

The barriers that we face in life
Are too numerous to mention,
We are the forgotten people
We don't warrant much attention.

"The cost would be so very great"
We often hear this phrase
"Let's look at a simpler option
We'll still get the praise"

My voice is usually my Mum's
She can speak for two,
I've heard her shout for this and that
Even for a loo!

No matter what the obstacle
She will fight and try
But the powers that be, just pat my head
And then they walk on by.

When will the world waken up
And take a look at me?
I'm the Forgotten People
And I'm longing to be free.

Chapter 1 Introduction

The transition from school to adult life is often a difficult time for many young people. For those with special educational needs it is usually a traumatic and stressful time in which they encounter greater difficulties than their non-disabled peers (Centre for Educational Research and Innovation (CERI), 1985). Recognising this, the Warnock Report (Department of Education and Science, 1978) recommended that young people with special educational needs should be provided with additional support in order to make a successful transition to post-school learning and employment. Warnock argued that if this skilled support is not made available to the young people and their family carers, the efforts made by schools to meet their special needs would come to nothing.

This study focused on the transition period from school to post-school provision for young adults with exceptional needs, namely those with profound physical and sensory disabilities, resulting in profound intellectual disabilities, all of which require pervasive supports. This definition of the young people involved in my study was derived from my own reading and in consultation with family carers (see Chapter 2). However, I recognise that this term is cumbersome, so it has been shortened to "profound physical and intellectual disabilities" in the title of my study and is used throughout the text to describe the young adults who are the focus of my study.

In this introductory chapter I begin by outlining the study's purpose and aims. The next section describes my personal background and involvement in the study and briefly discusses how this has influenced my research. I conclude the chapter by providing a rationale for studying the transition period from school to adult provision for young people with profound physical and intellectual disabilities.

Chapter two consists of two parts. The first is concerned with definitions and numbers. It identifies the group at the centre of my study and defines key terms used in the study. The second part reviews literature and research related to the topic and sets the study in context.

Chapter three begins by looking at the ways in which people have tried to make sense of the world around them and focuses on the research process. It also describes how I have investigated the topic and why particular methods and techniques were employed.

Chapter four looks at the nature of local service provision and the theoretical underpinnings of national and local policies and services. It also explores implicit and explicit theories and assumptions about disability and impairment held by the family carers and professionals.

Chapter five, using data provided by the individual and dyadic interviews and Future Needs Assessment documents, tells the young people's stories – their experiences of schools, Future Needs Assessment meetings, the transition process and their post-school placements. This is done through the eyes of the young people's family carers, as all of the young people have no speech and limited forms of communication.

Chapter six looks at the difficulties encountered by the young people, their family carers and professionals involved with this group, during the transition stage. Using data obtained from the focus group discussion and the nominal group technique, it explores ways in which these difficulties might be overcome.

Chapter seven looks at the young people's current post-school provision, suggests criteria for good quality post-school provision and the family carers' hopes and aspirations for their young people.

Chapter eight considers the study's implications for theory, research methodology and service provision.

PURPOSE AND AIMS OF STUDY

The purpose of my study was to investigate the experiences of young adults with profound physical and intellectual disabilities and their family carers, during the transition period from school to adult provision. The views and opinions of the young people themselves were indirectly obtained through their family carers, as the young people have severe communication impairments. They have no speech, however, they have all developed ways of communicating (see Chapter 5). Faye communicates through eye pointing, facial expressions and crying; Simon and Kylie through facial expressions, vocalisations and gestures and Geri through body language and coughing. However, it takes considerable time and experience to become "tuned in" to the young people's means of communication. For example, Geri uses different kinds of coughing to indicate displeasure, make requests and initiate interactions. Therefore I used the young people's family carers to assist me to understand the young people and recount their experiences:

Imagine if you can
How it feels to be me
Trapped in a body without a voice
And longing to be free.

The study also hoped to identify the nature of local service provision and the theoretical underpinnings of national and local policies and services. In addition, it explored the implicit and explicit theories and assumptions about disability and impairment held by family carers and professionals. Furthermore, having identified the difficulties experienced by the young people and their family carers during the transition period, the study suggested ways in which these difficulties might be overcome. Moreover, as there seemed to be little, or no provision for this group in adulthood, the study aimed to suggest criteria, generated by both family carers and professionals, for good quality services and provision for this group.

Three principal objectives were established:

- to look at the transition period from school to post-school provision for young adults with profound physical and intellectual disabilities from the perspective of the young people themselves and their family carers
- to raise awareness of the needs of this group of young people
- to help family carers and professionals influence policy-making decisions and bring about social change.

The research questions were as follows:

- What theories and assumptions underlie national and local policy-making for this group?
- How do the family carers and professionals view impairment and disability?
- What was/is your son/daughter's experience of school provision, the transition period and post-school provision?
- Are there problems with the present system?
- How could the transition process be improved?
- What kind of adult services would you like for your son/daughter?

By starting from the experiences of the young people and their family carers, I hoped that this study would add to knowledge about the transition into adulthood for young people with profound physical and intellectual disabilities. Furthermore, I hoped that the information gained from the study would be helpful to those responsible for commissioning and providing services to the young people and their families; services which would recognise their rights of citizenship, increase their quality of life and include them in society. Finally, I hoped that my study would raise awareness of this group as they are often "the forgotten people" when it comes to the delivery and provision of services (see p. xii).

In the following section I describe my personal background and involvement with the study in an attempt to make clear my assumptions. I agree with Kincheloe and McLaren (1998) that:

> Critical researchers enter into the investigation with their assumptions on the table, so no one is confused concerning the epistemological and political baggage they bring with them to the research site.
> (Kincheloe & McLaren, 1998, p. 265)

PERSONAL BACKGROUND AND INVOLVEMENT WITH THE STUDY

After leaving school, I trained to become a primary school teacher and on qualifying, taught for nearly five years in mainstream primary schools until the birth of my first child. I might have considered the possibility of returning to teaching after my children had begun school but with the birth of my second daughter, Anne, I became a full-time carer. As caring for Anne involved twenty-four hour a day care and there was little, or no support for me from service providers, especially during Anne's pre-school years, I felt unable to return to work. When Anne started to attend school, I found I had more time to myself and I began an Open University course about children with special educational needs to increase my knowledge and understanding of this area. However, as my interest in the subject grew, I went on to take a Bachelor of Arts (Honours) degree and Masters in Education degree, as well as an Advanced Diploma in Special Educational Needs. On completion of my Masters Degree, I undertook some part-time work as a fieldworker for a group engaged in health and social research. I had hoped to do a Doctorate of Education with the Open University but other family commitments, along with involvement with parental groups to establish post-school provision and short break facilities for young people with profound physical and intellectual disabilities, meant that these plans had to be shelved. However, having found temporary post-school provision for Anne, I decided to study for a Doctor of Philosophy part-time.

My personal experiences of being a carer of a child, and latterly a young adult with profound physical and intellectual disabilities, has also meant that I have chosen to become involved in carers movements, such as Carers Scotland and support groups for family carers of people with disabilities, such as the Princess Royal Trust for Carers (PRT) and the Profound and Multiple Impairment Service (PAMIS). As a result, I represent carers on various groups set up by voluntary and statutory agencies, at both local and national levels. Although this research was done for a Ph.D., my interest in the topic stems mainly from personal experience as shown below.

In 1980 my daughter, Anne, was born. She suffers from cerebral palsy. She has profound physical and intellectual disabilities. She cannot walk, sit, roll or crawl and wears a body brace to help her maintain a sitting position. She has very poor head control and little functional use of her hands. Her profound physical disabilities mean that she is totally dependent on others for her daily care. She also suffers from bulbar palsy and so food is given to her through a gastrostomy tube. She does, however, receive tastes of her favourite foods orally. Anne is also epileptic, has microcephaly and suffers from reflux problems.

Anne has no speech but communicates by eye-pointing and has a "yes-no" response, smiling for "yes" and looking down for "no". A pushing movement in her arms enables her to operate a simple switch which provides access to simple cause-effect programmes on a computer, allows her to operate electrical equipment such as tape recorders and to drive a Smart Wheelchair, a specially adapted electric wheelchair.

Anne loves all kinds of music – at the moment her favourites being "Cher", "Steps" and "S Club". Her hobbies include listening to music, swimming, ten-pin bowling, curling and dancing. She is a very happy, sociable girl and enjoys company and lots of attention.

In 1985 a Record of Needs was drawn up for Anne and this gave us, her parents, a chance to express our views and opinions about appropriate provision to meet her needs. We felt that Anne's multiple disabilities required an eclectic, holistic and multi-disciplined approach to met her physical, educational, social and emotional needs. As there was no such provision locally, we urged the local authority to send Anne to a voluntary school, thirty miles away from her home, as a day pupil. With persuasion, the local authority agreed and Anne attended this school until she was eighteen and a half. Anne was very happy at school and made progress in terms of increasing her motor skills, extending her cognitive abilities and developing both personally and socially.

However, when Anne reached fourteen and we became involved in the Future Needs Assessment (FNA) process and the transition period from school to adult provision, we encountered various problems and experienced considerable stress. Having undergone the assessment process, with all its deficiencies, we found out that there was no provision for Anne. Through talking to other parents from various regions, we found that, either no provision existed for this group of young people, and where provision did exist, it was usually inappropriate and did not meet the needs and aspirations of the young people. However, by forming a parents' group in our area, we managed to persuade the local council to open two new units for this group of young people and Anne attends one of them. Both, however, are three year pilot projects and we do not know what provision will be provided for Anne and her peer group once these three years are up.

We had hoped that the Beattie Committee Report (Scottish Executive, 1999) would make some recommendations about developing services for this group. However, I feel that the Committee focuses on provision in further education colleges (Hardin, 1999) and employment, rather than looking at the needs of this group (only one chapter looks at resource centres). Although the Committee accepts that for some young people employment is unlikely to be an option, most of its recommendations are:

> ...geared towards helping young people to improve their skills and capabilities to obtain, and sustain, employment.
> (Scottish Executive, 1999, para. 9.1)

Therefore it seems to me as if the needs and aspirations of this group have been overlooked once again. Thus I decided to carry out research into the transition period for this group of young adults. I did not want my study, when completed, to lie on a shelf and gather dust. I was concerned that it should provide a "step to action" (see Chapter 3, Table 16, p. 120) and that the findings would improve practice and delivery of services in some way. Therefore I decided not only to identify and investigate the problem, but to suggest ways of overcoming it by involving the participants in the study.

However, past experiences have made me realistic about hoping that research alone will make an impact on the disablement policy agenda. Furthermore, an isolated doctoral thesis is unlikely to change practices and service provision for young people with profound physical and intellectual disabilities. At best I can only hope that my research will serve the interests of this group of young people and their family carers and be research which "reflects the reality of disabled people and acts... as validation and affirmation for disabled people" (Shakespeare, 1996, p. 118). Since beginning this research, "The same as you?": A report of services for people with learning disabilities (Scottish Executive, 2000) has been produced. Although it undertook research into the needs of people with "profound and multiple disabilities", it focused mainly on social and healthcare. Nevertheless, parents of young adults with profound physical and intellectual disabilities feel that this report has put "profound and multiple learning difficulties" on the disablement policy agenda for the first time (see recommendation 29, p. 93). However, they fear that the report does not pay sufficient attention to the needs of people with "profound physical and learning disabilities" and their family carers and will make little or no difference to their quality of life.

The above shows how my study stemmed from my own personal experiences and a desire to change the situation. However, my personal and socio-cultural experiences, as well as certain convictions, also influenced my approach to the study and the methods I employed to collect and analyse the data. Therefore I believe they need to be made clear and explicit before describing my study further.

My personal interest and involvement in the study means that I am not a disinterested observer but a participant in the process I seek to describe. Therefore my study could be criticised for not being conducted by an "independent" researcher. Furthermore, my study is based on the conviction that people with profound physical and intellectual disabilities have the same right to life as everyone else, that they are people in their own right and should have the same rights, opportunities and entitlements as other members of society, including education, healthcare and social provision. Thus I support the cause of disability rights. This is an ethical and a political position which I have chosen to adopt and it influences my research. In addition, I question some of the sociological assumptions surrounding the currently dominant model for researching disability – the social model. I explore the utility of this model for helping to increase understanding of the lived out experiences of people with profound physical and intellectual disabilities and suggest an alternative framework of analysis – the transactional model (see Chapter 3, Figure 9, p.115).

RATIONALE FOR THE STUDY

As indicated above my interest in this topic is a personal one. I too am a parent of a young adult with profound physical and intellectual disabilities and have had experience of going through the transition period with my own daughter. Like other family carers, I found this period particularly stressful. As family carers of these young people we know that they have special educational needs and require extra care and medical services, but we also recognise that our young people have the right to the same chances and opportunities as their non-disabled peers. Thus we face a dilemma:

> On the one hand they [parents] want their child to become as independent as possible, and on the other hand they wish to extend their protection of them... The parents have probably fought many battles both within the home and with external agencies over the years to maximise their child's independence. The approach of adulthood in

> their child may be a time when early hopes are finally dashed and, or where the hopes being realised cause an onset of panic.
> (Gascoigne, 1995, p. 138)

The problems I encountered and the emotional upset I experienced during the transition stage were as traumatic as those I encountered after Anne's birth and the realisation that she was disabled. Conversations with other family carers, as well as research, suggests that my experiences are not unique. Lambe (2000) describes the transition from children to adult services as traumatic for both the families and the young people involved. She suggests that both the Future Needs Assessment (FNA) and the Community Care Assessment procedures are very complex processes and that many family carers find them a daunting, frustrating and stressful experience. Moreover, having undergone these assessments, they discover that adult services are not mandatory and their young person has no legal right to a five-day-a-week adult service.

Whilst the last two decades have seen a marked increase in literature concerned with the transition to adulthood for people with disabilities (CERI, 1983, 1985, 1986, 1988; Ward, Riddell, Dyer & Thomson, 1991), little is known about the experiences of young people and their families during this period, or their fears and hopes for the future. Yet, McConkey and Smyth (2000) argue that information about their hopes, aspirations and experiences are essential if education, social and health services are "to evolve and develop in accord with the "needs-led" philosophy they espouse" (McConkey & Smyth, 2000, p. 3). Morris (1999a, 1999b) endorses this, arguing that if services are to make a difference to the lives of these young people, they need to start from the experiences of the young people themselves.

Beresford (1995) accounts for this lack of research into the experiences of young people with disabilities and their families as partially due to differences between the latter groups and professionals in their perceptions of the problems confronting families with disabled members. In a survey of parents of children with "severe disabilities", Beresford (1995) found that one of their most pressing needs was assistance with planning their children's future; whilst Szymanski's (1994) study found that professional discussions on transition tended to be more limited in scope, concentrating mainly on the school leaving stage and transition to employment. In contrast, Morris' (1999b) report, which included accounts by young people with "complex health and support needs" of their experiences of the transition period and their aspirations for the future, found that these young people wanted the same things as any young person approaching adulthood: friends, relationships, money, independence and freedom to do the things they enjoy doing.

Of the studies that exist, most have tended to focus on young people with learning difficulties (McConkey, 1989; McConkey & Smyth, 2000; Redmond, 1996), or those with physical and sensory impairments (Hirst & Baldwin, 1994; Monteith & Sneddon, 1999). Others are concerned with the transition period from school to employment or further education (Scottish Executive, 1999). However, the group of young people who are the focus of this study are unlikely to be going into full-time, further or higher education, or considering any kind of employment (Hubbard, 1999). Costley and Maguire (1999) found few studies that focus on the experiences, needs and aspirations of young people with profound physical and intellectual disabilities. This may be partly due to difficulties in communicating with this group. However, Wertheimer (1998) maintains that ways need to be found to help those with severe communication impairments to communicate their needs and make choices about their lifestyles. She suggests that staff, if they are given time to spend with the young people in a variety of settings, can become "tuned in" to their non-verbal means of communication, such as eye-pointing, vocal tone, postures and expressions and "best guess" the kinds of choices they are likely to make. Similarly, she sees families as having a vital role in assisting professionals, service providers and researchers to understand these young people as they usually know their offspring better than anyone else. Indeed researchers, such as Morris (1999b), have interviewed family carers about their offspring's experiences when the young person's level of communication impairment was such that it was not possible to ask him/her about their experiences.

Although I found that there is considerable interest in the issue of transition to adulthood for this group of young people, like Costley and Maguire (1999) I found that literature is limited. Eiser (1993) points out that in the past, little research was carried out because of the limited life span of these children whose condition meant that they were unlikely to survive into adulthood. However, recent medical advances have resulted in longer life spans for this group, as well as improvements to their health and care. The latter has increased their ability to function and their quality of life. These factors, along with raised expectations of family carers, an increased recognition of people with disabilities' basic human rights; together with pressure for equal opportunities for people with disabilities, has led to a greater awareness of the existence of this group. This in turn has led to developments in further education for this group (Dee, 2000; Hogg, 1991) and to a more positive and optimistic view of their capabilities (Hogg, 1999; Lacey & Ouvry, 2000). Research has shown that these people are capable of making choices and have preferences (Glenn & O'Brien, 1994), show an interest in their surroundings (MOVE, undated) and can develop relationships (Ware, 1996).

Nevertheless, Hogg (1999) cautions that these positive changes do not mean that society is adequately meeting the full spectrum of their needs. He maintains that people with "profound intellectual and multiple disabilities" have "less choice about their lives, less social integration, fewer chances of employment, a less active lifestyle, more chance of being underweight, and less access to leisure and community-based activities" than their more able peers (Hogg, 1999, p. 5). Moreover, they still tend to be overlooked when it comes to policy-making and the provision of services (Mencap, 2001 November; Scottish Executive, 1999; Shared Care Scotland, 1997; Whoriskey, 1999 September). In addition, recent research suggests that the transition period for young adults with "severe and multiple disabilities" (Hubbard, 1999) and "complex health and support needs" (Morris, 1999b) does not go smoothly and that outcomes are unsatisfactory for a significant number. These studies suggest that young adults with profound physical and intellectual disabilities are particularly vulnerable to failures by health services and social work departments to meet their needs during the transition to adulthood because of significant problems surrounding the transfer from children's to adults' services:

> It is now generally recognised that young adults are "hurtling into a void" of unco-ordinated or absent health services or other provision.
> (Chamberlain & Rooney, 1996, p. 88)

Thus their transition period, because of the nature of their disabilities, social attitudes and disorganised and fragmentary support systems, is more likely to be prolonged, unfocussed and ultimately unsuccessful in obtaining appropriate, good quality provision, than other groups of young people with disabilities (Cohen, Khan & O'Sullivan, 1998 December, 1999 March; Ward, Thomson & Riddell, 1994) (see Chapter 2, Figure 4, p. 76).

As regards post-school provision, research (Dee, 2000; Hogg, 1999; Mencap, 2001 November; Morris, 1999b) has indicated that existing services seem to find it difficult to provide services to meet this group's needs and enable them to access a good quality of life:

> It is significant that people with quite exceptional needs so often find themselves last in the long wait for services and the support they require to lead a life of good quality. The tendency to put them at the margins not only of society in general, but even at the margins of provision for their less needy peers, is an ever present threat that works against this goal. This is nowhere more true than in the case of people whose disabilities embrace not only profound intellectual impairments, but multiple physical and sensory disabilities as well.
> (Hogg, 1991, p. 163)

Hogg (1991, 1999) provides a number of reasons that this should be the case. Firstly, people with profound physical and intellectual disabilities not only present considerable challenges to those who care for them in terms of personal, developmental and healthcare needs, but also to those who plan and provide services. The complexity of this group's needs means that no one person, discipline or agency has the depth of knowledge and skills to met the full spectrum of their needs. Their need for continual health and social care, as well as education, means that several agencies need to be involved throughout their lives. Thus services for this group tend to be more costly than for other groups of people with disabilities. All this necessitates pooled budgets and an integrated, collaborative approach to both the commissioning and provision of services for this group, as well as effective partnerships between agencies, professionals, family carers and the young people themselves (Morris, 1999b; Scottish Executive, 2000; Wertheimer, 1998). However, although agencies are aware of the unsatisfactory way in which they work together (Davie, 1993), and projects to support effective multidisciplinary teamwork have been set up (Stalker, 2002 June; Wistow & Hardy, 1991); agencies have still not achieved collaboration, or established what Lacey describes as "multidisciplinary collaborative teamwork" (Lacey, 2000, p. xii).

Secondly, it is only recently that further education for adults with profound physical and intellectual disabilities has begun to be developed. In the nineteenth century this group was labelled "idiots" and hidden away in asylums or institutions. They were considered "ineducable and untrainable" and their right to be educated was only recognised legally in 1974. Nowadays, although educational provision is being provided for this group and school-based provision has improved throughout the 1970s and 1980s, there is no guarantee of post-school provision. Indeed, there is often little post-school provision for this group (Tomlinson Report, 1997), or no provision at all (Collier, 1997; Stalker, 2002 November). Moreover, where there is provision for this group, it is often inappropriate (Association of Directors of Education Services (ADES), 1999) or seen by family carers as not recognising the needs of this group of very vulnerable young people (Enable, 1999). Often dependent care and trivial and meaningless activity is seen as the only future for the group. Moreover, opportunities and expectations for them are generally limited. They tend to be either overlooked, or at best, recognised and then dismissed. Hence the title of my study "The forgotten people".

However, at the time of writing there is a desire to change the situation, not only from the people involved in the process (Stalker, 2002 June), but from central Government (Tomlinson Report, 1997) and the Scottish Executive. In 1999 the Scottish Executive commissioned the Beattie Committee to look at the transition to post-school education and training or employment for young people who require additional support. In the Minister's foreword, Henry McLeish, the then Minster for Enterprise and Lifelong Learning, expressed the Government's commitment to "equality of opportunity for everyone" (Scottish Executive, 1999, p. i). In the following year, the Scottish Executive carried out a review of services for people with learning disabilities and Iain Gray, Deputy Minister for Community Care, reiterated the Government's commitment to "social inclusion, equality and fairness, and the opportunity for people to improve themselves through continuous learning" (Scottish Executive, 2000, p. iii). In addition, in its publication, "A Paper on Lifelong Learning," the Scottish Executive maintains that it aims to create, by 2002, a situation in Scotland whereby "all Scottish citizens will have the means to access learning at any stage of their lives" (Scottish Office, 1998a, p. 5). However, at the time of writing, this group has no legal right to post-school provision and where provision exists, it is often inappropriate. Moreover, they are often excluded from services and provision because of their healthcare needs, people's attitudes and values and service structures. It remains to be seen whether this will change.

This study looked at the experiences of young adults with profound physical and intellectual disabilities during the transition period from school to post-school provision from the perspectives of the young people themselves and their family carers. Both McConkey and Smyth (2000) and Morris (1999a, 1999b) emphasise that service provision must start from the experiences of the young people themselves and this study was conducted to add to the limited research currently available into the needs, experiences and aspirations of this particular group. It focused on the transition period from school to post-school provision for this group, as personal experience and discussion with other family carers, as well as research into this period for other groups of young people with disabilities, suggested that it was a time of considerable stress for the young people and their families. Few studies have explored this topic from the perspectives of young people with profound physical and intellectual disabilities, their families and the professionals involved in service delivery and provision (Stalker, 2002 June). By starting from information provided by the young people and their family carers, the study endeavoured to suggest ways in which problems could be overcome and services provided to ensure that these young people experience:

> ...a good quality of life, characterised by met needs, fulfilling relationships and stretching activities which lead to life-long development and enjoyment.
>
> (Lacey, 2000, p. xvii)

Chapter 2 Literature review

This chapter consists of two parts. The first part looks at definitions and numbers. I believe it is essential that my study clearly identifies not only the group of young people who are the focus of my study, but also makes clear the experiences and expectations involved in the "transition to adulthood". I also believe that the way in which we define disability influences our thinking, policy-making and practice. Therefore this chapter begins by looking at the terminology used by other researchers to describe the group of young people at the centre of my study and gives reasons for my choice of the term "profound physical and intellectual disabilities". The second section looks at the number of young people likely to fall into this group in order to make clear the population being studied. In the third section I consider different views of disability and how these definitions have influenced disability research and the provision of services. In the final section I look at what we mean by "transition to adulthood".

The second part of the chapter looks at literature and current research related to my study and aims to set the study in context. It considers the three stages of transition identified by researchers – the Future Needs Assessment (FNA) process, post-school provision and employment and independent living – and relates them to the young people who are the focus of my study – those with profound physical and intellectual disabilities. The chapter concludes with a summary.

DEFINITIONS AND NUMBERS

Profound physical and intellectual disabilities

In a review of recent literature I found a variety of different terms to describe the young people at the centre of my study (Table 1, p. 18). This confusion over terminology makes it difficult for researchers to discuss ideas with colleagues both in this country and overseas. It also causes problems when it comes to identifying the number of people with "multiple impairments" and for planners in the delivery and provision of services:

> In one local authority area, a joint planning group which was set up to consider transitional arrangements for young people with "complex needs" found that their initial discussions were dominated by disagreement and misunderstandings about "prevalence and definitions".
> (Morris, 1999b, p. 14)

Table 1. Examples of terminology in recent literature used to describe the young people in the study

Complex disabilities
Complex needs
Complex and multiple impairments
Complex health and support needs
High support needs
Profound and multiple disabilities
Profound cognitive impairment
Profound disabilities
Profound and multiple learning difficulties
Profound intellectual disability
Profound and complex difficulties
Profound and complex learning difficulties
Profound intellectual disability and additional physical and/or sensory disabilities
Profound/complex physical and learning difficulties
Profound physical disabilities and complex learning needs
Multiple impairments

In educational spheres terms such as "profound and multiple learning difficulties" tend to be used to describe the group of young people in my study (Hogg, 1991), whereas social work departments favour terms such as "complex needs" (Scottish Executive, 2000). Moreover, terms are continually changing. In the 1950s terms such as "imbecile", "idiot" and "subnormal" were used to describe the young people in my study. These terms were replaced by "profound mental handicap", "profound learning difficulty or disability" and more recently "profound and multiple learning difficulties/disabilities". Not only are there a variety of terms, but the same term can be defined differently by different researchers. Other researchers also appear to use different terms but mean the same thing, whilst others provide no definition of the terms they adopt.

Looking at the term "profound and multiple learning difficulties", Whoriskey (1999) admits that there is no widely agreed definition of this term. However, she argues that:

> ...it is generally accepted that people will have pronounced developmental delay, additional physical disabilities and/or sensory impairment. 80% will have mobility problems and most will not be able to walk. People will also have significant difficulties in communication and a range of complicating health needs such as epilepsy, feeding and other general health needs.
> (Whoriskey, 1999, p. 3)

Like Whoriskey's definition, Lacey's (2000) emphasises the principal characteristics for distinguishing people with "profound and multiple learning difficulties", namely more than one disability and that one of these is profound intellectual impairment. However, her term "multiple disabilities", unlike Whoriskey's, includes not only sensory and physical impairments, but autism, mental illness and "challenging" or self-injurious behaviour. Moreover, she views "profound learning difficulties" in terms of people with an IQ below 20 (World Health Organisation (WHO), 1992), equating their developmental stage with Piaget's (1952) sensory-motor stage and their functioning level as equal to, or less than, one fifth of their chronological age (Sebba, 1988).

However, Hogg (1991) rejects the term "profound and multiple learning difficulties" as being euphemistic and degrading. He maintains that the term "learning difficulties" does not encompass the extensive difficulties experienced by these people. He argues that they not only have problems in learning, but also difficulties with perception, information processing, memory and motivation. Moreover, he views the word "difficulties" as unrealistic when applied to a group of people whose intellectual impairments are the result of massive brain damage, resulting not only in significant restrictions to their physical functioning, but also in serious medical problems. He also criticises the term for failing to stress the importance of physical and sensory impairments on learning by subsuming them under the term "multiple learning difficulties". Lastly, he points out that the term "learning difficulties" is an educational term mainly used to describe pre-school and school-age children (Department of Education and Science, 1978) and therefore is demeaning to adults. Instead he favours the term "profound intellectual disability and multiple physical and/or sensory disabilities". He uses the word "profound" to indicate the extent of the impairment and defines "intellectual" as "the outcome of a variety of psychological and experiential processes that enable a person to understand and act appropriately in relation to the world in which they live" (Hogg, 1991, pp. 165-166). He sees "disability" as "the consequence of an impairment to physical or mental performance imposing constraints on the individual's functioning, though not necessarily with handicapping consequences" (Ibid., p. 166). Nevertheless, he sees the term as a provisional one:

> ...and only helpful in so far as it focuses attention on those who are intellectually most impaired and who have significant physical and/or sensory impairments that over and above their intellectual status impede their day to day competence.
> (Hogg, 1999, p. 10)

Both Lacey and Whoriskey's definitions of "profound and multiple learning difficulties" are similar to the definition of the term "profound and complex learning difficulties" as used by Dee (2000) in the Enhancing Quality of Life Project. This project aims to develop transition programmes for people with "profound and complex learning difficulties". The definition states that:

> People with profound and complex learning difficulties share two characteristics:
>
> - a profound cognitive impairment or learning difficulty and
> - a complex aggregation of difficulties in more than one area of their lives.
>
> These people make extreme demands upon services, often because of additional combinations of physical disabilities; sensory impairments; medical complexities; and/or social or behavioural difficulties. Staff will most certainly experience exceptional difficulties in establishing reliable and consistent methods of communicating with them. Staff may find it difficult to view people with profound and complex learning difficulties as adults as they grow older because of their extensive and ongoing support needs.
>
> (Dee, 2000, p. 2)

Like Lacey, Dee emphasises the same two important facets of the difficulties experienced by these people but does not define what she means by "social or behavioural difficulties". Thus it is unclear whether people with mental illnesses, autism and challenging behaviour are included. Moreover, Hogg's criticisms above of the phrase "profound and multiple learning difficulties" are also relevant to this term.

The term "complex learning" is also used by a working group of family carers and professionals in Fife who looked at the transition of children with special needs from children's services to adult services (MacArthur, 1997). The term they used to describe this group was people with "profound physical disabilities and complex learning needs". Their definition was based on Seed's (1991) criteria for admission to the White Top Centre in Dundee:

> Young people who are unable to perform basic daily living tasks such as dressing, feeding, toileting or washing without substantial assistance. The majority also have physical disabilities and additional sensory impairments, resulting in multiple handicaps. Most have major communication problems and little or no speech. These young people are likely to require health, social work and educational input.
> (MacArthur, 1997, p. 9)

This definition emphasises the profound physical difficulties of these young people, as well as the multiple disabilities they face. It excludes young people with challenging behaviour and autism but fails to emphasise the profound intellectual impairments and disabilities likely to be experienced by these young people. However, it makes an attempt not only to describe the needs of this group, but to suggest the kind of input required to enable the young people to develop to their full potential.

The words "complex needs" also appear in "The same as you?": A Review of Services for People with Learning Difficulties/Disabilities (Scottish Executive, 2000). This term is used to describe young people who have needs:

> ...over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour.
> (Scottish Executive, 2000, p. 128)

The review also provides a definition of "learning disability":

> People with learning disabilities have a significant lifelong condition that started before adulthood, that affected their development and which means they need help to:

- understand information;
- learn skills; and
- cope independently.

(Scottish Executive, 2000, p. 3)

However, this definition does not emphasise the profound nature of this group's intellectual disabilities.

Like Dee and MacArthur's definitions, Morris' (1999b) term "complex health and support needs" recognises this group's need for ongoing services. Her term encompasses the following groups of young people:

- people with physical/sensory/communication impairments and high levels of support needs
- people with physical/sensory/communication impairments and/or learning difficulties
- people with physical/sensory/communication impairments and/or learning difficulties and mental health needs
- people with physical/sensory/communication impairments and/or learning difficulties and challenging behaviours
- people with significant learning difficulties
- people with compromised health and life expectancy arising from conditions such as cystic fibrosis
- people with chronic conditions such as ME, epilepsy or sickle cell anaemia
- people whose experience of cancer or other disease has left them with continuing health care and/or support needs

(Morris, 1999b, pp. 7-8)

Whilst Morris admits that this term covers a large group of people with a range of experiences, she maintains that this group share a number of common experiences, namely, their needs during the transition to adulthood, their relationships with services and their need for health and support services in order to access a good quality of life. However, she recognises the danger in describing people's health and support needs as "complex" as this can result in the person's needs being seen as the "problem" rather than the system and the services. She argues that it is not people's needs which are complex but the processes they have to go through and the barriers they have to break down in order to get their needs met. However, she justifies her use of the term "complex health and support needs" on the grounds that it is "a way of alerting its audience to what the report covers" (Morris, 1999b, p. 7). She argues that the term also helps to highlight the distinction amongst people's needs, impairments and disabling barriers.

However, Hogg (1999) is critical of the word "complex" when referring to this group's needs:

> It is difficult to know what the term "complex" refers to here as distinct from other forms of complexity in human behaviour and needs. It is difficult to imagine anything more complex than high functioning autism or any activity more complex than meeting the needs of someone with Alzheimer disease. Perhaps the term conveys some of our bewilderment at the challenges that we have to meet in the face of these particular patterns of disability.
>
> (Hogg, 1991, pp. 9-10)

Whilst academics and professionals are concerned with terminology, definitions and categorisation, Lambe (2000) points out that parents and carers who look after the young people who are the focus of my study, show less concern. They are more concerned with the every-day problems they encounter in caring for, and meeting the needs of this group of young people. She suggests that the American Association on Mental Retardation's work on a definition of "mental retardation" (AAMR, 1992) might help to combine family carers' perceptions of their role and professional definitions and categories. The AAMR classification system considers the person in an environmental context and takes into account their support needs, their intellectual and adaptive abilities and the causes of their impairments. It has abolished the terms "mild", "moderate", "severe" and "profound", replacing them with "intermittent", "limited", "extensive" and "pervasive" support. The latter term relates to our term "profound disability" and refers to "supports characterised by their constancy, high intensity; provided across environments; potentially life-sustaining nature" (AAMR, 1992, p. 26). According to Lambe (2000), this approach not only emphasises the extent of need, but also the input required for the person to realise his/her full potential and enjoy a good quality of life. However, whether this classification system is adopted in this country remains to be seen.

There will always be problems surrounding the use of terminology to label and categorise people. Arguments about the usage of words such as "impairment", "disability" and "handicap" will continue and questions will be asked about the meaning of terms such as "profound", "severe" and "complex". However, I believe it is important to have descriptive definitions so that people with disabilities get the services and support they require. I agree with Söder (1989) who argues that a non-labelling approach only gives the fact of disability a new meaning, namely "that disability is no problem and that it should be disregarded and not seen" (Söder, 1989, p. 124). This can result in specialist services and supports being discontinued on the grounds that they lead to labelling and segregation. MacKay (2001 June) supports this view arguing that:

> Disability is part of the diversity of everyday life. We should recognise that it is there, and we should do something positive about it. There are times when people with disabilities are harmed by the various ways in which disability is taken from them under false pretences. When this happens, the services we offer them are likely to be second-rate and inappropriate, decreasing their chances of leading a life that is valued by others and fulfilling to themselves.
>
> (MacKay, 2001 June, p. 2)

Nevertheless, I also acknowledge the dangers of descriptive labelling. According to Goffman (1968), labelling people according to their disabilities leads to stigmatisation, tends to diminish their status, reduce the respect given to them by other members of society and results in them being viewed as "not quite human" (Oliver, 1999, p. 22). This view is also held by young people with learning disabilities and their families:

> ...the young people are known first and foremost by the nature of their disability or disaffection. The "labels" they carry weigh the young people down and in their view prevent the people they come into contact with from viewing them as individuals with personality and skill set strengths and weaknesses just like other young people.
> (Scottish Executive, 1998 December, p. 8)

Nevertheless, students with disabilities themselves, although expressing a dislike for labelling, acknowledge its usefulness for accessing and obtaining the support they require (SCPR & Skill, 1996). It also helps agencies to plan services. However, the planning of services based on the categorisation of people with disabilities can sometimes result in pre-determined pathways or restrictive options. Moreover, there is the additional danger that it can influence thinking about what people with disabilities can or cannot do. They tend to be grouped into "client groups", with assumptions made about their capabilities, based on labels associated with that particular group; whereas in fact they are individuals, and their degree of dependence/independence is as variable as are individuals. Therefore the planning and provision of services requires to be "needs-led". Hubbard (1999) argues that if services were completely "needs-led", labelling and categorisation would come to be regarded as of less importance.

Whilst recognising the problems surrounding the labelling of people with disabilities and the confusing array of terminology to describe the group of young people who are the focus of my study, I nevertheless believed that it was necessary to adopt a term to describe the young people in my study. This enabled me to make clear the group of young people being discussed, as well as distinguishing them from other young people with disabilities as they have specific needs which are constantly changing (Male, 1996). Moreover, I felt that it was also important to define my term so that readers of my study would have a shared and consistent understanding of the characteristics and needs of this group. In addition, by defining the term I hoped to clarify the needs of this often overlooked group and identify the support and provision that may be needed by them to participate fully in adult life. The problem was to find a term which described not only the extent of the young people's needs, but also the support that would be required for the young people to develop to their full potential. Thus I decided to adopt the term "profound physical and sensory disabilities, resulting in profound intellectual disabilities, all of which require pervasive supports". However, I recognise that this term is cumbersome, so throughout the study the term "profound physical and intellectual disabilities" was used to describe the young adults who are the focus of my study. When referring to other writers' research, however, I used the terms adopted by them in their studies and indicated this by using inverted commas. This is because of the confusion over terminology to describe this group. Moreover, some researchers did not provide definitions of the terms they used and this made it difficult for me to determine whether their research findings applied to the group in my study.

In choosing the term, profound physical and intellectual disabilities, I have been influenced by the arguments of Hogg (1991, 1999), the AAMR's (1992) approach to classification (see pp. 24-25) and discussions with family carers. I wanted a term which would describe the person's needs, as well as indicating the input required to enable that person to reach his/her full potential. Therefore I chose the word "profound" to qualify the extent of the person's physical and intellectual disabilities. I also used the term "pervasive supports" to indicate the intensity of the health and support needs required and to emphasise the ongoing nature of this support. I adopted the AAMR's definition of "pervasive supports":

> Supports characterised by their constancy, high intensity; provided across environments; potentially life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive time-limited supports.
> (AAMR, 1992, p. 26)

The extent of their physical impairments means that these people require twenty-four hour care and are totally dependent on others for their daily care in areas such as feeding, bathing, dressing, toileting, therapeutic exercises. For many these impairments also mean specialised interventions such as tube-feeding, nebulisation, suctioning, postural drainage and the giving of oxygen and medication, including rectal diazepam. All have mobility problems and use wheelchairs. Many require splints and body braces to maintain postural positions. They have no speech and use non-verbal means of communication such as eye-pointing, facial expressions and gestures. Some have sensory impairments which include not only visual and hearing impairments, but also other forms of sensory input such as tactile, olfactory, gustatory, vestibular, proprioceptive and homeostatic (Bartley, 1980).

The term I have adopted also emphasises the physical nature of these people's disabilities, viewing their intellectual disabilities as stemming mainly from their profound physical and sensory impairments. This is a view put forward mainly by family carers who argue that their offspring's intellectual abilities are often "trapped or locked away" inside their physical bodies. Their profound physical and sensory impairments often make it impossible for them to communicate or demonstrate their intellectual abilities to others. However, family carers also recognise that their offspring's intellectual abilities must be impaired as their profound physical and sensory disabilities mean that they have had limited opportunities to explore their world using sensory-motor skills and this must affect their intellectual development (Piaget, 1952).

I use the term "intellectual" as defined by Hogg:

> ...the outcome of a variety of psychological and experiential processes that enable a person to understand and act appropriately in relation to the world in which they live.
> (Hogg, 1991, pp. 165-166)

This definition allowed me to include not only problems in learning, but other cognitive processes such as perception, attention, information-processing, memory, problem-solving, thinking, communication and motivation.

Finally, I chose to use the word "disability", in preference to "impairment" or "handicap", and adopted Hogg's definition of disability:

> ...the consequence of an impairment to physical or mental performance imposing constraints on the individual's functioning, though not necessarily with handicapping consequences.
> (Hogg, 1991, p. 166)

The terms "impairment", "disability" and "handicap" are considered more fully below.

The above definition is a provisional one and its purpose is to draw attention to this often overlooked group of young people with disabilities. It tends to give a negative picture of the young people who are the focus of my study. However, as demonstrated by the young people's stories (Chapter 5), these young people also have abilities, individual personalities, and are capable of real achievements and forming relationships. With the help of others they can realise their potential and achieve a good quality of life.

Prevalence

The SAY Report (Scottish Executive, 2000), found that, whilst there is not sufficient detailed information about the number of people in Scotland with learning difficulties/disabilities, studies suggest that 20 people for every 1,000 have a mild or moderate learning difficulty/disability and 3 to 4 for every 1,000 have a "profound or multiple disability" (Department of Health, 1995). Thus there are likely to be around 120,000 people in Scotland with learning difficulties/disabilities and up to 20,000 with severe learning difficulties/disabilities who require substantial help to cope with daily living. Of these 25% (4,000-5,000) were identified as having "complex needs" (see definition on p. 22).

The SAY Report also estimates that of the 15,000-20,000 people who "need a lot of help to cope with daily living", 25% (4,000-5,000) are under sixteen. However, statistics from the Scottish Office (Scottish Office, 1998) show that in 1996 and 1997 around 8,000 pupils were based in publicly funded special schools; of these approximately 30% were considered to have moderate learning difficulties with around 9% considered as having severe learning difficulties and a third as having "complex and multiple impairments" (Table 2, p. 31). In September 1997 the same statistics showed that 14,912 pupils (1.9% of the school population) in Scotland had a Record of Needs and that 20% of pupils in Scottish schools were likely to have a special educational need at some point during their school life. These figures do not correspond with the SAY Report estimates. Anomalies may be partly due to the Beattie Committee Report's omission of figures from special schools run by voluntary organisations, but the discrepancies are more likely to be due to varying definitions of disabilities and needs. The SAY Report draws on data from health service studies (Department of Health, 1995; Farmer, 1992), whereas Beattie's figures are based on school census bulletins. Morris (1999b) points out that these discrepancies are likely to continue as there is no nationally agreed categorisation of people with disabilities which applies over health, social services, education and voluntary agencies. In addition, registers of people with disabilities often do not allow for the identification of those with "multiple impairments". This results in them either being registered as having a learning disability, being physically disabled, sensory impaired or any combination of the three (Miller, 1996).

Table 2. Pupils attending publicly funded special schools with learning difficulties and "multiple impairments".

Impairment	1996		1997	
	Number	Percentage	Number	Percentage
Moderate learning difficulties	2559	31.6	2348	29.1
Severe learning difficulties	857	10.6	675	8.4
Profound learning difficulties	123	1.5	107	1.3
Specific learning difficulties	23	0.3	33	0.4
Dual sensory impairments	22	0.3	23	0.3
Moderate learning difficulties & other	806	10.0	994	12.3
Severe learning difficulties & other	827	10.2	963	12.0
Profound learning difficulties & other	786	9.7	759	9.4
Other	128	1.6	37	0.5

Adapted from Scottish Executive, 1999, p. 191

Looking at statistics for young adults with learning difficulties/disabilities, approximately 21,604 students were enrolled on special programmes in 46 further education colleges in 1997/98; of these 19,350 were enrolled on part-time vocational courses (Scottish Office, 1998). However, although studies (Hirst & Baldwin, 1994; Watson, 1996) indicate that similar percentages of disabled (10%) and able-bodied young people (9%) between the ages of 15-22 attend further education, young people with disabilities are under-represented in the population as a whole. For example, Watson (1996) found that 0.3% of the total number of students attending universities were disabled, to be representative of the age group, the figure should have been 3%. Similarly, Meager, Evans and Dench (1996) found that students with learning difficulties/disabilities in colleges in England and Wales only made up 5% of the student population. However, the majority of young people with severe learning difficulties/disabilities usually attend day care centres or adult resource centres (Figure 1, p. 32). Statistics show that in 1998, 8,300 people with learning difficulties/disabilities attended social day centres (Information and Statistics Division, 1999) with 489 attending hospital day places (Information and Statistics Division, 1998/99). For those with "profound and multiple learning difficulties/disabilities", the Tomlinson Report (1997) and Collier's (1997) study found either little or no provision for this group in England and Wales.

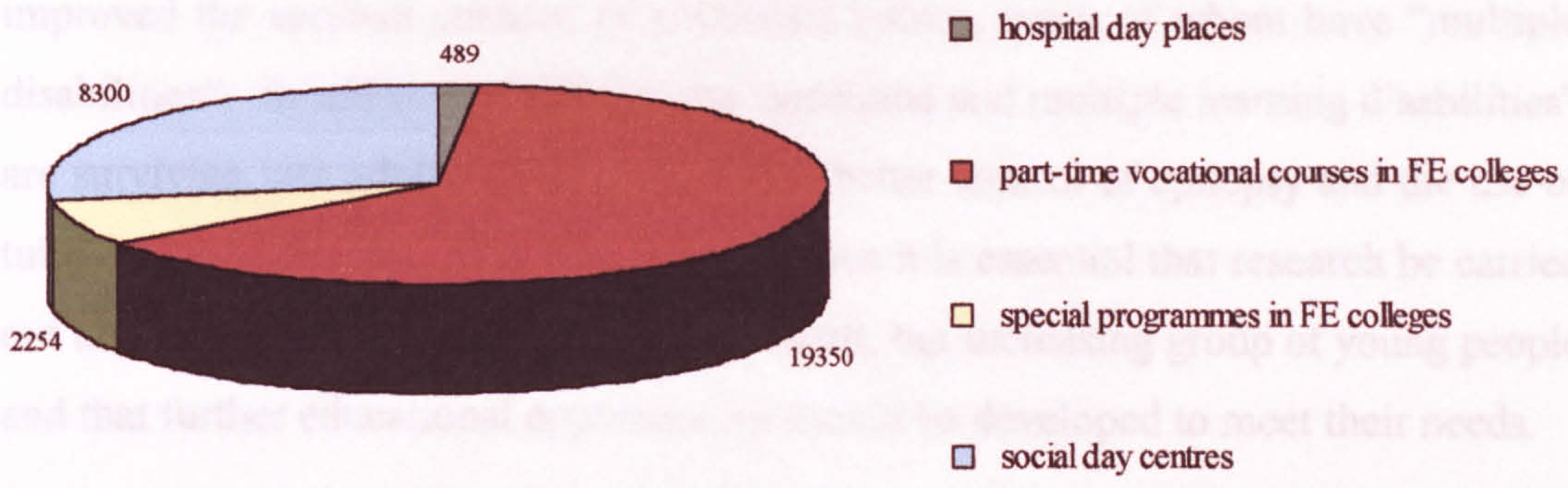

Figure 1. Numbers of young adults with learning difficulties/disabilities attending post-school provision between 1997 and 1999
Source: Scottish Office, 1998; Information and Statistics Division, 1999, 1998/1999

There is a lack of information on the numbers of young people with profound physical and intellectual disabilities. However, studies, both internationally (Blum, 1991) and nationally (Alberman, Nicholson & Wald, 1992; Stevenson, Pharoah & Stevenson, 1997), indicate an increase in the number of "people with a range of impairments and high support needs". Anecdotal evidence (Morris, 1999b) also suggests that residential schools catering for children with "multiple impairments" are finding that their numbers are increasing and that there is an increase in referrals of young people between the ages of fourteen and sixteen. In addition, the philosophy and practice of inclusion means that people with profound physical and intellectual disabilities are less likely to be "institutionalised" and more likely to use specialised, community-based services:

> The national picture shows that there are an increasing number of people with high support needs, including people who have non-verbal communication, who will be entering the service in the near future. As more people with learning difficulties go straight to college and jobs, day services are more likely to be supporting a greater proportion of people who have high support needs.
> (Changing Days Bulletin, August 1997, cited in Morris, 1999b, p. 21)

This rise in numbers is thought to be due to developments in technology which has improved the survival chances of premature babies, many of whom have "multiple disabilities". In addition, children with "profound and multiple learning disabilities" are surviving into adulthood because of the better control of epilepsy and the use of tube-feeding (Mencap, 2001 November). Thus it is essential that research be carried out into the needs and aspirations of this small, but increasing group of young people and that further educational opportunities should be developed to meet their needs.

Having selected a descriptive label for the group who are the focus of my study and having endeavoured to establish numbers, the following section examines different views of disability and how these perceptions have influenced disability research, policy-making and provision of services.

What is disability?

It is difficult to define disability. Firstly, definitions of disability have changed and been modified over time. In our society different models of disability have been dominant at different times and these models have gradually influenced and modified the ways in which we view disability. Secondly, within our society, groups of people tend to view disability in different ways. There are general views of disability (Barnes, 1992; McConkey & McCormack, 1983), there are professional and legal definitions (Oliver & Sapey, 1999) and the "lived out" experiences of people with disabilities and their families (Brisenden, 1999; Finkelstein, 1996; Hunt, 1966). This is explored further in Chapter 4. Thirdly, there are cultural variations in the ways that people regard disability. Oliver and Sapey (1999) suggest that the dominant view of disability in our society is one of personal tragedy or disaster. However, in some societies disabilities are viewed as a sign of being chosen (Safilios-Rothschild, 1970; Shearer, 1981), of possession, either by God, or the devil (Aall-Jilek, 1965); whilst others view disabilities, not in terms of personal afflictions, but as issues to be resolved by the community (Gwaltney, 1970; Groce, 1985). Hanks and Hanks (1980) identified several factors to account for these cultural variations:

> The type of economy is a factor with its varying production units, need for manpower, amount of surplus and its mode of distribution. The

> social structure is important, whether egalitarian or hierarchical, how it defines achievement, how it values age and sex. To these may be added the "Weltanschauung", the position of the group in relation to its neighbours, the esthetic canons and many more functionally related factors.
>
> (Hanks & Hanks, 1980, p. 13, cited in Barnes, 1999, p. 51)

From the above discussion it can be seen that definitions of disability are not fixed. They have changed through time and vary from society to society and within different social contexts. They are socially and culturally created:

> ...disability definitions are not rationally determined but socially constructed. Despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments.
>
> (Albrecht & Levy, 1981, p. 14)

The following section looks at the ways in which disability has been defined in our society and the theories and models which underpin these definitions. This is crucial to my study as the way disability is defined affects our attitudes and behaviour to people with disabilities, professional practice, social policies and the delivery and provision of services.

Theories and models of disability

One of the most dominant influences on both professional and common-sense definitions of disability has been the individualistic medical model (Figure 2, p. 36). This model stems from the disease model used in medicine and is rooted in the work of Parsons (1951), an American sociologist. Parsons argued that the "normal" state of being in Western developed societies is "good health", therefore sickness and impairments are deviations from "normality". His model suggests that when people become ill they should adopt the sick role. This involves recognising their own situation as "abhorrent and undesirable", relinquishing responsibilities and normal expectations and seeking help from professional medical experts in order to regain their former status. Parsons' model resulted in medical sociologists focusing on the experience of "illness", rather than the environmental and social barriers faced by people with disabilities. However, the term "medical model" emanates from the surveys carried out by the Office of Population Censuses and Surveys (OPCS) (Harris, 1971) in this country, and the World Health Organisation (WHO) (Wood, 1980) and their International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Table 3).

Table 3. Classification of impairment, disability and handicap

	OPCS' definitions	ICIDH's definitions
Impairment	Lacking all or part of a limb, or having a defective limb, organ or mechanism of the body	Any loss or abnormality of psychological, physiological or anatomical structure or function. Thus an impairment could range from a scar on the skin to the malfunction of the liver or heart.
Disability	The loss or reduction of functional ability	Any restriction or lack of ability to perform an activity, as a result of impairment, in a manner or within the range considered normal for a human being, for example the ability to climb the stairs or walk to the shops.
Handicap	The disadvantage or restriction of activity caused by disability	A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role for that individual (depending on such factors as age, sex and social and cultural factors). Handicap refers to the disadvantage the individual encounters, as a result of the impairment and/or the disability, when compared with his or her peers.

Source: Swain, Finkelstein, French & Oliver, 1996, p. 62; French, 1994, p. 13

The medical model views disability in terms of a disease process, abnormality and personal tragedy. It sees the problems that people with disabilities experience as a direct result of their individual physical, sensory and intellectual impairments and disability as the result of impairments due to damage or disease (Figure 2, p. 36). Thus the role of the professional is to help the individual to adjust physically and psychologically to the disabling condition through rehabilitation programmes and programmes designed to help the individual come to terms with his/her limitations. This medical and individualistic stance to disability was also adopted by other disciplines and institutions in society such as psychology (Llewellyn & Hogan, 2000), education (French, 1994) and social work (Oliver & Sapey, 1999).

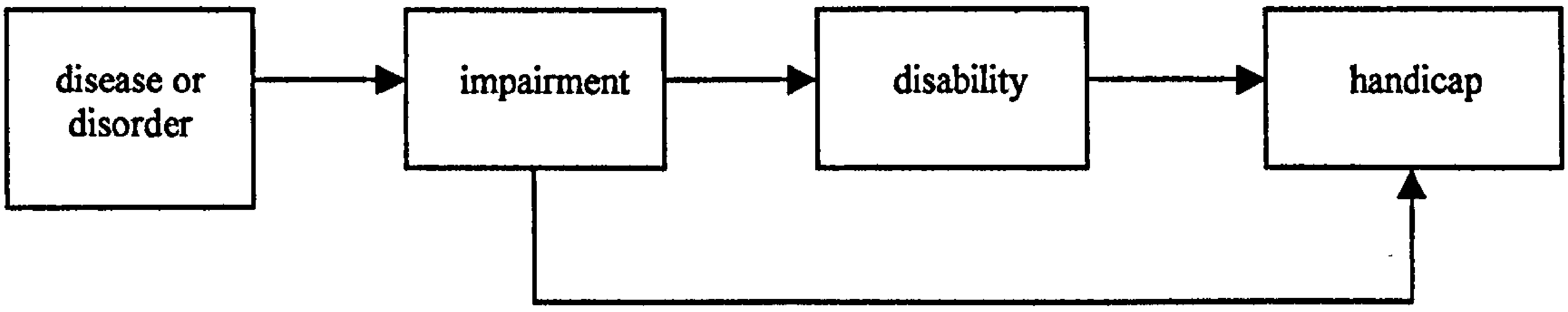

Figure 2. Individualistic medical model of disability
Source: Johnston, 1996, pp. 205-210

According to Oliver (1990), the "personal tragedy" theory of disability underpins this model. As the name suggests, this theory views disability as a tragedy and people with disabilities as victims of tragic events who need to be compensated for their afflictions. The problem with this theory is that it does not provide a universalistic explanation of disability. Historical and anthropological studies suggest that the tragic view of disability is unique to capitalist societies and that other societies view disability differently. Moreover, people with disabilities have rejected the medical model and OPCS and WHO's classifications. In 1975 the Union of the Physically Impaired Against Segregation (UPIAS) redefined the concepts of disability and impairment (Table 4, p. 37). These definitions made a clear distinction between impairment and disability and located the causes of disability firmly within society and social organisations:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1975, p. 14)

Table 4. UPIAS' definitions

Impairment	Lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.
* Disability	The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

Source: UPIAS, 1975, pp. 3-4

* This definition of disability was later broadened to include all impairments – physical, sensory and intellectual.

Disability movements criticised the medical model for viewing individually based impairments and/or medical conditions as the determining factor in accounting for disability, for ignoring the disabling effects of society and for failing to consider people with disabilities' viewpoints and experiences. Around the same time, social theorists in the United States of America, were also beginning to question the validity of the medical model (De Jong, 1979; Goffman, 1968; Scott, 1970). These theorists, using a structural functional framework, saw the problem of disability as a social construction, as the inevitable outcome of the evolution of industrial society (Albrecht, 1992; Stone, 1985). However, Barnes (1998, 1999) has criticised this functionalist account of the emergence of disability. He argues that this account failed to challenge the central values on which Western society rests and took little notice of the work of people with disabilities and their organisations, preferring to base its arguments on the work of established academics. In contrast to their American counterparts, British theorists, may of whom were disabled themselves, were beginning to argue that disability and dependence were socially constructed by the material, ideological and cultural changes which emerged with Western industrial capitalism (Finklestein, 1980; Hunt, 1966; Oliver, 1990). This materialist approach to disability viewed it as "a relationship mediated by the interactions between economic and social structures and individual impairment" (Oliver, 1999, p. 26) and along with views expressed by disability movements, led to the development of a new model – the social model of disability.

The social model of disability views the problems faced by people with disabilities as emanating from within society and social organisation, rather than from within the individual:

> For many years doctors, social workers and other people have told disabled people that they are disabled because of "what is wrong with them" ...This is known as the medical model of disability. It says that it is the person's "individual problem" that they are a disabled person.
> What we say is that yes, we do have bits of us that don't work very well, this we call our impairment: for example a person who cannot hear very well has a hearing impairment. What we say is that it is not this impairment which makes us a disabled person, it is society which makes us disabled. Society does not let us join in properly – information is not in accessible formats, there are steps into buildings, people's attitudes towards us are negative. So society puts barriers before us which stop us from taking part in society properly – it disables us. This is known as the social model of disability.
> (Greater Manchester Coalition of Disabled People, 1996, Resource Sheet 1)

Thus the social model separates out impairment – "the functional limitations of someone's body or mind as measured against a notational norm or average" (Morris, 1999b, p. 5) from disability; viewing disability as the result of "practices embedded within the society's institutions" (Reindal, 1995, p. 67). The social model is more optimistic in its approach than the individualistic medical model. It offers solutions to the problem of disability by identifying disabling barriers which can be dismantled in order to create more opportunities and a better quality of life for people with disabilities (Figure 3, p. 39).

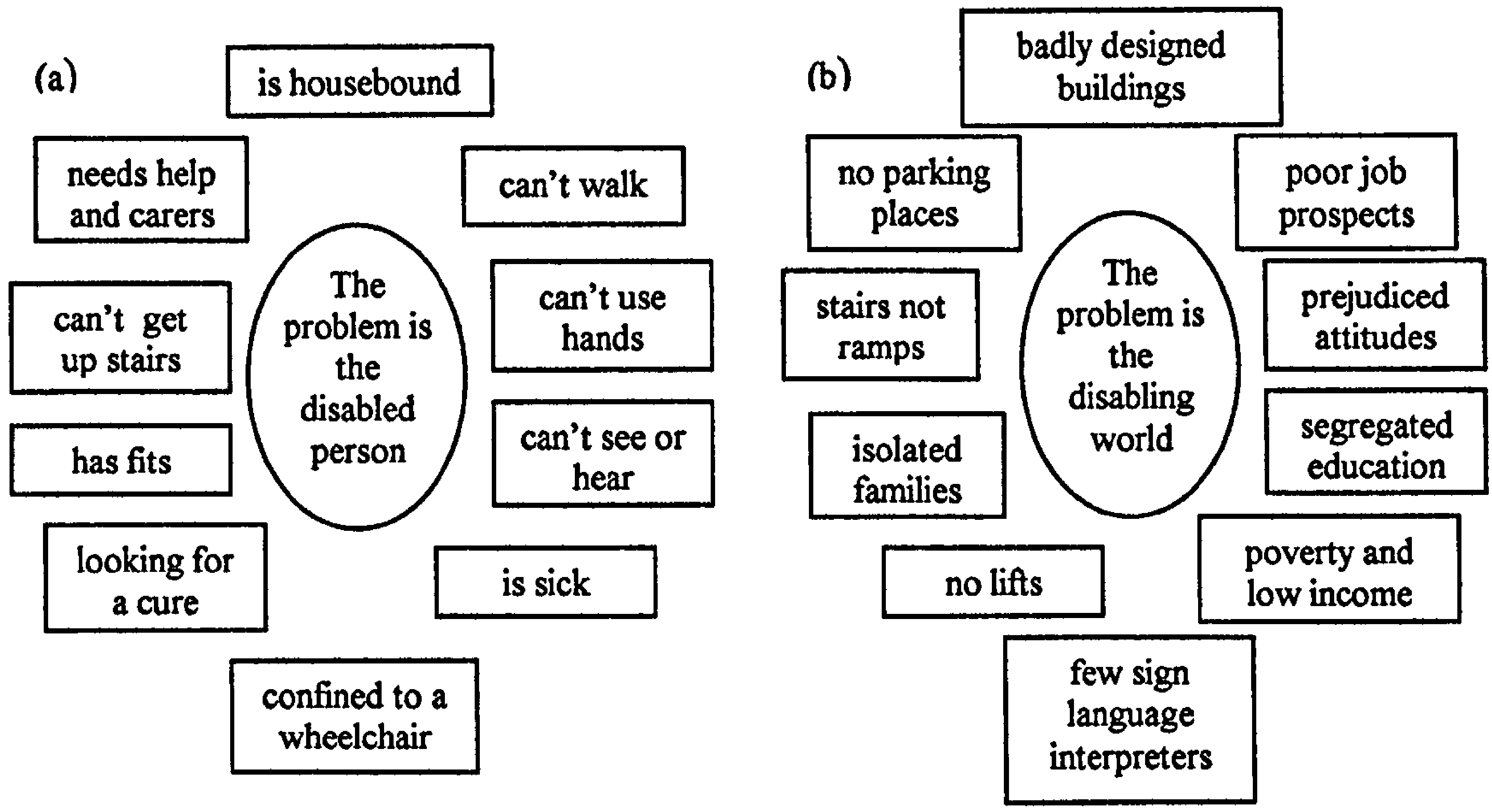

Figure 3. Comparison of the individualistic medical model and the social model of disability. (a) The individualistic medical model of disability; (b) the social model of disability
Adapted from Barker (1998)

Underpinning the social model is the social oppression theory which argues that in our society disability is a form of social oppression. Barnes (1998, 1999) argues that social oppression of people with disabilities can be traced back to early Western society with its obsession with physical and intellectual perfection. This oppression was exacerbated in the nineteenth century when industrialisation and its accompanying ideologies took hold (Finklestein, 1980; Oliver, 1990). The rise of capitalism meant that many people with disabilities could not compete in the new market economy and so they were re-defined as passive and dependent. Thus they became a clearly defined and devalued group who were then segregated from economic and social activity into a variety of residential institutions such as workhouses and asylums (Finklestein, 1980). Recent research indicates that people with disabilities in our society still face discrimination in terms of housing (Borsay, 1986a), employment (Lonsdale, 1986), finance (Townsend, 1979) and education (Anderson, 1979), as well as "disabling expectations" of independence, adjustment, acceptance and normality (Swain & French, 2000).

Since its development there have been criticisms of the social model, both from outside and within disability studies. From the outside, medical sociologists, such as Bury (1997) and Pinder (1997) have criticized the social model for being oversocialised, unidemensional and reductionist:

> Such an approach [Oliver's] can easily gloss over social realities and reduce complexities of individual and social responses to a unidemensional view of disability. In particular it can systematically miss the point... that the vast majority of disabled people suffer from chronic illness.
>
> (Bury, 1997, p. 138)

Moreover, Bury also questions social modellists' oppression theory, arguing that most people with disabilities do not see themselves as oppressed. Thomas (1999) contends that Bury uses what she refers to as the property version of the definition of disability (disability is restricted activity of the person and is caused by social barriers) and that this allows him to reject the social model on the grounds that illness and impairment do cause restrictions of activity. She asserts that Bury would have more difficulty in dismissing the social model if he engaged with a social relational definition of disability. In this definition disability is a social relationship between people. Disability is the "social imposition of restrictions of activity on impaired people" (Thomas, 1999, p. 42). This definition recognizes that some restrictions of activity may be caused by having a physical, sensory or intellectual impairment but that these restrictions do not constitute "disability". For example, some of the young people who took part in my study (Faye and Geri), have impairments which make it difficult for them to chew and swallow. Therefore they are fed through gastrostomy and nasal gastric tubes and only receive "tasters" of food. This restriction of activity – eating – is due to the effects of their impairments but it does not constitute disability in the social relational sense. However, the restriction of being unable to eat orally may result in restrictions of activity which do constitute disability. For example, people in power may decide that because Faye and Geri cannot be fed orally, they should not be fed via their tubes in public places, such as restaurants and so on. In this case the disability resides in the denial of rights and social exclusionary and discriminatory practices. Thomas refers to restrictions of activity directly caused by illness or impairment, such as Faye and Geri's difficulty with eating, as "impairing effects":

> These are the direct effects of impairment which differentiate bodily functioning from that which is socially construed to be normal or usual. In our society, these impairment effects generally, but not always, become the medium for the social relational enactment of disability: social exclusionary and discriminatory practices. The lives of people with impairments are profoundly shaped by the interaction of disability and impairment effects, and in lived experience these join together with other dimensions of individuals' social positioning (gender, "race", age, class, sexuality).
> (Thomas & Corker, 2002, p. 20)

From within disability studies, several writers have argued that the social model neglects the everyday experiences of people with disabilities. Thomas (1999) asserts that masculinist, anti-experiential perspectives have dominated much of social modellist thinking and has resulted in privileging the "restrictions on doing" dimensions of disability (what people with disabilities do or are prevented from doing) over its "restrictions on being" dimensions (who people with disabilities are, how they feel) (Thomas & Corker, 2002). She argues that disability studies need to consider not only disablist practices which restrict people with impairments' activities in the world, but also what she refers to as the "psycho-emotional dimensions of disability" – "disablist practices that undermine the psychological and emotional well-being of people with impairment" (Thomas, 2002, p. 53). (Examples of this can be found in Chapters 5 & 6) when both Faye and Simon's mothers are hurt by the reactions and behaviour of other people towards their daughter and son). Thus she defines disability as:

> A form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.
> (Thomas & Corker, 2002, pp. 19-20)

Other feminists, such as Morris (1991, 1996) criticise the social model for assuming that men represent the general experience of disability. Morris contends that the social model may be as oppressive as the individualistic medical model, if it is not expanded to incorporate the issue of gender. Similarly, Stuart (1992), Begum, Hill and Stevens (1994) argue that the social model needs to recognise that racism operates within the disability movement and that an understanding of disability also needs to consider ethnic status and perceptions of disability. Similar arguments are presented by Shakespeare, Gillespie-Sells and Davies (1996) regarding the issue of sexuality and by Robinson and Stalker (1998) and Zarb and Oliver (1992) regarding age. Whilst admitting that the social model has not addressed these issues, Oliver (1996) points out that multiple oppression is only just beginning to be acknowledged as regards disability. He contends that the social model cannot explain disability in totality and that what is needed is a social theory of disability. He sees the social model as contributing to the development of such a theory.

Other theorists (Abberley, 1987, 1997; Barnes, 1991, 1996; Hevey, 1992; Shakespeare, 1994) argue that the social model, based solely on economic-materialistic accounts, devalues the role of cultural processes and discourses in the generation of disability and disablism (Corker, 1998; Corker & French, 1999). They reject ideas which separate the body from the mind, the biological from the social and the cultural from the economic. Rather they assert that disability and impairment need to be understood in terms of cultural values, language and discursive practices, as well as material relations of power (Priestley, 1998; Thomas & Corker, 2002). They suggest that the social model be expanded to take into account not only the means of production but the role of culture in creating and maintaining exclusion (Barnes, 1996, p. 51).

Other writers criticise the social model for failing to include all aspects of disability and accuse it as having been "constructed for healthy quadriplegics" (Humphrey, 1994, p. 6, cited in Oliver, 1996, p. 42). This argument is reiterated by Chappell (1998) who claims that the social model has tended to focus on the experiences of people with physical and/or sensory disabilities and marginalised the experiences of people with learning difficulties. Goodley (2001) endorses this and argues that:

> ...as part of a social model of disability, there is a need to work with and for an understanding of "learning difficulties" as a fundamentally social, cultural, political, historical, discursive and relational phenomenon, rather than sensitively recognising the existence of an individual's "naturalised impairment."
>
> (Goodley, 2001, p. 210)

Similar arguments are put forward by Thomas and Corker (2002) in a dialogue which examines the interplay between modernist and postmodernist approaches to analysis of disability. They maintain that specific forms of disablism, especially those experienced by people with sensory impairments, cognitive differences and learning difficulties, have been largely ignored by social modellists until recently. They acknowledge that this group, whilst experiencing forms of disability which are common to all people with disabilities, such as employment discrimination, also encounter specific forms of disability which are more connected to their impairments.

French (1996) contends that it is crucial that we think about all aspects of disability, even if they do not appear able to be addressed by social and environmental solutions. She argues that differing experiences of people with a variety of impairments must be taken into account, otherwise people whose impairments are ignored will become alienated from the disability movement. Furthermore, if people with certain impairments are excluded, then their specific problems will not be recognised, nor ways of reducing them investigated. She further argues that if we do not endeavour to understand all disabilities, then we cannot attempt to change people's attitudes towards disability. She, along with John Swain (Swain & French, 2000), propose a new model of disability – the affirmative model.

They claim that this model presents a non-tragic view of impairment and disability and rejects perceptions of people with disabilities as being dependent and abnormal. They argue that being disabled is not always considered by people with disabilities as tragic. In a review of literature and research, they show that being impaired and disabled can have economic (Swain & French, 2000) and social benefits (Morris, 1989; Shakespeare, 1996) as well as giving people with disabilities an increased understanding and empathy of other people who experience hardships and disadvantages (French, 1991). They see the affirmative model as building on the social model. Like the social model, it aims to create a society without structural, environmental and attitudinal barriers, however, it also looks towards creating a society which celebrates differences and values people irrespective of impairment, age, race, gender, class or sexual preference. They describe the affirmative model as:

> ...a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experiences of being impaired and disabled.
> (Swain & French, 2000, p. 569)

Other writers have criticised the social model for excluding the impaired body (Crow, 1996; Hughes, 1999). Crow (1992 July), De Wolfe (2002) and French (1996) argue that the social model's definition of disability, in terms of a "socially imposed restriction", fails to acknowledge "the pain of impairment":

> ...illness often does constitute tragedy, both for its victims and those close to them. It can turn minuscule daily tasks into draining chores; make valued activities impossible, or ruin enjoyment in them; abort short- and long-term plans; strain relationships to breaking point. Many of these problems result from the bodily condition of the sufferer and no

> amount of social accommodation can totally compensate for lost quality of life. This does not mean, however, that social arrangements and atmosphere do not make a great difference to the experience of illness.
> (De Wolfe, 2002, p. 261)

Morris (1991; 1996), French (1993) and Corker and French (1999) also argue that the social model ignores the importance of impairment – both conceptually and in terms of its impact on daily living:

> ...there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying.
> (Morris, 1991, p. 10)

However, Oliver (1996) and Barnes (1998) maintain that the social model does not deny the importance of impairment, appropriate medical intervention or treatment. Instead, it focuses on identifying and addressing issues that can be changed through collective action, rather than medical or professional treatment. They see the social model as a framework within which policies can be developed to change and improve the lives of people with disabilities. They argue that personal experiences of living with impairment are not the concern of disability studies and that intellectual and political activities should focus on tackling the wider social causes of disability. They view pain, medication and ill-health as being the concern of a social model of impairment, arguing that the inclusion of impairment in the social model will be counter productive for people with disabilities (Shakespeare, 1992). They also maintain that emphasising personal experiences and impairments may result in a return to the individualistic medical model and personal tragedy theory:

> The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e. discrimination and prejudice. To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is "really" about physical limitation after all.
> (Shakespeare , 1992, p. 40)

This debate about the body and impairment has led to theorists such as Abberley (1997) and Thomas (2001) arguing for the development of a theoretical understanding of impairment – a social theory of impairment. They maintain that impairment and impairment effects do play an important part in the lives of people with disabilities (Wendell, 1996) and that impairments are not just naturalistic phenomenon but are socially produced. Abberley (1987, 1996) argues that impairment is socially produced, either directly by social processes and practices which create impairment by damaging the body, for example, wars, accidents and injury in work places, drug therapy, violent acts, lack of medical treatment, medical mistakes and so forth, or by producing higher levels of impairment through surgical advances and medical technologies, which enable people with impairments to increase their life expectancy. Thus these writers argue that impairment is as much social as it is biological and that it is "created at the biological-social interface in particular historical contexts" (Thomas, 2002, p. 74) However, the development of a social theory of impairment and the relevance and nature of impairment has led to much heated debate in disability studies amongst materialist, social constructionist and feminist perspectives.

Oliver (1996b) sees disability as "wholly and exclusively social ...disablement is nothing to do with the body" (pp. 41-42). He sees disability as socially created and impairment as a biological phenomenon. Although he acknowledges that a sociology of impairment may well be a field of study, he maintains that it should not be the concern of disability studies. However, as already seen, not all materialistically orientated disability study writers agree with this view (Abberley, 1987, 1996).

Social constructivists (Corker, 1998; Corker & French, 1999; Price & Shildrich, 1998), working from a feminist perspective, argue that impairment and disability are socially constructed. Shildrick and Price (1994) argue that the body is not a biological given but:

> Rather the body is materialized through discourse as both word and practice, through what Foucault calls, the exercise of power/knowledge ...that is, both our sense of our bodies and ourselves, cannot be understood by reference to any fixed or essential bodily core.
> (Shildrick & Price, 1994, p. 176)

They argue that bodily impairments and socially constructed disability are both constructs held in place by powerful discourses and other regulatory practices which produce and govern bodies. This view questions the idea of the body as an essential biological given. Instead it argues that there is "nothing inherent, or "pre-social", in individuals' bodily states that can sustain the idea of "real" bodily differences – "impaired" and "disabled" people are entirely discursively constructed" (Thomas, 2002, p. 51). However, not all feminists analyse impairment in this way.

Wendall (1996) and Morris (1991) argue that people with disabilities' own personal experiences of their bodies tell them that their bodies have "real" intellectual and physical characteristics which make their experiences different from the rest of the population. These bodily differences are "real" but they are part of the diversity of human experience. Whilst recognizing that there are essential, biologically based differences between bodies, these writers recognize that these differences are influenced by social meanings in different socio-cultural contexts.

This debate between essentialist and constructionist views about the impaired body continues in disability studies. However, there is also a growing recognition that in order to develop a sociology of impairment within disability studies, there also needs to be a breaking down of unhelpful dualisms such as biology/social, nature/culture, mind/body (Williams & Bendelow, 1998). Furthermore, bodies need to be seen as bio-socially produced and culturally constructed. According to Thomas (2001, 2002) this requires the development of a theory which combines a materialist ontology of the body and of impairment but also recognizes that any material differences are interpreted culturally. In my view, Crow's (1996) suggestion that we think about impairment in three related ways is relevant here.

Crow suggests that we look at impairment in three different ways. The first looks at objective experiences of impairment. This refers to intellectual, physical and sensory impairments. The second way of looking at impairment is from the subjective experience of impairment. This way recognises individual meanings and interpretations of impairment. For example, some people may regard their impairment as positive, others as neutral, whilst others may see it as negative. Furthermore, it also recognises that perceptions of impairment can differ according to time and changing circumstances (Shakespeare et al., 1996) (see also Chapter 4). This way of looking at impairment also acknowledges that for some people impairment is problematic, especially if they experience pain, illness or a shortened lifespan. It accepts that, for some people, impairment can be intolerable, so much so that they may no longer wish to live. The third way of looking at impairment is in terms of the social context. This involves looking at the impact of the wider social context upon impairment, issues such as misrepresentation, social exclusion, discrimination and so forth. In my opinion, this approach recognizes the biological dimensions of impairment, as well as acknowledging personal experiences of living with impairments and impairment effects. It also recognizes the similarities and differences in disability experiences associated with a full range of impairments. In addition, it takes into account the wider social context, as well as the constructionist view that impairment is socially constructed. Thus it allows impairment to be theorized as a bio-social phenomenon which acknowledges both the materiality of the body and "real" bodily differences. This approach avoids both biological and cultural reductionism and combines an essentialist view of the body with constructionist insight.

However, Crow (1992) and Abberley (1987, 1996) argue that developing a separate theory of impairment is not enough, impairment also needs to be included in disability studies and a social model of disability:

> Integrating all the external and internal factors into the social model is vital if we are to understand fully the disability-impairment equation. This does not in any way undermine the social model ...Disability is still socially created, still unacceptable, and still there to be changed, but integrating impairment into the equation gives us the best route to creating a world that includes us all.
> (Crow, 1992, p. 9)

Crow (1996) and Hughes and Paterson (1997) argue that the social model's refusal to link disability to impairment, has resulted in a disembodied notion of disability. The latter argue that the social model's distinction between disability and impairment "produces a theoretical rigidity which involves the medicalisation of disabled peoples' bodies and the politicisation of their social lives" (Hughes & Paterson, 1997, p. 331). They see impairment and disability, not as separate entities, but as part of a complex interaction of affliction and oppression:

> In such narratives [of impairments], the corporeal, the personal and the cultural collapse into one another and the experience of impairment and of disability dissolve into a living unity.
> (Hughes & Paterson, 1997, p. 333)

Thus they argue for an expanded social model of disability, one which "encapsulates the total experience of both disability and impairment" (Crow, 1996, p. 218). They contend that the social model's emphasis on structural barriers, only helps us to understand one aspect of disability. Pinder (1997) maintains that if the lived out experiences of people with disabilities are to be fully understood:

> ...we need to come to grips with the many interlocking webs of significance in which impairment and disability are embedded. On their own neither tells the whole story.
> (Pinder, 1997, p. 302)

However, as already discussed, there is a reluctance on the part of some social modellists to incorporate impairment into the social model. This has resulted in calls for "a more holistic version of the social model" (Pinder, 1997, p. 302) – one which embraces:

> ...a theoretical understanding of the relationship between impairment, modes of communication and forms of disablism, together with an understanding of the political implications of this for the disabled people's movement.
> (Thomas & Corker, 2002, p. 28).

Thus some writers propose a transactional model of disability (Dryden, 2000; Llewellyn & Hogan, 2000) based on social constructivism. Social constructivism sees disability as a consequence of "social meaning that is interrelated within social structures" and impairment as "a natural biological variety within the species" (Reindal, 1995, p. 67). Thus the transactional model views the environment as an "interactive structure" and individuals as "active synthesisers of information from the environment" (Llewellyn & Hogan, 2000, p. 161). Like Crow's (1996) approach, it recognises that people construct their own meanings of impairment and disability through interaction with the environment. In addition, it emphasises that there is not just one explanation for disability. It views disability as the result of a large number of interacting variables. Moreover, it advocates looking at impairment and disability from different levels of analysis – the personal, interpersonal and societal level. It recognises individual variations in the way that impairment and disability can be perceived, experienced and responded to by people with disabilities and non-disabled people, as well as within different societies and cultures. Although this model needs to be developed more fully, it allows impairment and disability to be viewed both as discrete entities as well as interacting. Thus it addresses some of the limitations of the social model. However, neither Dryden, nor Llewellyn and Hogan, see it as providing a full explanation of every aspect of disability. Rather they see it as a tool to increasing our understanding of disability in both clinical and research work.

I have tried to develop a transactional model for my study to help increase understanding of people with profound physical and intellectual disabilities and their lived out experiences at the transition stage from school to post-school provision. This is discussed in Chapter 3.

This section has looked at the ways in which impairment, disability and handicap have been defined in our society and the theories and models which have influenced these definitions. As already stated the way in which disability is defined affects our attitudes and behaviour to people with disabilities, professional practice, social policies and the delivery and provision of services. According to the Centre for Educational Research and Innovation (CERI, 1986), the many ways in which disability is viewed by different government agencies and departments, during the transition period from childhood to adulthood, results in young people with disabilities becoming either the focus of a variety of services, or falling through the gap between them. For example, educational criteria define disability in terms of whether or not the individual needs special educational help; employment services in terms of employability; health services in terms of amount of medical supervision, nursing care and therapies that are required and social work departments by degrees of functional disability for receipt of pensions and benefits and the need for supporting services. Whilst there are overlaps between the four sets of criteria, there are also clear differences and whether or not a young person is considered disabled, or not, varies from agency to agency. However, this is not usually a problem encountered by the young people and their families who are the focus of this study. Although their disabilities and needs are usually recognized, they are not always met. They find that the transition from childhood to adulthood services is traumatic – assessment procedures are complex; there is no legal entitlement to a five-day-a-week day service; and educational and medical services, received in childhood, are often discontinued when adulthood is reached (Lambe, 2000).

Before looking at existing research into the transition period from school to adult provision for young people with profound physical and intellectual disabilities, I believe it is necessary to make clear what experiences are included in the phrase "transition to adulthood". Therefore the following section discusses the terms adolescence, transition and adulthood.

Adolescence and the transition to adulthood

People experience many transitions throughout their lives – starting school, transferring to secondary school, going into employment, getting married, retiring from work and so on. However, the most important one is probably the transition from childhood to adulthood – the period from early teens to middle twenties, known in industrialised societies as adolescence. CERI (1988) defines adolescence as:

> ...a period when new roles are taken on, one's self image, after some turmoil and conflict, is consolidated, independence and autonomy from one's parents are gained (after considerable battle in many cases) and one is ready, with the support of one's peers, to envisage entry into adult life.
>
> (CERI, 1988, p. 22)

Whilst cross-cultural (Condon, 1987) and historical (Fox, 1977; Gillis, 1974; Kett, 1977) studies indicate that adolescence may only be regarded as a stage of development in industrialised countries (Cole & Cole, 1993; Lee & Devore, 1976; Shostak, 1981) and in societies where extensive education is needed in order for people to become competent members of society (Aries, 1962; Demos & Demos, 1969); both suggest that it is a difficult time for young people as they need to come to terms with sexual maturity and adult roles. It is a time of anxiety, confusion and uncertainty. Erikson (1980) describes it as a time of "sturm und dang" (storm and stress). Social groups break up and reform as young people leave school and enter further education and employment. Hopes and dreams have to be reconciled with reality. New identities have to be developed and established through informal learning and the testing out of personal relationships (Erikson, 1968). Self-esteem and confidence need to be built up so that young people have the confidence to survive without parental support but still have the confidence to ask for help and support, if necessary.

Thus adolescence and the transition from childhood to adulthood is a difficult time for all young people, but it is even more so for young people with disabilities, not only because of material and practical reasons, but also for social and psychological ones.

CERI (1986) and McGinty and Fish (1992) have identified three main stages in the transition from childhood to adulthood:

- The final years of compulsory schooling
- The post-school period of further education and vocational preparation
- The early years of employment and independent living

They maintain that these three stages of transition cover different time spans depending on the needs of the individual, on the way educational and vocational training are organised locally and on the cultures, values and contexts in which transition takes place.

Morris (1999b) uses the term "transition to adulthood" to refer to "both a particular stage of life experiences and to experiences of services" (p. 9). In terms of life experiences, she sees transition to adulthood as consisting of transition from school to training or employment/unemployment; moving out of the parental home; transition to adult sexuality, coupledom, marriage and parenthood and financial independence from family carers (Barnardo's, 1996, p. 9). In terms of services, the process of referral to adult services, in the case of children with Records of Needs, generally takes place between the ages of fourteen and fifteen years three months with the first Future Needs Assessment (FNA) meeting.

CERI (1986) and McGinty and Fish (1992) also define the transition period from childhood to adulthood in terms of life experiences (process) and experiences of services (phase):

> ...the process by which an individual grows through adolescence to adulthood in the social, cultural, economic and legal contexts provided by families, communities and national policies. It is also a phase covering the final years in school, continued education and training and the early stages of adult life. The words "process" and "phase" indicate two major aspects of transition. The process aspect refers to the social-psychological development of the individual whereas the phase aspect refers to the pattern of services provided for individuals during transition.
> (CERI, 1986, p. 15)

> It is a phase or period of time between the teens and twenties which is broken up educationally and administratively. During the phase there are changes of responsibility from child to adult services, from school to further and higher education and from childhood dependence to adult responsibility.
> It is a process by which the individual grows through adolescence to adulthood and achieves the balanced state of dependence and independence which a particular community expects of its adult members.
> (McGinty & Fish, 1992, p. 6)

They point out that both aspects of transition can be helped, or hindered, by the interventions of agencies, services and families. However, both the CERI study and McGinty and Fish argue that it is not enough just to define transition; goals and objectives for transition from childhood to adulthood must also be specified. In order to do this we must firstly define what we mean by "adulthood".

Cross-sectional studies suggest that in small non-industrialised societies where technological advancement is relatively low, childhood ends abruptly and transition to adulthood is usually brief. The beginning of puberty, together with various social rituals that mark entry into adulthood, give the young people of that society immediate access to full adult status (Mead, 1935; Schlegel & Barry, 1991). In contrast, in modern industrial societies there are usually no rituals or ceremonies to mark the passage out of adulthood. Furthermore, as there are more roles to perform and more skills to be acquired in an industrialised society, transition to adulthood is usually prolonged and complex. Adulthood is not recognised as a single event, instead progress towards adulthood occurs over a number of years (Table 5, p. 56).

This makes adulthood difficult to define precisely in complex societies, both from a social-psychological viewpoint and a legal one. From the legal standpoint, there is usually no fixed age when adult responsibilities are recognised. For example, different countries have different ages when drinking, driving, sexual relationships, marriage, joining the armed forces and voting are permitted as adult behaviours. From the social-psychological perspective, adulthood is often an uneven collection of behaviours, which still contain elements of childhood behaviours. There is no clear agreement about what constitutes adult behaviour or responsibility. For example, in this country at eighteen young people are legally adults, with all the rights, responsibilities and obligations of adulthood. However, most eighteen-year-olds are not regarded as having full adult status. This is because unless they are married, or had children when they were young, they are not seen as having taken on the responsibility to, and for others, which is crucial to adult status. Thus although adult status involves physical maturity and personal development, there are also a wide variety of legal and social indicators. Nevertheless, people are able to recognise adult behaviour even although they cannot define it precisely. Moreover, the majority of young people aim to achieve adult status and are encouraged by their families and society to do so. Thus by the mid-twenties most societies assume adulthood to be achieved and most legal systems acknowledge adult rights and responsibilities.

Table 5. The shift of responsibility from childhood to full adult status

Phase	Level of responsibility
Childhood	Others are responsible for making provision for the child. Childhood exemption (Gagnon, 1977) also ensures that everything a child does is viewed in a way which protects him/her from responsibility. Children are seen as not understanding the consequences of their actions. For example, a child under the age of ten cannot be charged with a criminal offence.
Late childhood/ early adolescence	Others are still totally responsible for making all provisions. The child is however, learning to take more responsibility for him/herself. "Childhood exemption" is beginning to fall away and the child is increasingly judged by, and held accountable for, his/her own actions.
Mid to late adolescence	Although others may still be providing totally or in part for the young person, he/she is taking considerable responsibility for his/her own life and is learning to, or beginning to provide for him/herself. "Childhood exemption" has almost fully lapsed in many areas of life.
Early adulthood	Full responsibility for oneself. Managing one's own affairs, being instrumental in decision-making about one's own life. Individual now accountable for his/her own actions and their consequences, although some allowances are still made for youth and inexperience.
Full adult status	Responsibility for oneself and others, either as part of a family or as part of society.

Adapted from Griffiths, 1994, pp. 3-4

Griffiths (1994) describes adult status as being:

> ...accorded to those who meet ...society's criteria for adulthood. These criteria are centred on physical maturity, personal autonomy, productive activity and separation from parents, as individuals develop the capacity to take responsibility for themselves. This change in status and identity is a major transition.
> (Griffiths, 1994, p. 1)

He argues that aspects of adult status are to some extent earned and are dependent on both the individual and society. At the individual level, young people need to develop certain skills and at the societal level, the members of that society have to acknowledge young people's rights to use these skills, to be responsible for making decisions about their own lives and careers and to develop and establish new social and family roles.

CERI's (1986) description of adult status is similar to Griffiths' but it stresses the need for a range of choices and opportunities to be available for young people if successful "adulthood" is to be achieved:

> "Adulthood" is a less than precise description both of a legal and social status and of a range of individual, social and economic opportunities and choices.
> (CERI, 1986, p. 7)

Having looked at the criteria for adult status in our society, it is now possible to consider the goals and objectives for adolescence and the transition period from childhood to adulthood.

Griffiths (1994) describes adolescence as a time in which young people are expected to develop physical, cognitive and emotional maturity, an individual identity and emancipation from parents and childhood (Table 6, p. 58).

Table 6. Goals of adolescence

Physical maturity – Necessary if young people are to reproduce and take on a range of roles within the family.

Cognitive maturity – Young people need to understand as much as possible about the world in which they live if they are to successfully take on adult roles within society, such as workers, voters, parents.

Emotional maturity – Necessary if young people are to understand responsibility towards another person, show empathy and tenderness and have the ability to give and receive affection.

An individual identity – Young people need to come to terms with their own strengths and weaknesses, fashion new identities to encompass new adult roles.

Emancipation from parents and childhood – Young people need to emancipate themselves from their parents and become capable of directing their own lives without depending on their parents.

In a review of literature about transition to adulthood, Harnisch and Fisher (1989) found that employment was considered to be a major goal of transition for many researchers as it was seen as giving freedom and choice to individuals (Thomson & Ward, 1994). Employment and personal autonomy were also seen as important in the CERI studies (1983, 1985, 1986, 1988). They emphasised the need for goals to be set in four main areas:

- Personal autonomy – involves taking full responsibility for one's own life and living independently.
- Productive activity – encompasses employment, useful work and valued activity and leads to economic self-sufficiency.
- Social interaction, community participation, leisure and recreation – taking on an adult role in society.
- Roles within the family – being a non-dependent son/daughter, a spouse or parent.

These goals are echoed by McGinty and Fish who contend that effective transition should lead to the development of the skills and knowledge required for open employment, for an independent life, for self-chosen leisure and recreational activities as well as social interaction, constructive self-advocacy and community participation.

CERI (1986) sees these transition goals as applying to everyone. McGinty and Fish concur with this, maintaining that the transitional needs of young people with disabilities are not different in kind from their non-disabled peers, and that many of the issues are pertinent to all young people leaving school. However, CERI admits that these goals are not always recognised as applying to young people with disabilities. Research (Riddell, Ward & Thomson, 1993) has shown that legal markers of adulthood have often been withheld from young people with learning difficulties and mental illnesses. Often the disability itself prevents the youngster achieving the level of competence necessary for adult status, however, sometimes young people are not given access to the learning experiences and opportunities which would enable them to develop greater competence. At other times the young person has the competence but their right to use it is not recognised by other people (Riddell, 1998). For many the transition period can be "an insurmountable barrier because of the impact which a disability has on the ways an individual is perceived and treated in every aspect of his or her life" (Griffiths, 1994, p. 8). This can result in the transition to adulthood being postponed, or prevented altogether, so that many people with severe learning difficulties find themselves remaining in "eternal childhood". For the young people who are the focus of my study – those with profound physical and intellectual disabilities – the problems of gaining adult status are even greater. They are unable to be responsible for almost any aspect of their lives; they are dependent on others for their daily care; they are not economically self-sufficient and they do not have adult roles within the family or the community. Yet they are still adults. They have the right to adult dignity and status. Griffiths argues that, for them, adult status and dignity must be conferred by others.

The next three sections look at CERI (1986) and McGinty and Fish's (1992) stages of transition as regards young people with profound physical and intellectual disabilities. As already mentioned, I found that literature is limited and little is known about the experiences of these young people and their families during the three stages of transition – the final years of compulsory schooling, the post-school period and the early years of employment and independent living. The study did not look at the curriculum offered to school leavers with profound physical and intellectual disabilities during the first stage of transition but focused instead on the Future Needs Assessment process, as research indicates that the procedure is far from satisfactory.

STAGES OF TRANSITION

The Future Needs Assessment (FNA) process

During McGinty and Fish's (1992) first stage of transition – the final years of schooling – responsibility for the education of young people with disabilities shifts from education authorities to employment services, or further or higher educational establishments, or usually, in the case of the young people who are the focus of this study, to social work departments. At this time there is also a transition from childhood services to adult services, as regards both social work and health services. The procedural management of this phase for young people with Records of Needs is the Future Needs Assessment (FNA) process.

The FNA process was made mandatory in the Education Act (Scotland) of 1980 (Chapter 44) and 1981 (Chapter 58) and implemented in January 1983. These Acts embodied several recommendations made by the Warnock Report (Department of Education and Science, 1978). However, they did not detail further and continuing education, as recommended by Warnock, and although a promise was made at the time to bring in separate legislation, nothing was done.

The Acts, however, did stipulate that between the ages of fourteen years and fifteen years three months, education authorities must assess the post-school needs of school leavers and consider what provision, including school provision, would benefit a recorded young person when s/he reaches school leaving age. In Scotland, the school leaving age is sixteen and beyond this age there is no duty on parents, or the young person concerned, to attend any educational establishment. It is for this reason that educational legislation does not give explicit and unequivocal rights to continued full-time education for young people with a Record of Needs over sixteen years of age.

Nevertheless, parents can request continued school education until the young person is eighteen years of age but local authorities have the right to refuse parental requests and ultimately the final decision rests with the education authority.

The assessment process consists of medical and psychological examinations and a report by a teacher familiar with the young person. Family carers can be consulted about the future needs of their young person and the Acts recommend that parents should be invited to discussions. Sections 60-63 of the Acts require the local authority to report the outcomes of the assessment and to produce a statement specifying whether or not the young person would benefit from continued school provision and the continuation of a Record of Needs. If it is decided that the Record of Needs should remain open, then further consideration of whether the Named Person should continue in his/her role, or whether another, more appropriate person, should be appointed to deal with the post sixteen situation. The Acts also require education authorities to send copies of the report to the local social work department, the health board for the area in which the young person lives and, with parental consent, any other agency thought to be able to provide appropriate provision for the young person. These copies must be distributed no later than six months before the young person is expected to leave full-time education. The education authority is also obliged to notify the social work department of the young person's assessment if they judge it to be in the interests of the young person concerned and where they think services may be required from the department. Parents have the right to appeal against any decisions and this process of appeal is specified in the legislation. However, unlike the Record of Needs, which stipulates what the authority must provide, the FNA report can only recommend what should be done.

Although the Acts outlined the FNA procedure, they produced no clear guidelines as to how a FNA should be conducted. However, guidance notes did suggest that the needs assessed should not just be "educational" needs and that the report should take into account vocational guidance, training, career service reports and reports made by the social work department and the health board. They also recommended that the reports should focus on the identification and assessment of need, as well as the availability of post-school provision. Although FNA meetings are not statutory, they have become regarded as good practice. In addition, it is also seen as good practice to invite parents, representatives from social work departments, further educational establishments and voluntary organizations, depending on the type of post-school provision being considered. However, social work departments do have a general duty to attend FNA meetings under the Social Work (Scotland) Act of 1968, Section 12. Moreover, the Disabled Persons (Services, Consultation and Representation) Act, Section 13, (Department of Health, 1986, Chapter 33) instructed education authorities to seek the opinions of social work departments as to whether a young person between the ages of fourteen years and fifteen years three months, who has a Record of Needs, is a disabled person before they make a FNA. If the social work department considers the young person to be disabled, they will then have to assess the young person's needs for statutory services within a maximum period of six months. Both the education authority and the social work department are required to review the reports and the education authority must give the social work department six months notice of the date a young person with disabilities is expected to leave full-time education.

Studies following the implementation of the 1980 and 1981 Education Acts indicate that individual education authorities have responded to the legislation in different ways (Adams, 1986; Committee on Special Educational Needs, 1988; Scottish Consumer Council, 1989) and that within an authority individual schools sometimes follow different procedures (Brown, 1997; Ward, Thomson, Macfarlane & Duncan, 1998). This is because the Acts gave no specific, practical guidelines and as a result education authorities have interpreted the Acts differently.

A report by the Committee on Special Educational Needs (COSPEN) (1988), which looked at provision for young people with "pronounced specific or complex special educational needs", found that some regions were more concerned with "allocation procedures" than with assessing the needs of the young people. Consequently, this often resulted in the recommendation of provision that did not meet the young person's needs. These findings concur with Finklestein (1980), Oliver (1983) and

Wilding's (1982) views. These writers argue that "needs" tend to be defined by service providers and thus services are built around professional skills which met the "needs" of the service providers and not the "needs" of the service users. The COSPEN Report recommended that:

> Those present at FNA meetings should discuss everything that seems relevant to making a placement, consider the needs of the child and review what is available in terms of provision, including the curriculum to be followed in the remaining time at school.
> A precise statement of needs should be produced and efforts should be made to provide for those needs as far as possible, if necessary in a number of different establishments, and/or by introducing new provision when required.
> (COSPEN, 1988, p. 12)

More recent studies, in both Scotland and England, seem to indicate that the situation has changed little since the COSPEN Report. In a study of FNA meetings in Scotland, Hubbard (1992) found that at all stages of the FNA procedure, discussion focused on post-school placements rather than post-school needs. Similar views are expressed by Wood and Trickey (1996). They examined the Code of Practice (Department of Education, (DfE), 1994) which looked at transition arrangements for young people with special educational needs in England. Like the COSPEN Report, their study emphasised the importance of "balancing the elements of the process" and "deciding on how services can be networked in order to assist the young people to achieve a successful transition to adult life" (p. 124). The researchers warn that if this balance is not achieved, the 14+ review and the transition plan may become a paper exercise which benefits no-one, instead of a collaborative and joint attempt by young people, their families and professionals to help young people towards adulthood.

Hubbard (1999) argues that because the FNA process involves a changing group of multi-disciplinary professionals, with nobody acting solely on behalf of the young person and their family, the result is that assessment and planning for post-school provision is service-led, instead of needs-led. This is endorsed by organisations consulted by the Beattie Committee (Scottish Executive, 1999):

> Some assessments seem to be based on what provision is available rather than the individual's wants or needs.
> (SKILL, cited in Scottish Executive, 1998, p. 10)

This problem was acknowledged by the Beattie Committee Report (Scottish Executive, 1999). They recommended that key workers should be appointed to support young people and their families. They describe the key workers' main function as a single point of contact for young people and their families. They also see key workers as providing guidance and support to young people and their family carers, acting on their behalf to negotiate the most appropriate package of provision to meet the young person's needs, as well as being the contact person for education, training providers and other agencies if problems arise (p. 51, paragraph 5.8). This idea is similar to the Kurator system in Denmark and the escort system in Sweden (CERI, 1986). At the time of writing, Capability Scotland is piloting a new approach which aims to support young people with "complex needs" and their families during the transition from school to adult services (see Chapter 6). This involves a Transition Co-ordinator to support the young people and their families from the outset of the FNA process (Hubbard, 1999) and is similar to the concept of the key worker, advocated by the Beattie Committee.

The COSPEN Report (1988) also found that the timing of FNA meetings varied greatly between regions, with some regions holding early meetings and others later ones. It maintained that as young people with differing special needs mature at different rates, the timing of FNA meetings should be flexible. They recommended a minimum of two assessment meetings; with the first reviewing not only post-school placements, but school learning programmes and the second making recommendations for future placements. However, they envisaged the need for further review meetings after the second meeting if required. In England Bowers, Dee, West and Wilkinson (1998) also found problems around the timing of the first transitional review and subsequent reviews. A similar view was expressed by the Social Work Services Inspectorate (SWSI) report "Sensing Progress" (1998) which was concerned with post-school implementation. The report found that there is usually no long term plan to look at the need for subsequent transitions and that often follow-up arrangements break down. Hodkinson, Sparkes and Hodkinson (1996) argue that the school leaving age is only one step in the process of career development which continues throughout life. Therefore, reviews should be seen as "an incremental process of decision-making through which young people and their parents can explore their ideas about the future and pursue different options as they change their minds" (Dee, 2000, p. 16). To help them do this the Beattie Committee recommends that services be co-ordinated by Area Strategy Groups. These Area Strategy Groups are to work with agencies to ensure that the FNA process has clear links to the key worker. In addition, long term planning arrangements and subsequent transitions are to be based on individual profiles and action plans (Table 7, p. 66). This review system is designed to identify the "next step" following assessment and match provision to individual learning support needs (pp. 90-91, paragraphs 7.42; 7.47; 7.48).

The SAY Report (Scottish Executive 2000) also identified a need for better long-term planning and proposed a personal life plan for people with learning difficulties. It envisaged that this life plan will replace existing community care assessments and describe how the young person, his/her family and professionals will work together to ensure that the young person leads a fuller life. The plan will also specify healthcare needs; the need for short breaks from both the young person's and their carer's viewpoints; work and day service opportunities; further education; housing and transport needs, as well as other special support. In addition, the plan will also specify how each of these needs will be met.

At the time of writing, the recommendations from both the Beattie Committee and the SAY Report have still to be fully implemented. It remains to be seen whether people with learning disabilities will have both Beattie's individual profiles and action plans and the SAY Report's personal life plan, or whether the two plans will be combined.

Table 7. Individual profiles and action plans

Personal or Individual Profile:

The profile should include:

The type and level of learning and personal skills support needs (from assessment); and the type and level of skills and abilities;

Particular circumstances (social/emotional/behavioural) likely to create barriers to learning and/or employment;

Aspirations of the individual e.g. job, training, further education, a house, drug rehabilitation, money;

Action Plan:

The profile should be the basis of an individual(ised) action plan which is discussed and agreed with the young person.

The action plan should specify:

The areas/aspects to be addressed;

The activities which will form part of the training programme;

Other actions to address other problems e.g. housing, drugs, and the agency responsible;

What will constitute progress and how it will be measured;

Dates for reviewing progress and who will be involved;

The main contact for the young person.

Adapted from Scottish Executive, 1999, p. 89, paragraph 7.41

The COSPEN Report (1988) also found problems surrounding the actual meetings themselves. Their study revealed that often those with the greatest knowledge of the young people, for example class teachers, parents and the young people themselves, were often excluded from discussions or the meetings themselves. The report recommended that both parents and the young people themselves should have the right to bring people to the FNA meetings to support them or to speak on their behalf. They also recommended that the class teacher, the appropriate social worker and possible future service providers should all attend FNA meetings. In addition, they recognised the need for staff training in relation to the management of FNAs and the development of interpersonal skills. However, subsequent research has revealed that these recommendations have not always been taken onboard by local authorities. Hubbard (1992) found that at only seven out of the seventy-six FNA meetings she observed, were the young people invited to attend and then only at the end of the meeting. Tisdall's (1996) study revealed that whilst young people and their family carers were present at FNA meetings and offered the opportunity to ask questions and express opinions, they rarely spoke. In Hubbard's study family carers felt that the meetings were too large, that they themselves played a minor role, that professionals used too much jargon and in some cases did not have sufficient knowledge about their young person:

> Mother attending first FNA meeting:
> I remember a lot of people there and [at] times I felt there were too many... it inhibits what you can say... don't know how to express myself.
>
> Mother attending first FNA meeting:
> I would have preferred the meeting to be more informal and with people who knew J rather than strangers reading off case notes.
> (Hubbard, 1992, p. 111)

In some cases the size of the meetings, unfamiliar professionals, confusing terminology and a lack of understanding about professional roles led to feelings of anxiety and nervousness, especially when it came to discussing issues. Hubbard found that family carers attended FNA meetings in the hope that they would alleviate their problems, but after several meetings, the majority were dissatisfied with the outcomes and did not see themselves as being any further forward.

As regards the young people's involvement in the FNA meetings, Tisdall (1996) found that their participation in meetings was constrained by its structure, duration and professional expertise. Both she and Hubbard found that often professionals, either individually or as a group, were insensitive towards the young person's needs, feelings or comfort. In addition, Tisdall found that the meetings she observed lasted on average nine minutes and this did not give the young people time to become comfortable with the situation so that they would gain the confidence to express their opinions:

> Father describing daughter's involvement in FNA meeting:
> She wasn't given enough time to prepare for it. She wasn't given enough time to speak her mind.
> (Tisdall, 1996, pp. 21-22)

Stalker's (2002 June) more recent study echoes these views. She found that young people with disabilities are still infrequently involved in planning for their future, especially those with communication and/or cognitive impairments.

Parental feelings that they and their youngsters played little part in the decision-making process at FNA meetings is supported by Hodkinson et al's (1996) study. They suggest that professionals, because they have power over policy and resources, play an influential part in the process. For example, parents may have limited choices about post-school provision or their choices may be restricted because of lack of funding:

> Mother attending second FNA meeting:
> She [Local Authority Social Worker] is suppose to be getting back to me. I'm still waiting.
>
> Mother attending second FNA meeting:
> It's always B (Name of a residential establishment) that comes up... yet when I voice doubts I'm told there is nowhere else.
>
> Mother who had attended several FNA meetings:
> I feel meetings are too indecisive... nothing ever decided... everything just left till next one, especially when decisions about finance... who pays what.
> (Hubbard, 1992, pp. 118-119)

Thus often policy and resources become the defining factors in what is decided. This has led to researchers such as Tisdall (1996) and Wood and Trickey (1996) to conclude that meetings centre around the needs of professionals to meet their procedural obligations, rather than a desire to involve young people and their family carers in the decision-making process.

In an effort to address these issues, the Beattie Committee recommended that mentors be provided to young people and their families to provide personal support; to help them to express concerns and anxieties; seek out information; build confidence and make choices (p. 56, paragraph 5.28). The Beattie Committee sees the provision of both key workers and mentors as helping family carers and young people "bridge the gap between the providers of services and the young people who need these services" (p. 49, paragraph 5.1). The key worker is viewed as a "broker" who will act on behalf of the young person to negotiate an appropriate package of provision to meet his/her needs. The mentor is seen as providing personal and emotional support to the young person and his/her family and taking on the role of advocate (see Scottish Executive, 1999, Chapter 5). However, Corbett and Barton (1992) would argue that increasing the effectiveness of the FNA process and improving the support offered to young people and their families, is not enough. They maintain that people with disabilities are not fully involved in decision-making processes because of structural inequalities in the economy and society. They argue that for them real choices do not exist; instead their choices are influenced and controlled by changes in the labour market and funding levels (Weymont, 1997 September) (see also pp. 84-87).

The COSPEN Report also found considerable ignorance about post-school provision by professionals, parents and the young people themselves. They recommended that all involved parties should be aware of all the provision available and should be given opportunities to visit provisions. In addition, the report recommended that the school leavers should spend time in the placements on link courses prior to a final decision being made. Hubbard (1992) and Morris' (1999a, 1999b) studies in Scotland and England support these findings:

> Mother attending first FNA meeting:
> Social Worker had little to say at the Future Needs ... he didn't know H, the case or places available. He told me that he didn't know why he was there ...didn't know anything about it and only given a few hours notice of the meeting.
>
> Mother at second FNA meeting:
> How can I say something about the place when it could be in Timbucktoo for all I know.
> (Hubbard, 1992, pp. 113-114)

Studies in Scotland (Scottish Executive, 1998 December) and in England (Dee, 1997, 2000) found that parents' main sources of information about the assessment processes and post-school placements came from other family members, neighbours, friends, other parents' experiences and the media. Both studies recognised that young people and their families need formal information, in good time, about the procedures for deciding post-school placements, as well as about available options. Acting on these findings, the Beattie Committee (Scottish Executive, 1999) recommended the appointment of a mentor – "a named person who is objective and whom they [the parents and young people] feel is outside the formal agencies and systems" (p. 15). The role of the mentor is to ensure that <u>all</u> information is given to the parents and the young people. The Beattie Committee stressed the importance of all the parties involved in the FNA meetings having information about the needs of the young people and their families, as well as post-school provision, so that everyone can make informed choices and be effectively involved in the decision-making process.

To summarise, a recent review of assessment practices across post-school provision in Scotland (Thomson, 1998) (Table 8, p. 71) suggests that the FNA process still faces some of the problems identified by the COSPEN (1988) Report ten years earlier. Moreover, the emphasis in FNA meetings still tends to be on procedural routines, rather than on how professionals, family carers and young people can work together to design an appropriate individualised needs-led service. Furthermore, all parties still seem to lack the necessary knowledge to make informed decisions. Some professionals often have little prior knowledge of the young person at the centre of the FNA meetings and little understanding of their personal, physical, social and educational needs. In some cases they lack knowledge of post-school provision. Similarly, family carers and the young people themselves also still seem to be ill-informed about the FNA process and post-school placements. This results in them finding the FNA process to be "negative, causing worry and anxiety and aggravating health problems" (Hubbard, 1992, 'p. 174). However, the FNA process is currently under review and legislation is proposed for next year. Hopefully it will address these issues.

Table 8. Problems identified with assessment procedures

Variations in practice between agencies and within agencies.
Assessments which do not identify all the barriers to learning.
Lack of information from school to post-school providers.
Lack of formal arrangements for transmission of information between agencies.
Over-assessment.
All agencies who could contribute to assessment are not involved.
Focus on existing services rather than needs-led person-centred planning.
Lack of regular review and monitoring.
No legal duty on agencies to put the FNA into practice.
Education authorities have no responsibility for putting the FNA into practice after the child has left school
Social work services rarely offer options that would include committing financial resources two to five years ahead.
Putting the FNA into practice often relies on resources provided by other agencies.

Adapted from the Scottish Executive, 1999, p. 78 and 2000, p. 81

The studies cited above were mainly concerned with young people with learning disabilities and multiple disabilities. This study looked at the experiences of young people with profound physical and intellectual disabilities and their families during the FNA process (see Chapter 5). It focused on McGinty and Fish's (1992) phase aspect of the FNA procedure and explored ways in which services and provision could be improved from the perspective of the young people themselves, their family carers and professionals involved with this group (see Chapters 6 & 7). Through personal experience and discussions with other family carers, the FNA procedure often seems to have negative outcomes for this group in that no post-school provision is available:

> There is a major gap in "post 16" provision for young people with multiple disability and visual impairment when they leave school. In many parts of Scotland there is simply no appropriate "post 16" provision for this group of pupils.
> (Royal National Institute for the Blind, Scotland, cited in Scottish Executive, 1998, p. 19)

In addition, these young people have continuing educational, social and healthcare needs which are not always met in adulthood (Lambe, 2000; Morris, 1999b). In the past, they have tended to spend their days in special care units or residential care settings where they have received physical care but been given little opportunity to integrate with their communities or to make choices about their lives.

The following section looks at McGinty and Fish's (1992) second stage of transition – the post-school period of further education and vocational preparation, focusing on young adults with profound physical and intellectual disabilities.

Post-school provision

Research shows that young people with profound physical and intellectual disabilities are unlikely to be going into further or higher education or vocational training. Angele, Heard and Kennedy (1996, cited in Morris, 1999b) and Bradley, Dee and Wilenius' (1994) studies found that people with "profound learning and multiple disabilities" are often denied access to further education. Morris (1999b) found that if young people requiring "high levels of support" do continue in further education, it is likely to be in a specialist residential college which focuses more on the provision of care than the development of knowledge, abilities and skills. Such colleges usually aim to develop independent living skills, which for most young people with profound physical and intellectual disabilities is unrealistic. Whilst acknowledging that further and higher educational opportunities for people with disabilities have increased in recent years, Angele et al. maintain that access to further education is still too often seen in terms of people with sensory impairments or restricted mobility. These findings were supported by the Tomlinson Committee (Further Education Funding Council, 1996), which examined current educational provision for people with learning difficulties/disabilities in England. It found that people with mental health difficulties, emotional and behavioural difficulties and "profound and multiple disabilities" were under-represented in further education. In addition, they found that the content of the curriculum had little purpose or relevance to students with learning difficulties and/or disabilities.

To address the problem of under-representation of the groups identified above, the Tomlinson Committee recommended, not better trained staff, more equipment and resources, but "a philosophy of inclusive learning". This philosophy views the system as the problem and not the student:

> We want to avoid a viewpoint which locates the difficulty or deficit with the student and focus instead on the capacity of the educational institution to understand and respond to the individual learner's requirement... There is a world of difference between, on the one hand, offering courses of education and training and then giving some students who have learning difficulties some additional human or physical aids to gain access to those courses and, on the other hand, re-designing the very processes of learning, assessment and organisation so as to fit the objectives and learning styles of the students... only the second philosophy can claim to be inclusive, to have as its central purpose the opening of opportunity to those whose disability means that they learn differently from others.
> (Further Education Funding Council, 1996, p. 4)

Despite these moves towards "inclusiveness" and recognition of people with disabilities' rights, Weymont (1997 September) found that policy decisions in further education colleges in England centred around funding and the organisation of the curriculum, rather than concerns about participation and human rights.

In Scotland, the Further and Higher Education Act of 1992 placed a duty on the Secretary of State to ensure adequate and efficient provision of further education and to have regard for the requirements of young people over school age who have learning difficulties. In addition, a framework for standards of services was set up in 1993. However, Hardin (1999) found variations in policies and practices of further education colleges and noted difficulties with the appropriateness of provision and arrangements for progression. This has led some researchers (Costley & Maguire, 1999) to contend that practice has yet to catch up with policy as regards further education and training for young people with disabilities.

The Beattie Committee (Scottish Executive, 1999), which looked at transition to post-school education, training or employment for young people who require additional support, like Tomlinson, also adopted an inclusive approach:

> The single, unifying principle at the core of the Beattie Committee's proposals and recommendations is Inclusiveness. It is central to our vision that all young people on leaving school – whatever their circumstances – should have access to adequate and appropriate learning provision within a learning environment matching their needs, abilities and aspirations. The principle of Inclusiveness is essential for an effective transition from school to further education or training and for later transitions... The Committee believes that Inclusiveness is essential to help young people reach their full potential.
> (Scottish Executive, 1999, para. 2.1)

They made several recommendations concerning the continuing needs of young people with a high level of learning and support needs:

- Social Work Departments should work with other agencies to refocus and re-orientate Resource Centre provision to give a higher priority to addressing the continuing learning needs of young people, either in the Centre or through attendance at a college or training provider (paragraph 9.9);
- the SFEFC should examine the case for enhancing and extending the range of continuing learning opportunities in colleges to meet the needs of young people who have a high level of learning and support needs (paragraph 9.10)
- the Implementing Inclusiveness Network at national and local level should give specific consideration to developing and co-ordinating enhanced learning and support opportunities for young people with a high level of support needs arising from disabilities, and including young people in Resource Centres (paragraph 9.13)
- the Area Strategy Groups should pay specific attention to developing and co-ordinating enhanced learning and support opportunities for this group of young people (paragraph 9.15)

(Scottish Executive, 1999, p. 122)

At the time of writing, the Beattie Committee's proposals have not been fully implemented and there are few, if any, learning opportunities in colleges of further education for young people with profound physical and intellectual disabilities. Post-school provision for them still tends to be in segregated day centres. Morris (1999b) found that most young people with "complex health and support needs" stay on at school until they are nineteen years of age, mainly because there is no provision for them to move on to. Snelgrove's (undated) study reported that young people with "high levels of support needs and/or continuing health care needs", whose childhood's had been spent mainly away from their families in hospitals, nursing homes, residential schools and so on, were more likely to move into long-term residential care when they reached adulthood. For those who remained with their families, the most likely pathway in transition, according to Thomson and Ward (1994), is to a segregated day centre or residential setting (Figure 4, p. 76).

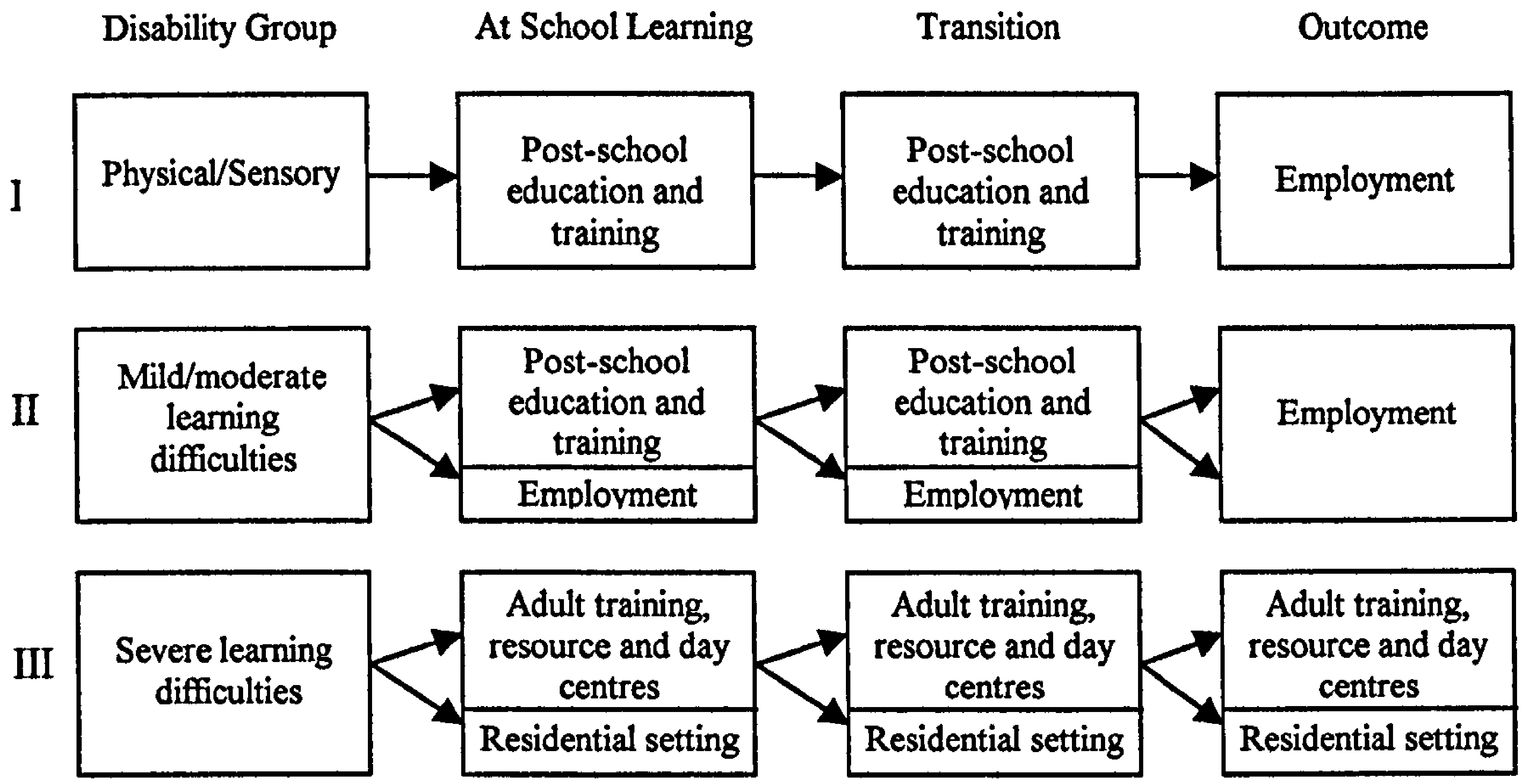

Figure 4. Outcomes in transition
Source: Thomson & Ward, 1994, p. 37

Seed (1996), in an update of his book, "Day Care at the Crossroads" (Seed, 1988), which evaluated day services for people with learning disabilities in Scotland, found that the majority of people with "profound learning difficulties" (75%) were in day centres based on a social care model. Young people attending these centres were mainly left to watch others and their main activities consisted of physical stimulus and exercises. Seed maintains that these centres tended to sustain a segregated lifestyle for their clients instead of encouraging integration into the community. The remaining 25% were either attending day centres based on the shared living model or the further education model (Table 9, p. 77). Seed found that whilst the centres closest to the shared living model welcomed and encouraged people with different kinds of disabilities to learn together, people with "profound and multiple disabilities" often did not benefit from the kinds of learning experiences provide by these centres. He found "a lack of comprehensiveness in the efforts made to stimulate and develop... potential... [and] stress was laid on informal interaction between clients and between staff and clients" (p. 50). He felt that the young people attending the centres based on the social care and shared living models would have benefited from the intensive and comprehensive programmes offered in centres based on the further education model. These centres' programmes aimed to provide continuing education for the young people and to stimulate and develop their physical, sensory, intellectual and social abilities. He also found that this model was the most effective in dealing with people with "profound disabilities".

Table 9. Models of practice

Features	The Social Care Model	The Further Education Model	The Shared Living Model
Objectives	To develop normal living potential, and social skills in family and community context	To provide continuing education To encourage assumption of adult responsibility	To provide a community within the ATC To break down staff/trainee barriers
Methods	Social/Behavioural assessment Problem-solving individualised programmes	Group learning Classes Projects Ed. assessment	Shared learning Shared residence/evening activities
Assumptions	Social work has a role in meeting individual and family needs	Society should allow slow learners to develop to their potential as adults	MH people have a possible valued contribution to make to other people
Staffing Implications	CSS & COSW	Teachers Lecturers	Members
Administrative implications	"Clients" Proximity to normal living situations Links with special housing	"Students" Location with access to FE Colleges and community facilities	"Members" possible links with philosophical movement Mixes groups e.g. physically and mentally handicapped

Adapted from Seed, 1996, pp. 122-123

Reports from Fife compiled by MacArthur (1997) and Brown (1997), which looked at provision for young people with "profound physical disabilities and complex needs", also found that the needs of this group were not being met. Brown reported that resource centres:

- were not equipped to deal with complex physical and/or medical needs
- had insufficient toilet and changing facilities
- did not have staff trained in meeting the needs and aspirations of this group
- had no nursing support and limited therapy provision
- suffered from a lack of appropriate specialist equipment and lacked the space to use it

(Adapted from Brown, 1997, p. 21)

In addition, the staff at the resource centres expressed concerns about mixing this group of very vulnerable young people with the clients already attending the centre and inspection officers were doubtful whether large centres were appropriate for these young people.

Concerns about lack of continuing learning opportunities for young people in day centres, were also voiced by parents and other organisations in representations to the Beattie Committee:

> Young people with special needs need more opportunities in post-school education and training... Some provision is neither structured or intensive.
>
> (Scottish Human Services, cited in Scottish Executive, 1999, p. 19)

Similar findings come from a survey of users and carers carried out by the SAY Report (Scottish Executive, 2000). It found that the young people using day centres described them as boring. This reflects the findings of other research such as that of Beyer and Kilsby (1995). Furthermore, day centres were also criticised by family carers for lacking direction, for failing to provide continuous learning experiences for the young people and for not providing opportunities for further development. These parental views were substantiated by research carried out by the National Institute of Adult Continuing Education (England & Wales) (NIACE) (1996). It found that people with "profound and multiple learning difficulties" were missing out on continuing education. The SAY Report also acknowledged this and stressed the importance of lifelong learning to people's development. It advocated the use of the Higher Still Programme (Sutherland, 1996) for all young people with learning disabilities.

However, continuing education for people with profound physical and intellectual disabilities, has only recently begun to be developed (Byers, Dee, Hayhoe & Maudslay, 2002). In many parts of the United Kingdom such services are either non-existent, insufficient in amount or offer inadequate, under-resourced provision (Collier, 1997; Hogg, 1991). Therefore, it is not surprising that attempts to develop a further education curriculum for these young adults is even more recent (Jones, 1989; Hogg, 1991). However, there is now some agreement about the core content of such a curriculum (Table 10, p. 80).

Hogg (1991) argues that these seven areas, when it comes to teaching, are not separate and require to be integrated into activities and individual teaching programmes. He also advocates a holistic or whole-person approach to the education of people with "profound physical and intellectual disabilities" and the use of interactive teaching:

> ...it [interactive teaching] consists of a member of staff working one-to-one with a pupil, concentrating all their attention on that pupil, and initially observing, and responding to any movement, expression or

> sound given by the pupil. The member of staff is not teaching in a traditional sense, but responding creatively to the pupil... Gradually games and sequences will emerge which the staff member will use and expand. The purpose of the games is to build a communicative relationship, and in so doing promote such things as pupil initiations, eye-contact, turn-taking, understanding cause and effect. Underlying all activities is the recognition of the importance of the pupil being an active partner in the engagement, consciously trying to move from the pupil as passive, and staff member as active paradigm.
> (Knight & Watson, 1990, cited in Hogg, 1991, pp. 175-176)

Table 10. Areas to be covered in a core curriculum for adults with profound physical and intellectual disabilities

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Cognition: i.e. the development of an understanding of the relations between objects, their place in space, causality in relation to objects and people.

Communication: with particular reference to the use of verbal and non-verbal communication to influence the world, as well as the expression of emotion as a communicative act.

Social behaviour: particularly with respect to awareness of others and sequencing of social acts.

Adaptive behaviour: typically with reference to diverse self-help activities ranging through self-feeding and drinking, coping with hygiene needs, self-dressing etc.

Movement: both with respect to "fine" (hand and finger) and "gross" (bodily posture and movement) motor activities.

Choice: to be seen as part of the curriculum as well as a determinant of the person's life. Choice needs to be taught and refined in order to optimise decision-making.

Affective experience and development: increasing emotional growth, sensory and aesthetic experience.

Adapted from Hogg, 1991, p. 171

However, Hogg recognises that these curriculum activities also need to take place in a wider community setting:

> ...care will need to be taken to ensure that the critical non-Centre environment in which people live, i.e. their home, and a variety of community settings, is embraced within the total approach.
> (Hogg, 1991, p. 177)

This has led to a debate about whether specialised day provision is required to meet the needs of people with profound physical and intellectual disabilities, or whether their needs can be more appropriately met within a more integrated setting.

Since the late 1980s in Scotland, there have been moves to develop specialist units for young people with profound physical and intellectual disabilities based on Seed's further education model, such as the White Top Centre in Dundee and the Aveyron Centre in Hamilton. The SAY Report also recognises that "those with multiple and profound disabilities... will continue to need structured day opportunities" (p. 55, paragraph 5.8)... [which] will vary from person to person but need to focus on personal and social development" (p. 56, paragraph 5.12). Similarly, the Beattie Committee, whilst advocating inclusiveness, does not rule out "the option of a separate learning environment where it is offered in response to the needs of the individual" (Scottish Executive, 1999, p. 9, paragraph 2.3). In contrast, in recent years there has been a commitment to move from segregated day centres and building-based services for young people with learning disabilities, to services which help individual people live the lifestyle they want – a lifestyle they are comfortable with and which offers them the same opportunities as everyone else (Wertheimer, 1998). However, this philosophy, as demonstrated above, does not always extend to people with profound physical and intellectual disabilities. Nevertheless, there are some writers who argue that "inclusion in the life of ordinary communities must be the goal for everyone with a disability, including those who may need intensive support" (Wertheimer, 1998, p. 67). McConkey (2000) also concurs with this. He sees specialist centres as a well-intentioned practice which prevents people with "profound and multiple disabilities" from being included in their local communities and from experiencing something approaching ordinary lifestyles.

The young people who are the focus of my study are often neglected by service providers, not only because of funding implications, but because they present a challenge to services. No one person, discipline or agency can met the full spectrum of their needs. In addition, educational, social and medical services are only just beginning to understand the nature of their needs and ways of meeting them and research to support practitioners is still in its infancy. Moreover, it is only recently that their rights to inclusion in society have been formally and internationally recognised (Centre for Studies on Inclusive Education (CSIE), 1995). Similarly, the belief that people with profound physical and intellectual disabilities could benefit from educational provision was only recognised by law in 1974 and their right to lifelong learning was only recently acknowledged in the Scottish Executive's "Opportunity Scotland: A Paper on Lifelong Learning" (1998):

> ...all Scottish citizens will have the means to access learning at any stage of their lives.
>
> (Scottish Executive, cited in Costley and Maguire, 1999, p. 76)

However, this may only be rhetoric. The Scottish Executive's pledge to provide access to lifelong learning for all by the year 2002 has not materialised. At the time of writing (2004), there is no legal duty on agencies to put the FNA into practice. In addition, although the Beattie Committee embraced the philosophy of inclusiveness, their remit excluded young people with profound physical and intellectual disabilities:

> ...the wider social support and health care ... *(which young people with profound physical and intellectual disabilities require)* falls outwith the Committee's remit.
>
> (Scottish Executive, 1999, p. 119, my addition in italics)

I feel that the Beattie Committee, with its emphasis on employment and its failure to adopt a holistic approach to the needs of these young people by not considering social support and medical care, has failed to include them in policy development. This is supported by Sense Scotland:

> People with more severe, complex and continuing needs, in particular those with severe communication difficulties, are under-represented [in further education]. As a result, there is a danger that policy development on post-school transition is formulated on the basis of a rather narrow set of needs, but applied to all.
> (Sense Scotland, cited in Scottish Executive, 1999, p. 116)

This means that it may be up to parent groups, with professional support to:

> Convince the statutory services and politicians that our children have rights, just like any other citizen – legal rights, the right to be treated with dignity and respect, and the right to anticipate a fulfilling and rewarding life.
> (Parents Advisory Group, 1995, p. 12)

The next section looks at McGinty and Fish's (1992) third phase of transition – the early years of employment and independent living, focusing once again on young adults with profound physical and intellectual disabilities.

Employment and independent living

McGinty and Fish (1992) maintain that their three stages of transition cover different time spans depending on the needs of the individual and on the way educational and vocational training are organised, as well as on the cultural context in which transition takes place. This third stage of transition – employment and independent living – is unlikely to be achieved by young people with profound physical and intellectual disabilities living in our society. Oliver (1990) argues that it is social, political and economic factors which hinder the development of people with disabilities and this stage of transition, like the others, is particularly influenced by socio-economic and political factors.

In the past transition into adulthood mainly involved young people themselves and their families. Achieving adult status occurred through physical growth and maturity and negotiations between parents and their adolescent youngsters concerning individual freedom and adult responsibilities. On leaving school young people were faced with three choices – further and higher education, which was traditionally academic; vocational training, which was job specific; or employment (Leonard, 1980). However, changing labour market conditions and increasing youth unemployment in the 1980s and 1990s resulted in most developed countries looking at the transition period from school to adult working life more closely. In the United Kingdom, in an attempt to reduce unemployment and provide a more skilled and flexible work force, successive governments introduced a variety of youth training and employment preparation schemes. These schemes focused not only on employment skills but on life and social skills (Fish, 1983; O'Mordha, 1985; Riddell, 1998). In addition, parents began to look to outside agencies for help with the sometimes difficult negotiations involved in their youngster's transition to adulthood (Rowan, 1983; Soder, 1985). As a result, transitional arrangements became a significant factor in government and agency policies (Molloy, 1985). However, access to these training schemes and services was only gradually extended to young people with disabilities as a result of pressure for equal opportunities for all young people from family carers of young people with disabilities, groups of people with disabilities and voluntary organisations. It was this pressure, along with a recognition of people with disabilities' basic human rights, that led to young people with disabilities being included in these programmes.

Today global, national and local concerns, together with economic, political and social factors, all influence preparation for adulthood. For example, global concerns about the ecology of the planet, population growth and global warming are likely to affect patterns of employment in this country, and in turn education and preparation for adulthood (Barton, 1995). Similarly, political and economic changes in Eastern

Europe are also likely to affect employment opportunities and living conditions. Therefore young people will need to be prepared for living and working in Europe and further afield.

Looking at national influences on the transition period from childhood to adulthood, McGinty and Fish (1992) argue that an emphasis on market forces, together with new legislation in education, social security, health and social services, are changing the process of growing up for young people in this country. For example, Sexton (1987) argues that the previous Conservative Government introduced free market forces into the education system by linking it into the labour market and the economic competitiveness of the country. Education was seen as an investment in the economy, as well as offering everyone an equal chance to exercise their powers of consumer choice and control. This human capital perspective however, does not recognise that social inequalities such as gender, class and race, can prevent access to resources. It argues that it is up to individuals to make the most of their opportunities and if they fail to do so, then the fault lies with them (Barton, 1995; Vincent, Evans, Lunt & Young, 1994). This viewpoint sees people with disabilities as:

> ...[striving] for employment not because they have a right to participate (or not) in the labour market, but rather because professionals deem that this is the appropriate goal for them.
> (Riddell, Baron, Stalker, & Wilkinson, 1997, p. 478)

In contrast, the current Labour Government has tended to reject this individual deficit model and, as already seen, has adopted policies of inclusion (FEFC, 1997; Scottish Executive, 1999) and life-long learning (Appendix R, p. 778). This is in line with the social capital perspective and the social model of disability. The social capital perspective is concerned with social cohesion and views education and training as:

> ...designed not so much to enhance an individual's employability but to promote quality of life, social networking and citizenship.
> (Riddell et al., 1997, p. 476)

Socio-economic and political factors also influence transition to adulthood for young people with disabilities. The social and economic cost of life-long dependency is costly for society. One way of reducing these costs is to encourage young people with disabilities to gain employment and lead an independent adult life. However, unemployment rates amongst people with disabilities are high – 70% of people with disabilities who want to work are unemployed (Morris, 1999a). Furthermore, Freshwater and Leyden (1989) also found that young people with disabilities were less likely to receive relevant vocational training than their non-disabled peers. Therefore current government legislation has tended to focus on welfare to work and increasing people with disabilities opportunities for paid employment (Mencap, 2001 November). However, for the young people who are the focus of my study, employment is generally not an option. Their impairments and disabilities mean that they are unable to take up employment.

Nevertheless, employment is seen by many researchers (Hughes & Kingsford, 1997; Ward et al., 1994) as being important as it gives young people freedom and choice. It also provides them with a sense of identity, as well as access to independent living and the formation of adult relationships. This view is echoed by young people with special needs. A focus group study (Scottish Executive, 1998 December) found that the young people wanted to be independent but also to participate in, and be part of, a social community. For them, the key to independent adulthood was employment. They saw employment as leading to an independent source of money which would make it possible for them to move away from dependence on family carers and allow them to take responsibility for their own lives. A job was also seen as giving them a meaningful role in society, helping them form new relationships, increase their participation in the social community, as well as providing them with the physical aspects of "success", such as a house, a car and so on. Thus employment is seen by the young people as giving them adult status. It is also viewed by researchers as helping young people with disabilities achieve the goals of adulthood (see pp. 58-59). However, a reduction in employment opportunities for young people with few or no qualifications, coupled with a demand for people with high level skills in recent years, means that it is less likely that young people with disabilities will be employed

(Riddell et al., 1997). Therefore there is now a growing recognition that employment opportunities will not be available for all and that people with learning disabilities need to be encouraged to participate in "productive daytime activity" (Thomson & Ward, 1994) and make "links into a full and active participation in community life" (Corbett, 1997, p. 165). In fact Thomson and Ward (1994) suggest that employment may not now be an indicator of adult status and suggest it might be replaced by "alternative ideas such as "productive daytime activity" and "quality of life" (p. 89).

Similarly, independence as an indicator of adult status has also been questioned. Kelly (1955) argues that adults, like children, are dependent:

> Adults are highly dependent upon a complex society made up of many people. They also grow to be dependent upon processes, resources, and services...
> (Kelly, 1955, p. 913)

Other writers (Wright, 1960, cited in Beail, 1985) maintain that dependence is essential in personal relationships and social networks. In our society however, independence is highly valued and seen as one of the goals of adulthood (pp. 58-59). However, research has shown that young people with disabilities do not have the same opportunities for independence as their non-disabled contemporaries. In a survey of young people with disabilities, which compared their experiences of growing up with their non-disabled peers, Hirst and Baldwin (1994) found that 30%-40% of young people with disabilities "find difficulty in attaining a degree of independence in adult life comparable to that of young people in the general population" (p. 110). They also found that young people with disabilities:

- were less likely to be living independently of their parents than young people in general
- were half as likely to be in paid work as other young people

- often faced long-term dependence on the security system, incomes were substantially below those of young people in general and restricted personal spending
- often did not control the money from their social security benefits
- were more likely than their non-disabled peers to report feelings reflecting a poor sense of their own worth and abilities and a limited sense of control over their own lives
- had more limited social lives, were less likely to have close friendships (including boy/girlfriends) and were more dependent on their parents for their leisure activities than their non-disabled peers

  (Hirst & Baldwin, 1994, cited in Morris, 1999b, pp. 10-11)

For the young people in my study with their requirements for ongoing personal assistance, healthcare and continuing support, independence seems impossible. They face a shortage of wheelchair accessible housing, a dearth of good quality services in the community (Esmond & Stewart, 1996), a shortage of supervised or staffed accommodation in the community and insufficient funding to meet their high dependency needs (Ward et al., 1994). For these young people the third stage of transition is rarely achieved. Their transition to adulthood is often postponed, or prevented altogether and they remain in what Griffiths (1994) describes as "eternal childhood". Furthermore, according to Morrow and Richards (1996), their transition tends to be towards “exclusion from” society rather than “participation in” society. This is supported by Emerson, Robertson, Gregory, Kessissoglou, Hatton, Hallam, Knapp, Jarbrink, Netten and Walsh (1999a) and by Hirst and Baldwin’s (1994) studies which found that people with “profound and multiple disabilities” had less choice; less social integration; fewer chances of employment; a less active lifestyle; more chance of being underweight and less access to leisure and community-based activities than their more able peers with intellectual disabilities. Morris (1999b) found that the young people who are the focus of my study, either remain at home with their parents and, if fortunate, attend day care services, or move out of the parental home into a residential establishment or a nursing home (see Figure 4, p. 76). She found that "people with complex healthcare needs" were:

> ...being "warehoused" in residential provision; they have little opportunity to make friends, be involved in their local community or do anything meaningful during the day. To a large extent, the scope for any personal development has ceased.
> Morris, 1999b, p. 78)

She argues that these young people need, and have a right to, make choices about their own lives. She maintains that independence for young people with "profound and multiple disabilities" is "not about doing everything for yourself but about having the support you need in order to do the things you want to do in your life" (p. 32). This means making the person who needs personal assistance responsible for choosing who provides the assistance and directs the support they need. One way of making it possible for these young people to communicate their preferences and make choices about the services and support they require is through person-centred planning (Sanderson, 1998). This is discussed in later chapters. Once the person's preferences have been established, grants may be available from the Independent Living Fund (ILF) and through direct payments to enable the young person to exercise choice and control over who provides the support they need. Unfortunately, at the moment, some people with profound physical and intellectual disabilities are not eligible for ILF as the cost of their care packages from social work departments exceeds the ILF's eligibility criteria. Moreover, although the direct payments scheme was extended in 2003 to all people with learning disabilities, there is a scarcity of both resources and services.

Although young people with profound physical and intellectual disabilities cannot achieve the goals of adulthood as identified by the CERI studies and other writers, as shown above, there is now a recognition that some of these indicators of adult status need to be replaced by alternative ideas. There is also a growing acknowledgement that young people with profound physical and intellectual disabilities have the right to adult dignity and status. Griffiths (1994) argues that as these young people are unable to earn adult status through the usual adult roles and activities, adult status needs to be conferred on them by others through recognition of their rights and capabilities as individuals. McConkey (2000) endorses this, arguing that people with "profound and multiple disabilities" have the right to ordinary lifestyles. Although he recognises that for these young people an ordinary lifestyle is impossible because their "very survival depends on extra-ordinary help and support" (p. 184), he maintains that, with extraordinary efforts, this group can join communities and experience something approaching ordinary lifestyles. However, he admits that society needs to broaden its perception of "ordinary" so that the needs of this group can be accommodated. He outlines three steps to developing community living for people with "profound and multiple disabilities" – maximising their presence in the community; providing them with a range of opportunities and experiences so that they begin to make choices for themselves and developing "circles of friends" (Neville, 1996 February/March) outside the disability community. To achieve this, according to McConkey, requires improving communication between able communicators and people with "profound and multiple disabilities", collaborative working between professionals, families and communities and the creation of an "opportunities culture" rather than a "care culture" (Table 11).

Table 11. The main features of a "care" and "opportunities culture"

Care culture	Opportunities culture
Dependence	Independence
Protection	Self-determination
Safety	Risk
Low expectations	Aspirations
Socially isolated	Community integration

Source: McConkey, 2000, p. 192

Hogg (1999 October) also sees the principle of inclusiveness as applying to people with "profound intellectual and multiple disabilities", but like Bradley (2000) he sees provision in the community for this group as depending "on a vision of a more equitable society, locally, nationally and internationally" (Bradley, 2000, p. 225).

Hogg accepts that barriers will have to be overcome in terms of physical access, social access to educational and leisure facilities and intellectual access to the arts. Like Kestenbaum (1996) and Bewley (1998), he also recognises that changes in attitudes are also important:

> People with learning difficulties still have to fight to have their voice heard, to have some control over their lives, to have access to their money, to have the right to marry and have children, to have the right to equal treatment for medical conditions such as heart disease, to be accepted as citizens of the world with equal dignity and value.
> (Bewley, 1998, p. 4)

This study aimed to help raise awareness of the needs of young people with profound physical and intellectual disabilities and to empower family carers and professionals so that the voices of these young people can be heard.

SUMMARY

This chapter looked at literature and current research related to my study. Like Costley and Maguire (1999), I found that literature is limited. There are few substantial pieces of research which focus on the experiences of people with profound physical and intellectual disabilities and their family carers during the transition period from school to post-school provision, even although statistics show a steady increase in the population of this group. I also found that the confusion over terminology, combined with a lack of definition of terms, meant that it was difficult for me to determine if some studies included the young people whom I have described as having profound physical and intellectual disabilities. Nevertheless, there is evidence which suggests that these young people are being socially excluded from society and that health boards, education and social work departments are failing to meet their needs as they grow into adulthood. However, there is now a growing recognition of their rights and their potential to develop. Moreover, these rights and entitlements are now formally stated both internationally (CSIE, 1995) and nationally (Appendix R , p. 778) and a philosophy of social inclusion is now being expounded by politicians and policy-makers. As Hogg (1991) says:

> We have then, the philosophy; if it is to be more than self-justifying rhetoric the values must be translated at every step into practical realisation of these beliefs to which we all pay lip service.
>
> (Hogg, 1991, p. 167)

Chapter 3 Research design

This chapter begins by looking at the ways in which people have tried to make sense of the world around them. It then focuses on one of these ways – research, and discusses the philosophic assumptions which influence that research. The remainder of the chapter provides detailed information about my research design. By this I mean the entire process of research – the broad philosophical and theoretical perspectives, the conceptualisation of the problem, methods of data collection and analysis, verification procedures and report writing (Creswell, 1998).

MAKING SENSE OF PHENOMENA

There are three main ways in which people have tried to make sense of their environment and the phenomena in it, namely, experience, reasoning and research (Mouly, 1978). Experience can be personal, based on the experience of others, or authoritative, based on "expert" knowledge. Whilst experiences can be useful in research as they provide rich data which can be used to investigate and explore issues, they have their limitations. Often "common-sense" knowing is based on haphazard events, with causal links being made unsystematically and hypotheses tested selectively. Likewise Mouly (1978) cautions against "expert" knowledge and authority sources:

> ... it must be remembered that no one is infallible, and even the best and most competent are not exclusive possessors of "the truth, the whole truth, and nothing but the truth".
> (Mouly, 1978, cited in Cohen & Manion, 1994, p. 2)

The second way in which people have attempted to understand the world around them is through reasoning. Reasoning consists of three types – deductive, inductive and a combination of the two, inductive-deductive reasoning. Deductive reasoning is based on formal logic whereby a conclusion can be deducted from a premise. For example,

All mammals suckle their young.
Elephants are mammals.
Therefore elephants suckle their young.

However, deductive reasoning can only be used with certain statements. It has been criticised because often major premises were preconceived, or based on authoritative sources, rather than observations and experience, resulting in biased conclusions (Mouly, 1978). Therefore scientists began to favour inductive reasoning, based on observation and experience, to verify premises. Eventually an inductive-deductive approach was developed. This consisted of:

> ...a back-and-forth movement in which the investigator first operates inductively from observations to hypotheses, and then deductively from these hypotheses to their implications, in order to check their validity from the standpoint of compatibility with accepted knowledge. After revision, where necessary, these hypotheses are submitted to further test through the collection of data specifically designed to test their validity at the empirical level.
> (Mouly, 1978, cited in Cohen & Manion, 1994, p. 4)

The third means by which people have set out to discover "truth" is research. Research is a combination of both experience and reasoning. Cohen and Manion (1994) define research as:

> ...the systematic, controlled, empirical and critical investigation of hypothetical propositions about the presumed relations among natural phenomena.
> (Cohen & Manion, 1994, p. 4)

They see research has having three characteristics which distinguish it from "common-sense" knowing. Firstly, research is systematic and controlled and its operations are based on inductive-deductive reasoning. Secondly, it is validated by empirical data based on experience which is checked against objective reality. Thirdly, it is self-correcting in that procedures and findings are open to public scrutiny.

This way of understanding, along with these principles of research, were used in my study of the transition period from school to post-school provision for young adults with profound physical and intellectual disabilities.

Educational and social science research

Much of the work of educational and social science researchers has been modelled on the methods used by the natural sciences (De Landsheere, 1993). This perspective, known as positivism, views educational and social research as essentially the same as research into the natural sciences. Therefore it is concerned with the discovery of natural and universal laws regulating and determining individual and social behaviour. It assumes that there are causal relationships between events which will allow the formation of laws which can be generalised and used to predict and control events. Moreover, it makes the assumption that the methodological procedures of natural science can be applied to the study of human behaviour and that science provides us with the clearest possible ideal of knowledge. This is because it uses methods and concepts which are objective, operationalisable, replicable, usually empirical and free from value judgements or bias. These assumptions are based on untestable postulates concerning ontology, epistemology, the nature of humans and methodology (Burrell and Morgan, 1979). In Table 12 (p. 97) I have tried to show the relationship between the postulates and the methodology of the research paradigms.

Ontological assumptions are concerned with the nature of reality (Table 12, p. 97). Positivism sees reality as objective; as existing "out there" for us to discover. Reality is external and imposes itself on individuals' consciousness from without. It can be broken down into parts and each part examined individually. This standpoint, known as realism, contends that objects have an independent existence and are not dependent for it on the knower. However, nominalists (Stevens & Sapsford, 1984; Kelly, 1955) argue that reality is constructed. They suggest that we construct our own personal reality through our senses, the concepts we have at our disposal and implicit theories which we are continually testing and modifying. Similarly, Mead (1934) argues that our social reality is constructed through our interactions with others:

> Our social reality is interpersonally defined and culturally conditioned. The meaning of an event or behaviour is not given absolutely, or imposed by individuals, but developed and negotiated between individuals in the context of existing social meanings.
> (Stevens & Sapsford, 1984, p. 102)

The way we view the nature of reality directly affects our epistemological assumptions. Epistemological assumptions are concerned with the nature of knowledge, how it can be acquired and how it can be communicated to others (Table 12, p. 97). Positivists view knowledge as hard, objective and tangible. Researchers adopting this standpoint believe they can distance themselves from the phenomena they are studying and be value-free. Positivists also argue that all knowledge is based on experience and can only be verified by observation and experiment. In contrast, anti-positivists view knowledge as softer and more subjective. Knowledge is based on personal, unique experiences and insights. It is constructed and the knower cannot be separated from what is known, as values will influence understanding. Hubbard (1979) maintains that in the past "value neutral" and "objective" knowledge was constructed by "university trained white males from privileged social backgrounds" (p. 31) and that the only way to achieve "objectivity" is to have a diversified group of women and men doing science from all kinds of different cultural and social backgrounds with very different ideologies and interests. Thus the personal bias that each person brings would cancel out the bias of the other person. Other feminists, such as Le Moncheck (1985), argue that "objectivity" does not exist as all researchers must adopt a perspective in order to begin their investigations.

Table 12. Positivism and phenomenology

Positivist approach		Phenomenological approach
Realism Reality is objective, external to individuals. By carefully dividing and studying its parts the whole can be understood.	Ontological assumptions – concerned with the nature of reality.	**Nominalism** There are multiple realities. People construct their own personal and social realities. These realities form an interconnected whole and can only be understood as such.
Positivisim Knowledge is hard, objective and tangible. The knower can stand outside of what is to be known. Knowledge can be value free.	Epistemological assumptions – concerned with the nature of knowledge.	**Anti-positivism** Knowledge is personal, subjective and unique. The knower and the known are interdependent. Values shape what is understood.
Determinism Human beings are determined by external situations. They respond in a mechanical way.	Human nature models of human beings.	**Voluntarism** Human beings are capable of autonomy. They initiate their own actions and are capable of creating their own realities.
Nomothetic Searches for universal laws. Usually employs quantitative research methods.	Methodology	**Idiographic/hermeneutic** Seeks to understand how people create, modify and interpret the world. Concerned with meanings. Usually employs qualitative research methods.

The third assumption is based on the nature of humankind – deterministic or autonomous (Table 12). Positivists tend to assume that people are the product of forces which are outside their control and that whatever subjective experience of autonomy people may have is essentially illusionary. However, other theorists

(Kelly, 1955; Mead, 1934) suggest that people, within limits, are autonomous beings. They regard humans as "agents", capable of "reflexive awareness" – the ability to reflect on themselves. It is this reflexive awareness that enables people to initiate actions, carry them out, make sense of situations in different ways and be creators of their own fate. Mead (1934) and Kelly (1955) argue that because the meaning of actions and experiences are not fixed but are constructed and open to reframing and change, people have the power to create their own personal and interpersonal realities.

Assumptions about the nature of humankind, knowledge and reality all influence the aims, nature of understanding and research methods in educational and social science research (Table 12, p. 97). For example, researchers who see humankind as deterministic, knowledge as hard, objective and tangible and treat the social world like the natural world – external to individuals, objective, a "given" out there, tend to adopt a nomothetic approach. They look for relationships and regularities between selected factors in the world and seek general laws using methods and concepts which are objective, clearly operationalised, replicable, usually empirical and free from value judgements (Kincheloe, 1991).

In contrast, opponents of positivism tend to favour idiographic and hermeneutic approaches. Both approaches are based on the assumption that the social world can only be understood from the standpoint of the individuals who are part of the ongoing action being studied. Therefore they reject the positivist view of the detached, objective observer and argue instead that individuals' behaviour can only be understood by the researcher adopting an insider perspective. This involves the researcher in sharing the participants' frame of reference in order to understand the participants' interpretations of the world around them. Thus social science is seen as a subjective rather than an objective undertaking – a way of looking at people's experience in specific contexts.

The idiographic approach investigates single cases in depth. It aims for a holistic understanding of the complete person and rejects the mechanistic model of humankind which sees people as consisting of a number of objective parts which can be investigated in isolation. Researchers using this approach stress the importance of understanding how individuals create, modify and interpret their world. They view people, within limits, as autonomous agents, arguing that as people are not totally determined, they cannot be understood in terms of cause and effect explanations which lead to prediction.

The hermeneutic approach maintains that meaning is at the heart of much of human behaviour and experience. Maykut and Morehouse (1994) define meaning as:

> ...what we can agree upon or at least accept as a working basis for seeking agreement about a concept at hand. We achieve meaning through shared encounters.
> (Maykut & Morehouse, 1994, pp. 37-38)

Thus Shotter argues that educational and social research should be concerned with "negotiations between people rather than interactions between things." (Shotter, 1974, p. 218). This hermeneutic approach aims to interpret meanings, explore their source and investigate how they are developed and maintained through interactions with others. It also involves finding out about:

> ...the significance and implications of actions and social situations for the people involved both at a conscious and unconscious level and within the shared conventions of their culture.
> (Stevens & Sapsford, 1984, p. 91)

Shotter (1974) argues that the ways in which people conceptualise themselves and situations affect what they do. He maintains that people "direct behaviour towards the attainment of socially constructed and established goals, sensing and correcting deviations from this task in the course of their behaviour" (p. 218). These rules are social, vary from culture to culture and change with the passage of time. He further contends that these rules are matters of convention, not laws of nature, and thus psychology is essentially a "moral" science rather than a "natural" science. A moral science which helps people make sense of their world and extends their vision of what human experience might be:

> The purpose of social science is to understand social reality as people see it and to demonstrate how their views shape the action which they take within that reality. Since the social sciences cannot penetrate to what lies behind social reality, they must work directly with man's definitions of reality and with the rules he devises for coping with it. While the social sciences do not reveal ultimate truth, they do help us to make sense of our world. What the social sciences offer is explanation, clarification and demystification of the social forms which man has created around himself.
>
> (Beck, 1979, citied in Cohen & Manion, 1994, p. 26)

If Shotter's and Beck's arguments are accepted, then awareness and concepts become the products of cultural evolution and individual development and vary as a result of historical, cultural and personal contact. Thus human beings individually and collectively "make" themselves and are capable of doing so in a variety of ways. Therefore explanations which apply in the case of one person cannot be generalised to another. Nor can human behaviour be totally governed by general laws characterised by underlying regularities. Thus social psychology searches for differences, patterns and underlying structures rather than cause-effect laws. Stevens and Sapsford (1984) describe it as a "dialectical psychology" – holistic and integrative, and concerned with processes (the way change comes about), hermeneutic understanding and possibilities:

> ...it will be concerned not with seeking deeply into the inner working of things and discovering their rock bottom, ultimate causes, but with options as to how to live. And I feel justified in claiming that such an enterprise can be called a scientific one as I take it that what distinguishes those activities we designate as "scientific"... is that in

> them we attempt to discover general principles by which we can transform ourselves from being victims to being masters of our fate.
> (Shotter, 1975, cited in Stevens & Sapsford, 1984, pp. 127-128)

Although I tended to favour this dialectic approach, I did not want to place myself within a single epistemological tradition. I believe that the best approach to research is to use whatever theory, paradigm or methods best fit the aims and purpose of the study. Therefore in my study I used an interpretive paradigm, developed a transactional model of disability and used a bricolage approach. These are discussed in the following sections.

Paradigms

Maykut and Morehouse (1994) define a paradigm as "a set of overarching and interconnected assumptions about the nature of reality" (p. 4). Two paradigms, the normative and interpretive, have tended to dominate disability research. I have chosen to use an interpretive paradigm in my study for a number of reasons. Firstly, the interpretive paradigm focuses on understanding actions and meanings rather than causes. My study was not concerned with understanding the human condition in general terms, or making generalisations about what causes people to behave in particular ways; but with how people create, modify and interpret their world. My study was concerned with individuals and aimed to understand the subjective world of human experience by trying to understand the participants' interpretations of the world around them. Secondly, my study did not set out to test a theory, but sought to generate theories which made sense to the participants from the data it produced, that is to say, it drew on the outlook of grounded theory (Dilori, 1989; Yount, 1991). Therefore it matched the interpretive paradigm's concern that theory should be built on experience and understanding gained during research, and not precede research. Thirdly, the study echoed the interpretive paradigm's concept that the researcher be personally involved with the study: I myself had undergone similar experiences to the participants with my own daughter's transition from school to adult provision (see Chapter 1). Finally, my study was a small scale study involving family carers and professionals involved with young adults with profound physical and intellectual disabilities.

Table 13. Normative and interpretive paradigms

Normative	Interpretive
Society and the social system	The individual
Medium/large scale research	Small scale research
Impersonal, anonymous forces regulating behaviour	Human actions continuously recreating social life
Model of natural sciences	Non-statistical
"Objectivity"	"Subjectivity"
Research conducted "from the outside"	Personal involvement of the researcher
Generalising from the specific	Interpreting the specific
Explaining behaviour/seeking causes	Understanding the action/meaning rather than causes
Assuming the taken-for-granted	Investigating the taken-for-granted
Macro-concepts: society, institutions, norms, positions, roles, expectations	Micro-concepts: individual perspective, personal constructs, negotiated meanings, definitions of situations
Structuralists	Phenomenologists, symbolic interactionalists, ethnomethodologists

Source: Cohen & Manion, 1994, p. 39

However, in recent years a new paradigm has emerged in disability research which questions and challenges both the normative and interpretive paradigms – the emancipatory paradigm. This paradigm has emerged because of criticisms of existing disability research by people with disabilities as well as researchers' reflections about their own practice. Looking at the former, Oliver (1983) argues that disability research based on the normative paradigm (see Harris, 1971; Martin, Meltzer, & Elliott, 1988; Wood, 1980) has reinforced the individualistic medical model of disability (Chapter 2, Figure 2, p. 36). Thus it has tended to see the difficulties that people with disabilities face as being the result of individual impairments. This conflicts with the experience of people with disabilities who argue that the problems of disability are caused by society (UPIAS, 1975).

Furthermore, Oliver (1983) criticises the normative paradigm for viewing the relationship between research and social change in simplistic terms. He claims that disability research within a normative paradigm assumes that:

> Given the facts, government will act and changes will occur for the better. This has been called "the social engineering approach" and has been widely criticised both for its epistemological assumptions and for its failure to provide social change in the manner prescribed.
> (Oliver, 1992, p. 109)

Thus writers such as Stone and Priestley (1996) and Rioux and Bach (1994) argue that disability research conducted within the normative paradigm has encouraged the marginalization of people with disabilities, segregational polices, eugenics and the denial of human rights.

Whilst Oliver (1992) admits that disability research, conducted within the interpretive paradigm (see Blaxter, 1980; Borsay, 1986a, 1986b; Oliver, Zarb, Silver, & Moore, 1988), has gone some way towards including the experiences of people with disabilities, he criticises this kind of research for failing to have any major impact on both services for people with disabilities and their quality of life. Although conceding that the interpretive paradigm views disability as a social problem and not an individual one, Oliver (1987, 1992) criticises it for failing to make a direct link between research and policy by adopting an enlightenment model (Figure 5, p. 104). He maintains that this kind of research offers little improvement in the lives of people with disabilities and only alienates them from the process of research. Other writers concur, arguing that research within the interpretive paradigm only adds to the social oppression of people with disabilities (Abberley, 1997; Finklestein, 1980; Goffman, 1968).

Although the emancipatory research paradigm arose because of criticisms of existing paradigms, it is also the outcome of researchers' self-reflections about their own work. Zarb (1992), in a critical appraisal of his own research involving people with disabilities, argues that disability issues can only be effectively tackled by building a new research paradigm which changes the existing material and social relations of research production. However, he recognises that changing the material relations of research production (e.g. who funds research, who has the power to define the subject matter and what counts as "knowledge") will be a slow process. He sees changes in the material relations of research production coming about mainly through social and political change, with research only playing a minor role.

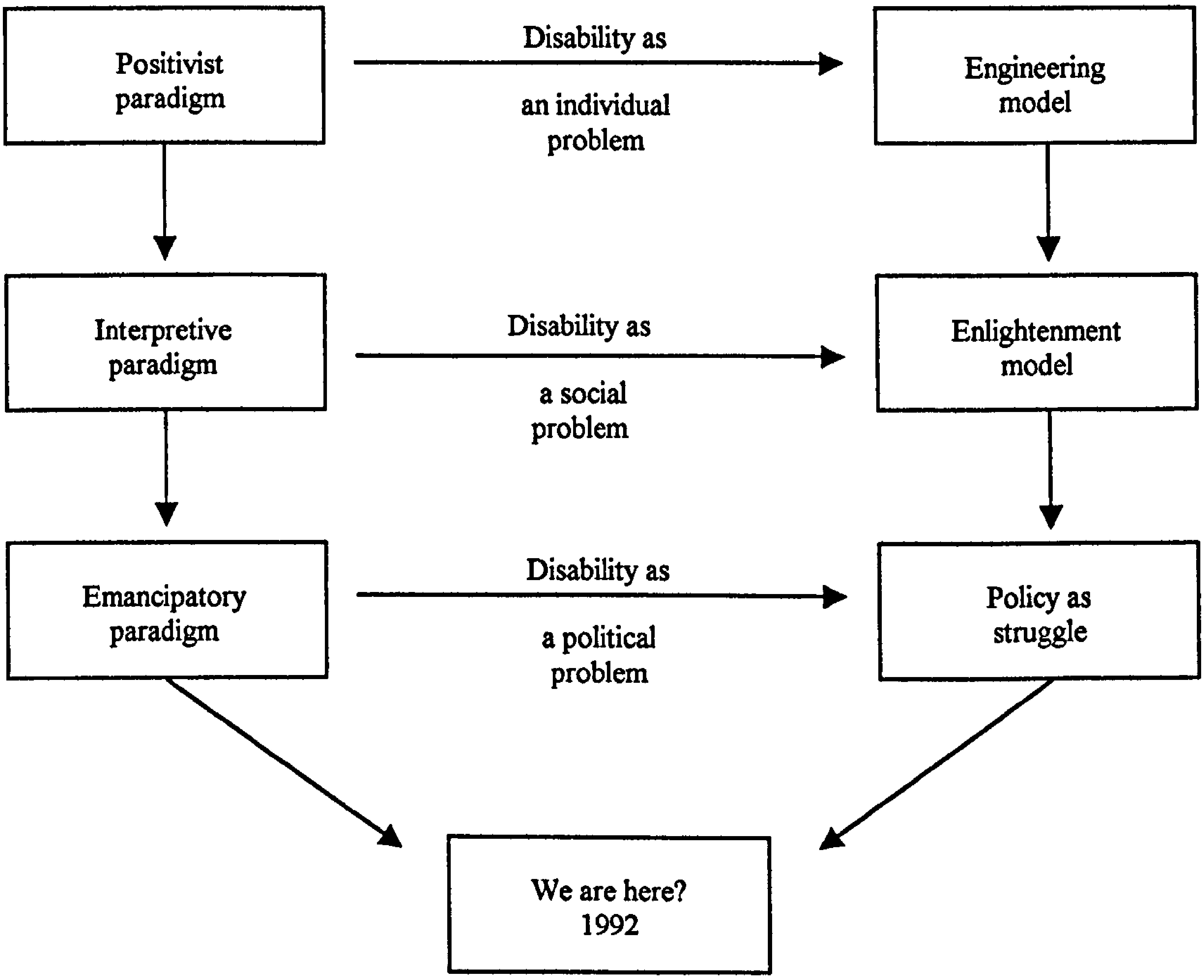

Figure 5. Social research and social policy
Source: Oliver, 1992, p. 108

Nevertheless, he argues that researchers can make changes in the social relations of research by engaging in participatory research. This involves working in partnership with people with disabilities and including them in the research process in a meaningful way (Table 14, p. 105). He sees participatory research as a "prerequisite to emancipatory research" (Zarb, 1992, p. 128) but he maintains that:

> Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how.
> (Zarb, 1992, p. 128)

Table 14. Participatory research and emancipatory research

	Participatory research	Emancipatory research
Methodology	Phenomenological (getting inside the experiences of research subjects), qualitative methods	Research as political action; either qualitative or quantitative methods
Ideology	Not prescribed; likely to be either normalisation or social model of disability, and to promote positive images of disabled people	Adoption of social model of disability; research only undertaken if it will practically benefit disabled people
Who is in control?	Researcher in partnership with disabled people, particularly at data collection stage	Disabled people in control of all aspects from formulation of questions to dissemination
Role of researcher	Expert, sharing expertise with research subjects; sometimes also advisor/supporter	Expertise at disposal of disabled people, accountable to disabled people
Subject matter	Issues relevant to the lives of disabled people	Explores and identifies appropriate avenues for change
Accountability	Accountable to funders	Accountable to disabled people and their organisations

Source: Walmsley, 2001, p. 196

Therefore he favours an emancipatory research paradigm (Table 14, p. 105).

The emancipatory research paradigm is still in the early stages of development and is a long way from becoming a practical reality (Zarb, 1992). It presents a number of challenges to researchers in terms of who conducts the research, the subject matter, objectivity, accountability and accessibility (Germon, 1998; Shakespeare, 1996; Stone & Priestley, 1996; Walmsley, 2001) and its advocates have still to provide examples of truly emancipatory research within the context of a field study. Nevertheless, Stone and Priestley (1996) have identified six core principles of the emancipatory research paradigm (Table 15).

Table 15. Core principles of the emancipatory research paradigm

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1 The adoption of a social model of disablement as the epistemological basis for research production

2 The surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation

3 The willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers

4 The evolution of control over research production to ensure full accountability to disabled people and their organizations

5 Giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences

6 The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

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Source: Stone and Priestley, 1996, p. 706

However, I have chosen not to use the emancipatory research paradigm in my study as I felt I was not able to meet all of its principles. Riddell, Wilkinson and Baron, (1998) acknowledge that it is difficult to fulfil all the principles of the emancipatory research paradigm in studies involving people with learning difficulties:

> Attempting to fulfil all three criteria (of emancipatory research) in action research with physically disabled people is imaginable...

> Attempting to fulfil these criteria with... people with learning difficulties is more complex. The expertise of the researcher... is not transmissible to some people with cognitive impairments; the involvement of people... may similarly be limited; current models... suggest that the pulls either to the trivial or to the professionally stage managed are hard to resist!
> (Riddell et al., 1998, pp. 81-82)

Chappell, Goodley and Lawthorn (2000) support this. They point out that whilst attempts have been made to apply the principles of the emancipatory research paradigm to methods in studies involving people with disabilities (March, Steingold, Justice, & Mitchell, 1997; Stalker, 1998; Williams & Nind, 1999), the content, in terms of exploring and identifying avenues for change, have been largely ignored.

One of the aspirations of proponents of the emancipatory research paradigm is that people with learning disabilities be meaningfully involved and in control of all stages of the research process. In my study the involvement of the young people was limited due to their profound impairments. This left me with the dilemma of who should represent the views of the young people. Research (Dowling & Dolan, 2001) suggests that it is not just people with disabilities who suffer from oppression and unequal opportunities but whole families. Therefore I chose the family carers to represent the young people's views as they too suffer directly and indirectly from the oppression faced by their offspring and because they frequently have to "fight the corner" for them. Moreover, they are skilled in interpreting their youngsters' non-verbal ways of communicating (see Chapter 5). This however, did not enable me to meet the emancipatory research paradigm's criterion of involving people with disabilities in the research process. Nevertheless, I tried to involve the family carers (Appendix Q, p. 771). However, as Zarb (1992) argues, the emancipatory research paradigm requires more than the participants' involvement and participation in the research process (see pp. 104-106). It requires full ownership of research production. This I was unable to do. Research has shown that the family carers in my study probably spend seven and a half hours a day carrying out basic care tasks for their sons and daughters. This does not include time spent on providing emotional and social support (Lambe, 2000; Mencap, 2001 November). Thus I felt that it was unfair to ask them to become involved in all aspects of the research. Moreover, they themselves were happy to let me undertake the research, seeing me as having the knowledge and skills required to undertake such a study:

> ...respondents are the experts on their own lives... ethnographers possess expertise which can be utilised in a variety of ways to contribute to processes of change. This expertise lies in their ability to produce writing which counters hegemonic discourses and their capacity to represent the complexity of people's lives through recognising the importance of individual experience, culture and structure.
> (Davis, 2000, p. 203)

We established a partnership, based on the understanding that we both had expertise but from differing frames of reference (Kitchin, 1999a). Thus I used a team approach, more in line with participatory research (Table 14, p. 105).

I also felt that I could only partially meet the emancipatory research paradigm's challenge of "exploring and identifying appropriate avenues for change" (Table14, p. 105). I felt my study was characterised by what Chappell et al. (2000) describe as "experiential issues" (what the world is like for young people with profound physical and intellectual disabilities and their families) and service issues (how we can create better services to improve people's lives). This kind of research, according to Chappell et al., has done little to empower people with disabilities or create political change which will further their interests. However, my study did attempt to "create an environment in which disabled people *(represented by their family carers)* are empowering themselves through research participation" (Stone & Priestley, 1996, p. 711, my addition in italics) by involving the participants in focus group and nominal group discussions. Stone and Priestley argue that these approaches not only address the need to collectivise personal experiences of disablement, but also involve collectivising the experience of taking part in the research process. Whilst an isolated doctoral research project is unlikely to change policies and practices, Stone and Priestley argue that "failure to transform individual lives need not be the sole criterion of 'good research'" (p. 715). They suggest that if research is to be disseminated, used to confront social structures of oppression, contributes to an understanding of disablement and puts disabled studies more firmly on the academic agenda, it is worthwhile. This I hope my study will do. In addition, Kieran (1999) argues that research within a traditional paradigm, whilst not having an immediate impact on the material and social conditions of people with disabilities, or on policies and practices, may influence policy reform in the future. Kieran cites research carried out in the 1950s which, although having no impact at the time, contributed to major policy reform in the 1980s and 1990s.

I also developed a transactional model for my study, whereas the emancipatory research paradigm favours the social model of disability. The reasons for this are explained below.

Models of disability

I developed a transactional model for my study because I felt that neither the individual medical model, nor the social model, could account for the lived out experiences of the young people and their families who are the focus of my study. Whilst I recognize that both the individualistic medical model and the social model of disability have made valuable contributions to our understanding of disability issues, neither, on its own, I believe, is sufficient for the purposes of my study. In my view the individualistic medical model:

> ...gives rise to an individualization of the problem and does not give grounds for research tools in order to change economic, social and physical structures in society.
> (Reindal, 1995, p. 66)

However, this model, with its emphasis on the medical and functional aspects of disability, is important in identifying the services which people with profound physical and intellectual disabilities require, for providing criteria about what an impairment and impairing conditions are (Reindal, 1995) and for preserving their rights (see Byggforsk, 1993, cited in Reindal, 1995, p. 67).

The social model unhooks impairment from disability and so ignores the lived out personal experiences of people with impairments. It ignores the social character of impairment and fails to acknowledge that some restrictions faced by people with disabilities are caused by their impairments – impairment effects (see Chapter 2). This has resulted in some groups of people with impairments, such as the young people in my study, being ignored and may be partially responsible for the dearth of services for this group. Therefore I felt I needed to develop a model which would help me to explore and increase understanding of the experiences of this group at the transition stage. Such a model needs to recognize that these young people and their families' lived out experiences of disability involve not just battling against social barriers, but also struggling with the effects of illness and other features of impairment. Thus I based my model on Dryden's (2000) and Llewellyn and Hogan's (2000) transactional model.

My model uses Thomas' (1999) social relational definition of disability:

> Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.
> (Thomas, 1999, p. 156)

This definition encompasses both barriers to "doing" and barriers to "being" (see Chapter 2), thus incorporating the psycho-emotional dimensions of disability, as well as disablist practices and structures which influence the lives of people with disabilities. This way of looking at disability is particularly relevant to my study. The young people in my study face restrictions both on "doing" and "being". For example, inadequate access and lack of equipment prevents them from engaging in a number of leisure activities and the profound nature of their physical and intellectual impairments can result in them remaining in what Griffiths (1994) describes as "eternal childhood" and being denied adult status, rights and roles.

This definition of disability also allows disability to be looked at from different levels of analysis. Thus I was able to consider forms of social relationships which operate at the personal, interpersonal, organizational, cultural and broader social structural levels, as well as how they intersect and interact, to produce disability (Thomas, 2001). My model sees disability "as a product of both cultural values and material relations of power (such as political economy, patriarchy and imperialism)" (Priestley, 1998, p. 87). However, it is careful not to focus exclusively on structural and environmental factors (Figure 6, p. 111). Whilst it recognizes that people with disabilities are embedded in a complex network of social structures and relationships which partly determine their lives, it also views them as agents, capable of changing the world and other people's perceptions of them:

> It cannot be denied that the physical, material and social organisation of our society promotes inequalities, and withholds rights and resources to some groups... [and] that this should be an important topic for researchers to investigate. However, this [reduces] the importance of people as social actors, reifying the role of structure and ignoring the diverse ways in which individuals and social groups relate to and resist such structures.
> (Davis, 2000, p. 196)

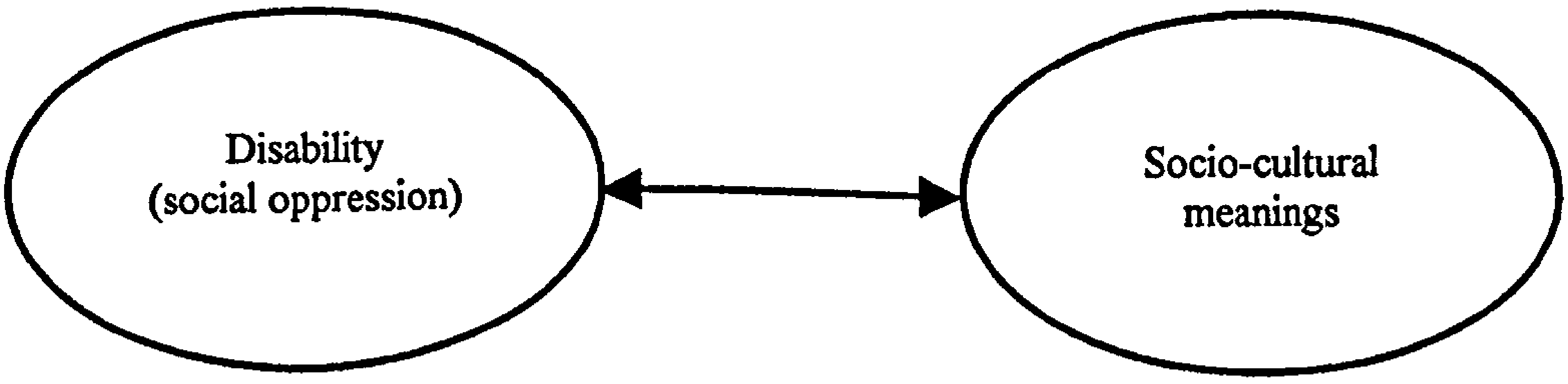


Figure 6. Developing a transactional model (a)

However, not all of the restrictions on "doing" and "being" encountered by the young people in my study are socially caused. Some are caused by their impairments or illnesses – impairment effects (see Chapter 2). By adopting a relational definition of disability I was able to take into account impairment and impairment effects.

My model also draws on Crow's (1996) ideas concerning ways of looking at impairment (see Chapter 2). Crow's objective level takes into account the "real" body and recognizes essential biologically based differences between bodies. Thus, unlike the social model which tends to neglect impairment and impairing effects, my model recognizes the profound physical and intellectual impairments of the young people in my study. The subjective level recognizes the importance of the lived out experiences of the young people and their families, acknowledges the similarities and differences of these experiences and recognizes that they construct their own meanings and interpretations of impairment (see Chapter 4). Morris (1991) stresses the importance of these personal experiences as a starting point for theorizing and Corker (Thomas & Corker, 2002) argues that if we want to liberate people with disabilities from oppression, research at this level is essential:

> If we interpret the social world without opening ourselves to knowledge that is *not* of our experience, then the way we make theory and engage in practice inevitably limits the liberatory possibilities of both.
> (Thomas & Corker, 2002, p. 21)

The social context level considers what Abberley (1987, 1996) refers to as the social production of impairment (see Chapter 2) and recognizes that impairment, like disability, is constituted and mediated through discourse, language and communication (Thomas & Corker, 2002). However, these three levels also interact. Impairment is both a biological and social phenomenon. Essential biological differences are overlaid and mediated through meanings and cultural interpretations:

> ...developing a social theorization of impairment requires an understanding of human bodies (as physiological, sensory and cognitive

> entities in social space) and their historical *interaction* with forms of production and cultural practices. Thus, this is not purely a matter of dealing with the social and the cultural, but requires of social scientists that they engage with (what is culturally labelled to be) biological.
> (Thomas & Corker, 2002, p. 29)

However, the biological reality of bodies also influences social and environmental processes and practices in a bio-social interaction. Connell (1995) describes bodies as "sharing in social agency, in generating and shaping courses of social conduct" (Connell, 1995, cited in Watson & Cunningham-Burley, 2001, p. 3). For example, the profound impairments of the young people in my study may lead to what MacKay, (2001 June) calls "the nothing can be done rationale" which results in policies and practices for this group being primarily concerned with aspects of care. Thus my model sees impairment and impairment effects as bio-social phenomena which are shaped by the interaction of biological and social factors and interwoven with socio-cultural meanings (Figure 7). However, the young people's lived out experiences (see chapters 5 & 6) also show that disability (social oppression) and impairment (bio-social features of our bodies) intersect and interact.

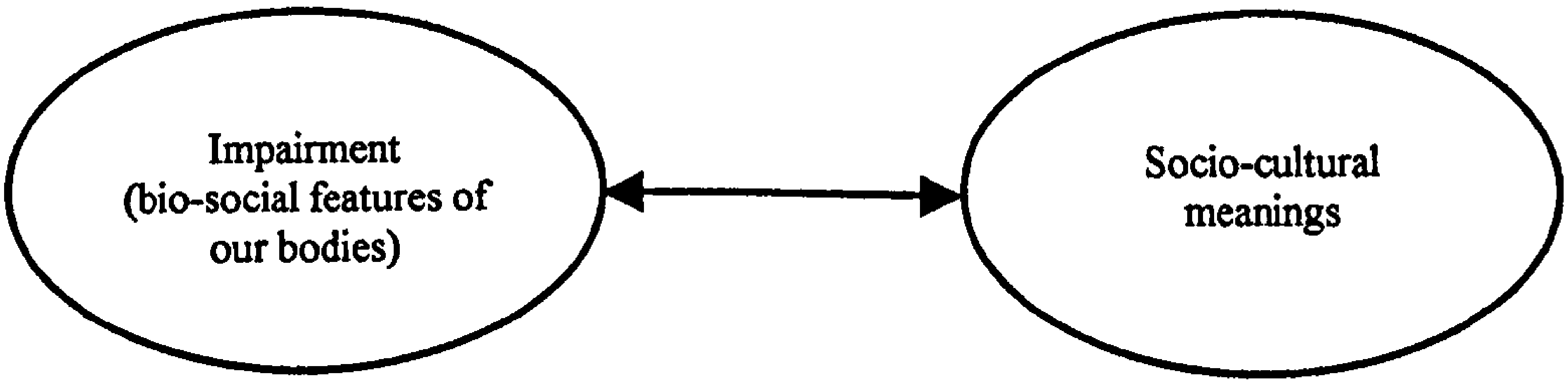


Figure 7. Developing a transactional model (b)

Thus I believe that we need both a social theory of disability and a social theory of impairment but that neither can exist separately. We need to recognize the relationship between impairment and disability. Therefore my model takes into account the idea that impairment and disability can exist independently but they also interact (Figure 8, p. 114).

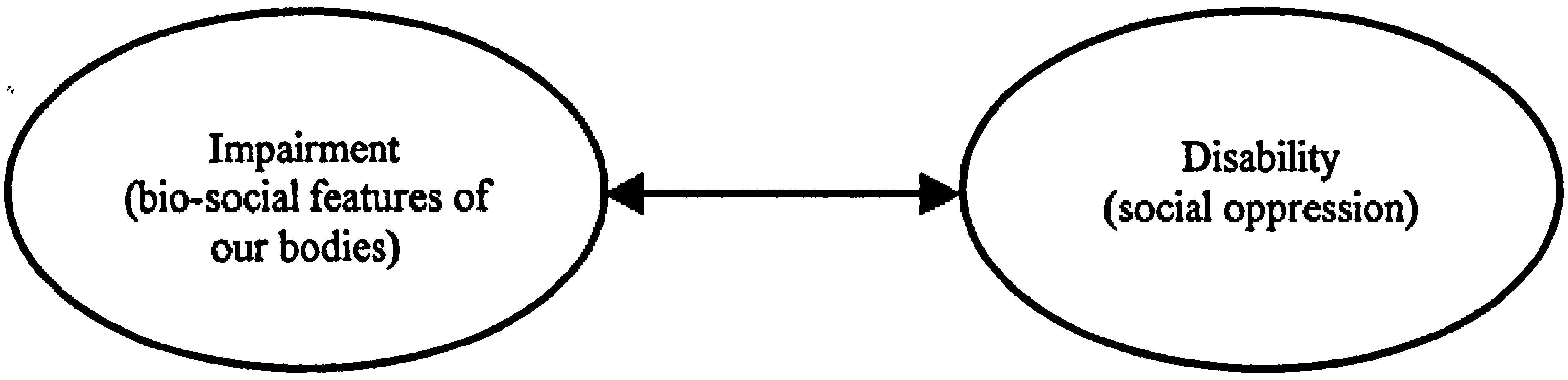


Figure 8. Developing a transactional model (c)

For example, Geri, one of the young people in my study, faces few restrictions to activity when she is at home because her house has been adapted to accommodate her physical impairments. However, when the family go on holiday, Geri faces physical and environmental barriers in a non-adapted house, although her impairment remains static. However, as Crow (1996) points out, there is also a shifting balance between impairment and disability. Faye, another participant in the study, frequently suffers from chronic bronchitis. When this happens external restrictions become irrelevant. However, with a return to health, structural barriers, such as inadequate changing facilities and equipment at swimming pools, are seen as restricting her activity. Similarly, impairment can be caused or worsened by disability. Often lack of adequate or inaccessible health services for these young people results in gastro-esophagus reflux disorders being undiagnosed or untreated. Like Crow (1996), my model sees impairment as a precondition for disability:

> Impairment must be present in the first instance for disability to be triggered: disability is the form of discrimination that acts specifically against people with (or who have had) impairments. This does not mean that impairment causes disability, but that it is a precondition for that particular oppression.
>
> (Crow, 1996, p. 220)

This is essential in distinguishing people with disabilities from other oppressed groups in society, such as women, people from ethnic minorities and so forth.

Placing all these dimensions of disability and impairment together, my model looks like this (Figure 9).

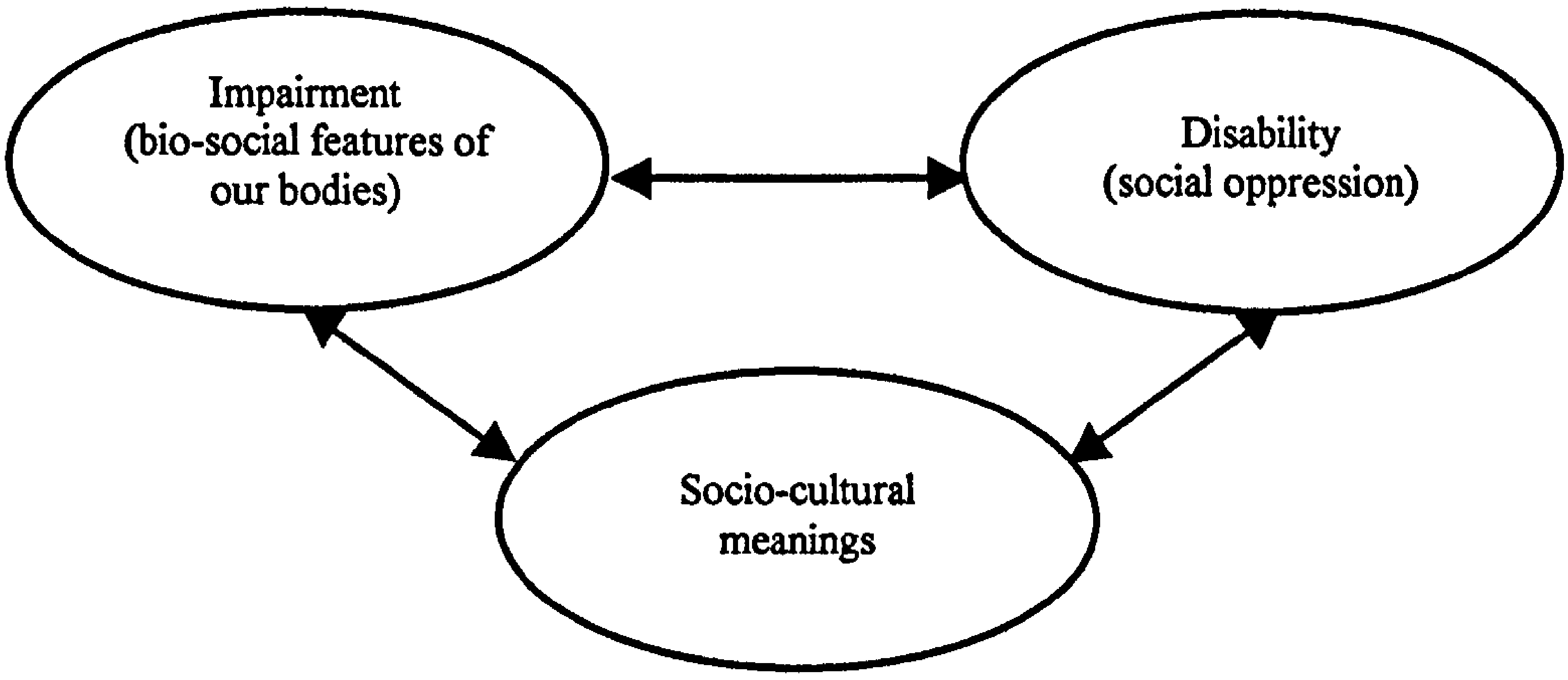


Figure 9. The transactional model of disability

My model views impairment and disability in terms of a number of interacting factors which operate at a number of different levels. It allows impairment and disability to be seen as both discrete entities as well as interacting. Furthermore, it takes into account Thomas and Corker's (2002) argument that we need to look at modes of communication, language and discourse as impairment and disability are given meaning through the discourses we live with in our cultures (see Chapter 4). This stresses the importance of the interactive relationship between people with disabilities and non-disabled people and recognizes that both groups' interpretations and meanings of impairment and disability can be deconstructed and changed, which hopefully will influence attitudes, policies and practices. Thus my model views impairment and disability as the consequences of social meaning interrelated within social structures, with the environment viewed as an interactive structure in which individuals act as active synthesisers of information (Llewellyn & Hogan, 2000, p. 161).

Although my model needs to be developed more fully and "tested out" in subsequent research, it makes an attempt to address some of the limitations of the social model. Whilst I accept that the model does not provide a full explanation of every aspect of disability, I see it as a useful tool for increasing our understanding of the specific difficulties encountered by young people with profound physical and intellectual disabilities; for investigating ways of reducing these difficulties and suggesting ways of developing their potential and increasing their quality of life.

The adoption of an interpretive paradigm and a transactional model have influenced my approach to the study, the problems I chose to investigate and the methods I used to collect and analyse the data. As stated previously, I believe in choosing the best methods to suit the aims and purpose of my study, endorsing Spender's (1985) view that:

> ...there is no one truth, no one authority, no one objective method which leads to the production of pure knowledge.
> (Spender, 1985, pp. 5-6)

Therefore I adopted what Kincheloe (2001) describes as a bricolage approach.

Bricolage

At first educational and social science research tended to be modelled on methods used in the natural sciences and to be based on positivistic assumptions concerning ontology and epistemology (De Landsheere, 1993). However, there is now a general acceptance that knowledge is socially constructed and value-laden. Moreover, researchers now recognize the limitations of objective science and its fragmentary nature which tends to "fold its methodologies and the knowledge they produce neatly into disciplinary drawers" (Kincheloe, 2001, p. 681). In addition, some researchers argue that:

> Since methods go with theories, there really are no grand categories of research like "quantitative research" and "qualitative research."
> (Gee, 1999, p. 6)

Gee also argues that research does not involve a set of "rules" that can be followed step-by-step to obtain guaranteed "results". He contends that there is no "scientific method", even in the "hard" sciences. Therefore researchers should use and adapt tools of inquiry to address specific issues, problems and contexts of study. This has resulted in writers, such as Denzin and Lincoln (2000) and Kincheloe (2001), advocating a bricolage approach.

The term bricoleur is French and refers to "someone who works with his (or her) hands and uses devious means compared to those of the craftsman" (Weinstein & Weinstein, 1991, p. 161). Levi-Strauss (1966) describes a bricoleur as a "Jack of all trades or a kind of professional do-it-yourself person" (p. 17). Research bricoleurs view research as an interactive process shaped by the researcher's personal history and biography, as well as by the people in the setting. Moreover, they view the phenomena that they study as inseparable from their historical, social and cultural contexts. They reject ontological orientations which examine phenomena in isolation. They adopt what Kellner (1995) refers to as a multi-perspectival approach, working between and within, competing and overlapping interpretive paradigms and perspectives. They view knowledge as ever-changing, culturally specific, value-laden and power-inscribed. Thus Kincheloe (2001) argues that bricolage:

> ...avoids both the superficiality of methodological breadth and the parochialism of unidisciplinary approaches... [it] recognizes the dialectical nature of the disciplinary and interdisciplinary relationship and promotes a synergistic interaction between the two concepts.
> (Kincheloe, 2001, p. 679)

He claims that this dialectic of disciplinarity avoids reductionism, disciplinary parochialism and domination. It also increases researchers' awareness of different tools of research and enables them to choose the methods most relevant to their study. The methods they use are not necessarily set in advance but usually depend on the aims of the study, the questions asked and the context of the inquiry (Denzin & Lincoln, 2000). This multi-method approach recognises that each method provides its own distinctive perspective and these perspectives can be used by the researcher as a means of comparison and contrast. It also produces different kinds of data on the same topic which is more likely to improve the quality of the research, increase the validity and utility of its findings and allow the researcher to view the phenomena from different perspectives, thus increasing understanding of the topic. In addition, Kincheloe (2001) claims that as well as helping researchers to gain new insights and perspectives, it also enables them to explore relationships between the object of inquiry and the context.

I used the bricolage approach in my study. I provided a detailed account of my personal background (Chapter 1). I also used a multi-perspective approach, agreeing with Albrecht, Seelman and Bury (2002) that disability studies need to be :

> ...open to perspectives and research across borders and disciplines... if it is to acquire maturity as an academic discipline and credibility in the activist world... [Disability studies] is more likely to mature as scholars, policy makers and activists listen to each other and engage in respectful discourse about the fault lines, issues, theories and applications of the field to the real world.
> (Albrecht et al., 2002, p. 33)

My study is interdisciplinary in nature as it draws on medical sociology (see Bury, 1997; Pinder, 1997, in Chapter 2), historical (Chapter 4) and anthropological studies (Chapter 2) and the writings of people with disabilities and their families (Chapter 2, see also p. xii). However, its emphasis is predominately a sociological one, although within this discipline it draws on a number of perspectives such as materialism, feminism and constructivism. For example, I have used a materialist feminist perspective to help me investigate the socio-economic structural barriers and impairment effects which exclude people with impairments (Thomas, 1999, 2002) and a post-structural feminist perspective to emphasise human agency and cultural processes (Corker & French, 1999). The young people and their families in my study encounter social barriers which restrict what they can do. They also have to deal with the emotional and psychological consequences of other people's reactions towards their profound impairments, as well as wider cultural representations of impairment and disability. In addition, they have to live with the pain of impairment, illness and limited functioning, as well as impairment effects. Therefore I felt that drawing on a range of theoretical perspectives and disciplines would enable me to clarify my ideas about disability and increase my understanding of the topic.

This approach also helped to break down the dualisms in disability studies between essentialism/constructivism, disability/impairment, social/biological and private/public. It also helped me to be more aware of the dynamic relationships connecting individuals, their contexts and their activities (Blackler, 1995). Furthermore, it enabled me to look at how systems and processes affect the lived out experiences of the young people and their families and how, in turn, the young people and their families operated to change the system and the processes. It also enabled me to avoid placing myself within a single epistemological tradition and helped me to employ methods best suited to my study.

As my study focused on relationships, processes, was concerned to provide a holistic perspective and favoured multiple methods, I chose a case study approach.

The case study

A dictionary of sociological terms defines case studies as:

> ...a method of studying social phenomena through the thorough analysis of an individual case. This case may be a person, a group, an episode, a process, a community, a society, or any other unit of social life. All data relevant to the case are gathered, and all available data are organised in terms of the case. The case study method gives a unitary character to the data being studied by interrelating a variety of facts to a single case. It provides an opportunity for the intensive analysis of many specific details that are often overlooked with other methods. This approach rests on the assumption that the case being studied is typical of cases of a certain type, so that through intensive analysis generalizations may be made which will be applicable to other cases of the same type.
>
> (Theordorson & Theordorson, 1969, cited in Reinharz, 1992, p. 164)

Table 16. Advantages of case studies

Case studies have a number of advantages that make them attractive to educational evaluators or researchers. Thus:

1 Case study data, paradoxically, is "strong in reality" but difficult to organize. In contrast, other research data is often "weak in reality" but susceptible to ready organization. This strength in reality is because case studies are down-to-earth and attention holding, in harmony with the reader's own experience, and thus provide a "natural" basis for generalization.

2 Case studies allow generalizations either about an instance or from an instance to a class. Their peculiar strength lies in their attention to the subtlety and complexity of the case in its own right.

3 Case studies recognise the complexity and "embeddedness" of social truths. By carefully attending to social situations, case studies can represent something of the discrepancies or conflicts between the viewpoints held by participants. The best case studies are capable of offering some support to alternative interpretations.

4 Case studies considered as products, may form an archive of descriptive material sufficiently rich to admit subsequent reinterpretation. Given the variety and complexity of educational purposes and environments, there is an obvious value in having a data source for researchers and users whose purposes may be different from our own.

5 Case studies are "a step to action". They begin in a world of action and contribute to it. Their insights may be directly interpreted and put to use; for staff or individual self-development, for within-institutional feedback; for formative evaluation; and in educational policy making.

Case studies present research or evaluation data in a more publicly accessible form than other kinds of research report, although this virtue is to some extent bought at the expense of their length. The language and form of the presentation is hopefully less esoteric and less dependent of specialised interpretation than conventional research reports. The case study is capable of serving multiple audiences. It reduces the dependence of the reader upon unstated implicit assumptions... and makes the research process itself accessible. Case studies, therefore, may contribute towards the "democraticization" of decision-making (and knowledge itself). At best, they allow readers to judge the implications of a study for themselves.

Source: Cohen & Manion, 1994, p. 123

I chose this approach as it focuses on individual units and enabled me to:

> ...seek greater understanding of the case... appreciate its uniqueness and complexity, its embeddedness and interaction with its contexts.
> (Stake, 1995, p. 16)

It also allowed me to analyse the individual cases and to examine the relation between the cases and particular social processes. Furthermore, the advantages of the case study approach, outlined by Cohen and Manion (1994) (Table 16, p. 120), also fitted in with my study's aims and research questions. One of my study's aims was to influence policy-making decisions and the case study can be a "step to action" (Table 16, p. 120, number 5).

In addition, Bernard (1987) argues that using the case study approach can increase understanding of subordinated groups, be instrumental in the revaluation of images of such groups, as well as raising awareness of the group (Sherr & Wright, 1985). Thus by using a case study approach I hoped to be able to document social reality, generate theories and help create change. Furthermore, as this approach emphasises specificity, exceptions and completeness rather than generalisations, I hoped it would help highlight phenomena important to this group of people, thus helping to put them "on the map of social life" (Reinharz, 1992, p. 174).

Having chosen a case study approach, my first task was to identify the case for study. In my study the case was an issue – the problems encountered by young adults with profound physical and intellectual disabilities during the transition period from school to adult provision. Thus it can be termed a "descriptive, issue-orientated case study" (Creswell, 1998, p. 87). I limited my study to the experiences of the family carers and professionals involved with this group because of the severe communication difficulties of the young people themselves, although their views were indirectly obtained by asking their family carers. The case was also bounded by time – fifteen months data collection.

Next I had to decide which kind of case study to use. Stake (1995) describes three types of case studies – the intrinsic case study, the instrumental case study and the collective case study. In the intrinsic case study the case is given. The focus of study is on the case because it is of particular interest to the researcher – s/he needs to learn about a particular case e.g. a teacher studying a child experiencing learning difficulties. Unlike the intrinsic case study where "the case itself is of primary, not secondary interest" (Stake, 1995, p. 171), the instrumental case study focuses on a specific issue rather than the case itself. Stake defines it as "research on a case to gain understanding of something else" (Ibid., p. 171). The collective case study involves "studying several cases within the same project" (Ibid., p. 169). It might be either intrinsic or instrumental but its defining feature is that the researcher examines several cases. I chose to conduct a collective case study as it enabled me to provide a detailed description of each case and the themes within the case (within-case analysis) and also to conduct a cross-case analysis which allowed me to look for themes common to all cases as well as unique themes. Although my case study was a collective one, it was also an instrumental one as each case study was instrumental in learning about the experiences of young adults with profound physical and intellectual disabilities and their family carers during the transition period from school to adult provision.

Thirdly, I had to choose the kind of sampling strategy to employ. As I was concerned to maximise my understanding of the issue, and as my time for fieldwork was limited, I "hand picked" cases which I thought most likely to produce the most valuable data, were hospitable to my inquiry and willing to comment on draft materials. My principal criterion in the selection of participants was "Given what I already know about the research topic, who is likely to provide the best information?". This is described by Cohen and Manion (1994) as purposive sampling. The sampling of attributes was not my main priority as I believe that representation in a small sample is impossible as the relevant characteristics are so numerous that only a few combinations can be included. However, I did try to establish balance and variety in the case study by varying the characteristics of the family carers and their offspring in terms of geography, parental occupations, the youngsters' sex, age, school and post-school provision. In addition, I tried to vary the characteristics of the professionals in terms of different disciplines and employment in the voluntary and statutory services. According to Miles and Huberman (1994), maximum variation "documents diverse variations and identifies important common patterns" (p. 28). I was not concerned with generalising the results but with understanding the case itself, viewing the purpose of the case study as "particularization, not generalization" (Stake, 1995, p. 8).

Next I had to decide on how to collect the data for the case study. As a case study involves collecting multiple sources of information in order to provide depth to the case, I used a range of methods – documentation, discourse analysis, individual, dyadic and group interviews and the nominal group technique. I also conducted a holistic analysis of the data (Yin, 1989). This involved looking at the entire case, producing a "narrative description" (Stake, 1995, p. 123), analysing themes and interpreting the meaning of the case (Lincoln & Guba, 1985). Using this case study approach I tried to understand how the people being studied perceived things and to convey the different perspectives of the participants about what was happening. However, I also recognised that ultimately my interpretations would be likely to be emphasised more than the people's studied. Thus I asked the participants to comment on my findings (Appendix Q, p. 771) and used triangulation to help support my findings.

Table 17. Stake's (1995) outline for writing a case study

Open with a vignette
Identify the issue, the purpose and the methods of study
Describe the case and context
Outline issues
Probe issues further
Present assertions
Close with vignette

Finally, I decided on how to write the report. I used Stake's (1995) idea (Table 17) of opening and closing the case with vignettes in order to draw the reader into the case and give him/her a feel for the study. However, instead of using an opening vignette, I introduced my study by using a poem composed by one of the family carers involved in my study. Then I identified the issue, the purpose and relevance of the study and related it to other research (Maykut & Morehouse, 1994) so that the reader was provided with information about how the study came to be, the background of the writer and the issues surrounding the case (Chapters 1 & 2). As I believe that a thorough discussion of the research design and methodology is vital to my study's credibility, I described in detail the research design, the ways in which I attempted to give my findings credibility and the methods used (Chapter 3). Then I discussed my findings by describing the case and identifying themes and issues (Chapters 4-7). Lastly, I discussed the implications of my study and the "lessons learned" (Lincoln & Guba, 1985) (Chapter 8). This format is based on Stake's ideas for reporting a case study (Table 17, p. 123) and on Lincoln and Guba's model for writing a case report – the problem, the context, the issues and the "lessons learned". By using this format I hoped to present the data and findings of my study in a readable form, thus making it accessible to a wide range of audiences (Table 16, p. 120). I also used cartoons to emphasise the main findings of my study.

Emergent design

Another characteristic of my study is its emergent design (Figure 10, p. 125). Studies using an emergent design usually have a focus of inquiry, but at the beginning the focus is broad and open-ended in order to allow important meanings to be discovered. Such studies are designed to discover what can be learned about phenomena. People are the participants and researchers are interested in their experiences and perspectives. Thus the design evolves over time and inductive analysis begins when the researcher has collected a subset of data. This analysis may result in initial research questions being modified, observing new situations in order to refine or substantiate meanings, the sampling of new people or the adoption of other methods. The aim is to thoroughly understand the phenomena being studied. Thus if early questions are not working, if new issues become apparent, then the design is changed. Parlett and Hamilton (1976) call this progressive focusing – "improving on the research questions as the study continues" (p. 172). This broadening or narrowing of the focus of inquiry is planned for by the researcher by adopting an emergent design.

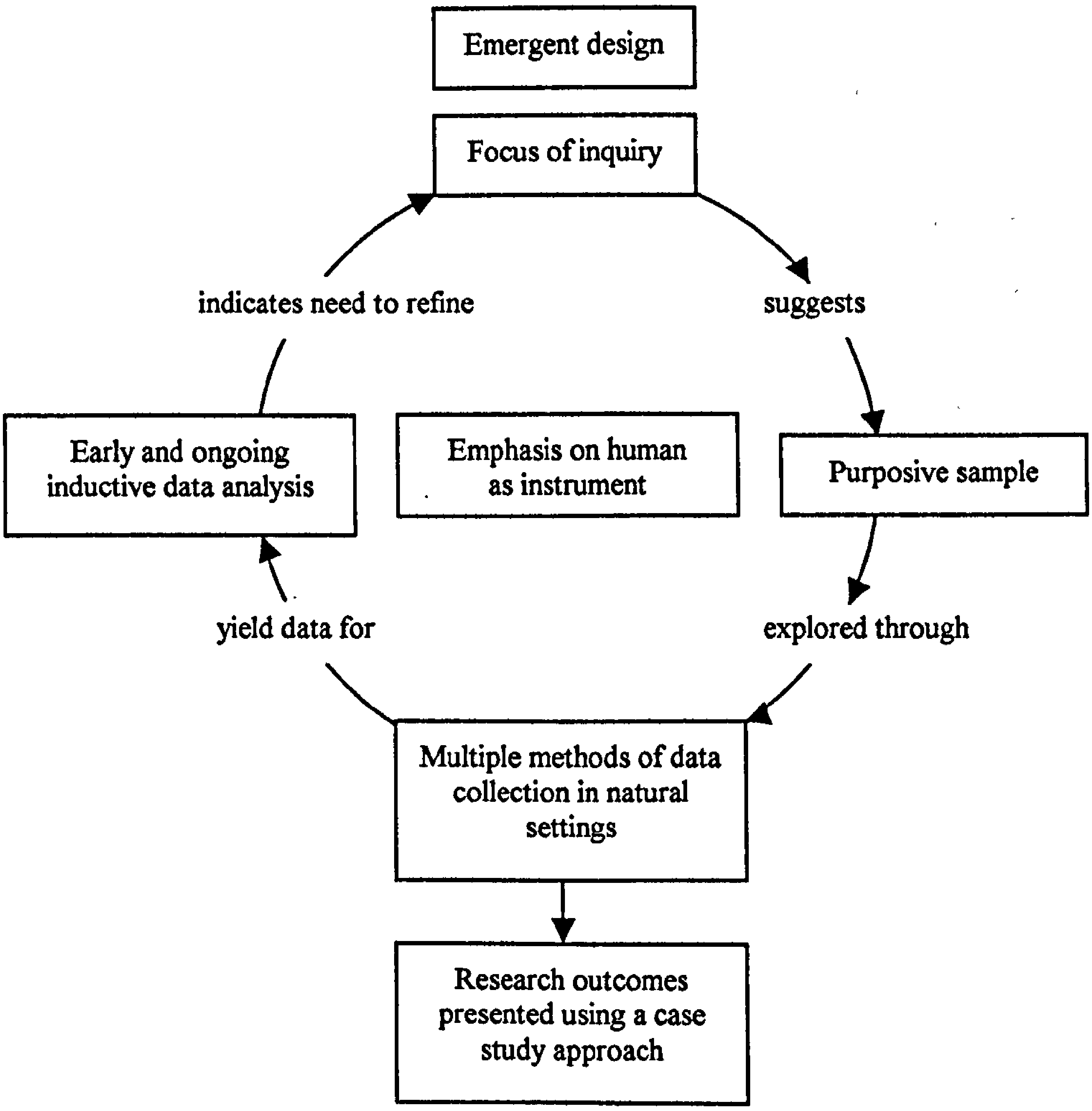


Figure 10. An emergent design
Source: Maykut & Morehouse, 1994, p. 48

My study began with an initial focus of inquiry and an initial sample and both were refined and extended as the data was collected and analysed. My focus of inquiry – the experiences of young adults with profound physical and intellectual disabilities and their family carers during the transition period from school to adult provision – suggested a purposive sample. The issue was explored using multiple methods, namely individual and dyadic interviews with the family carers and analysis of minutes of FNA meetings. The data collected from these interviews and documents was used to identify the problems encountered by the families and their offspring during the transition period. From this information an interview guide for a focus group discussion, involving not only family carers, but professionals involved with this group of young people, was devised. The rationale behind the focus group was to bring together participants from different backgrounds and perspectives and use their experiences and knowledge to suggest ways of improving the current system. As the data revealed that either no provision, or poor quality provision, tended to be provided for this group of young people, a nominal group discussion was then held to suggest criteria for appropriate, good quality post-school provision and services for young adults with profound physical and intellectual disabilities. However, it became clear that the lives of people with disabilities are also dependent on social, political, ideological and economic factors. This was explored by identifying the nature of local service provision, the theoretical underpinnings of national and local policies and the theories and assumptions about disability and impairment held by the family carers and the professionals.

Having discussed my study's research design, I will now go on to discuss the provisions of trustworthiness for my study. This term is used by Lincoln and Guba (1985) to refer to the credibility of a researcher's findings.

Provisions of trustworthiness

Researchers' views regarding the definition and importance of verification in research vary (Table 18. p. 127). Some (Le Compte & Goetz, 1982) use positivist terminology or equivalents from quantitative research, others use alternative terms (Lincoln & Guba, 1985; Eisner, 1991), whilst others (Lather, 1993; Richardson, 1990; Wolcott, 1994) propose a "reconceptualizing of validity" (Lather, 1991, p. 66). Despite these differences in perspectives and terms, Creswell and Miller (1997), from a review of major qualitative studies, identified eight ways of assessing the accuracy of accounts used by researchers, irrespective of their perspectives (Table 19, p. 128).

Table 18. Selected studies, perspectives, and terms about verification

Study	Perspective	Terms
LeCompte & Goetz (1982)	Parallel qualitative equivalents: Compare issues of validity to counterparts in experimental and survey research	Internal validity External validity Reliability Objectivity
Lincoln & Guba (1985)	Alternative terms: Pose alternative terms that apply more to naturalistic axioms	Credibility Transferability Dependability Confirmability
Eisner (1991)	Alternative terms: Reasonable standards for judging the credibility of qualitative research	Structural corroboration Consensual validation Referential adequacy
Lather (1993)	Reconceptualized: Four frames of validity	Ironic validity Paralogic validity Rhizomatic validity Situated/embedded voluptuous validity
Richardson (1990)	Reconceptualized: Metaphor of a crystal	Crystals: Grow, change, alter, reflect externalities, refract within themselves
Wolcott (1994)	Distraction: Neither guides nor informs	Understanding better than validity

Source: Creswell, 1998, p. 200

I have used six of these procedures to increase the trustworthiness of my research – triangulation, peer review, researcher bias, respondent validation, rich, thick description and external audits.

Table 19. Verification procedures

Procedure	Description
Prolonged engagement and persistent observation	Involves building trust with participants, learning the culture and checking for misinformation that stems from distortions introduced by the researcher or participants.
Triangulation	Involves the use of multiple and different sources, methods, investigators and theories to shed light on a theme.
Peer review or debriefing	Involves an external check on the research process by a peer.
Negative case analysis	Involves the researcher in refining working hypotheses as the study advances in the light of negative and disconfirming evidence.
Clarifying researcher bias	Involves the researcher in commenting on how past experiences, biases, prejudices and orientations may have influenced the interpretation and approach to the study.
Respondent validation	Involves the researcher in asking the participants to comment on the credibility and interpretations of the study.
Rich, thick description	Enables the reader to transfer information to other settings and to determine whether the findings are characteristic.
External audits	The auditor examines the study to determine whether the findings, interpretations and conclusions are supported by the data.

Triangulation

Cohen and Manion (1994) define triangulation as "the use of two or more methods of data collection in the study of some aspect of human behaviour" (p. 233). I have chosen this technique (Table 20, p. 129) to increase the trustworthiness of my study for various reasons. Firstly, triangulation allows the researcher to explain the richness and complexity of human behaviour more fully by studying it from various viewpoints and ways of knowing. Thus by using a multi-method approach the credibility and usefulness of my study should be increased (Komarovsky, 1985). Secondly, triangulation also helps researchers "to link past and present, "data gathering" and action, and individual behaviour with social frameworks" (Reinharz, 1992, p. 197). This fits in with the aims and objectives of my research which attempts to link school and adult provision, suggest ways in which the transition period can be improved and link individual experiences with broader social and economic issues. Thirdly, according to Reinharz, by combining methods the researcher is more likely to gain new insights into previously unexamined or misunderstood experiences. Therefore as there has been little research into the transition period for young adults with profound physical and intellectual disabilities, this technique also fitted in well with my study.

Table 20. The principal types of triangulation used in research

1. Time triangulation: this type attempts to take into consideration the factors of change and process by utilizing cross-sectional and longitudinal designs
2. Space triangulation: this type attempts to overcome the parochialism of studies conducted in the same country or within the same subculture by making use of cross-cultural techniques
3. Combined levels of triangulation: this type uses more than one level of analysis from the three principal levels used in the social sciences, namely, the individual level, the interactive level (groups), and the level of collectivities (organizational, cultural or societal)
4. Theoretical triangulation: this type draws upon alternative or competing theories in preference to utilizing one viewpoint only
5. Investigator triangulation: this type engages more than one observer
6. Methodological triangulation: this type uses either (a) the same method on different occasions, or (b) different methods on the same object of study

Source: Cohen & Manion, 1994, p. 236

Denzin (1970) has identified six types of triangulation (Table 20) and I have used three in my study – combined levels of triangulation, theoretical triangulation and methodological triangulation. Combined levels of triangulation involves looking at more than one level of analysis. In my study I looked at the phenomena from the perspective of individual family carers of young adults with profound physical and intellectual disabilities, as well as professionals involved with these young people (the individual level), from the interactive level by conducting group interviews and nominal group discussions and from the cultural and societal level by looking at the social, political, ideological and economic factors which influence the lives of people with disabilities. By doing this I hoped to provide a more meaningful account of the phenomena. As discussed previously, this is in line with the transactional model of disability which advocates studying impairment and disability from different levels of analysis.

As seen in the section above about bricolage, I also used theoretical triangulation. I adopted what Kincheloe (2001) refers to as a "dialectic of disciplinarity" and Kellner (1995) describes as a multi-perspectival approach. This involves working between and within, competing and overlapping interpretive paradigms, perspectives and disciplines.

I also used methodological triangulation – both "within methods" triangulation and "between methods" triangulation (Denzin, 1970). By using the same method on different occasions i.e. interviewing five family carers individually, I hoped to increase the reliability of my study (Smith, 1975). By using a multi-method approach to investigate the topic i.e. analysing documents, interviewing, nominal group technique and discourse analysis ("between methods" triangulation), I hoped to increase the validity of my findings. Lin (1976) argues that by using multiple methods researchers are more likely to reduce the chances that their findings are attributable to similarities of method. Furthermore, using such an approach helps to overcome "method-boundedness", whereby researchers use pet methods, either because of familiarity with the technique, or belief that a certain method is superior (Smith, 1975). I agree with Reinharz (1992) that there is no "methodological correctness" and that researchers should develop "original" methods which meet their research questions (Hammersley, 1992a), even if this involves using ideas from other disciplines (Sherif, 1982).

Peer review

Peer review or debriefing provides an external check on the research process (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991; Erlandson, Harris, Skipper, & Allen, 1993; Glesne & Peshkin, 1992). In this process the peer debriefer goes through the researcher's audit trail and asks questions about methods, meanings and interpretations. Lincoln and Gruber (1985) describe the role of the peer debriefer as the "devil's advocate" – the person who questions the researcher's honesty and raises questions of bias when necessary. In my study my supervisors acted as my peer debriefers and regularly reviewed the research process.

Clarifying researcher bias

Feminist researchers generally view personal experiences as an asset in feminist research. Some begin their study with their own experience, analyse it and do not collect other data (Bernard, 1973; Hughes, 1973). Others start with their own experiences and then collect other data to compare with their experiences (Borg & Lasker, 1981; Millman, 1980). Yet others study people's experiences but recognise they are a part of the group studied and use this to deepen the study (Rush, 1980). This is in contrast to research in a positivist framework which views personal experiences as irrelevant or contaminating objectivity.

My research starts from my own experiences as a parent of a young adult with profound physical and intellectual disabilities who has undergone the transition period from school to adult provision. My experiences have helped me to define the research questions and been the source for finding people to take part in the study. Hopefully, it has also helped me to gain the trust of the participants (see Finch, 1993; Whitmore, 1994). Thus my study of the problem is a "blend of intellectual question and personal trouble" (Reinharz, 1992, p. 260).

By starting from my own experiences it can be argued that I am ignoring the conventional expectation that researchers need to be detached, objective and "value neutral". However, as already discussed (Chapter 2), some researchers (Hubbard, 1979; Le Moncheck, 1985; Oakley, 1985) have challenged these concepts and argue that objectivity does not exist "since as inquiring subject one must assume a perspective from which to launch the inquiry" (Le Moncheck, 1985, p. x). In my study I have tried to present the material objectively, whilst recognising that my study was guided by an explicit perspective. I have done this by firstly providing an explanation of "the researcher's standpoint" and by describing my relationship to the topic investigated (see Chapter 1). Secondly, I have described the actual research process by producing an audit trail which contains interview guides and transcripts (Appendices B, D, I, K, M & O) and paper work pertaining to the data analysis process (Appendices L, N & P). Lastly, I have engaged in the "Epoche" process (p. 166) and reflected on the entire research process from problem formulation to presenting the outcomes (see also Appendices C, F,H & J) in order to reduce personal bias and personal reactivity.

Respondent validation

Lincoln and Guba (1985) argue that the standard of qualitative research, where the objective is to reconstruct the events and experiences of the participants from their own perspectives, is the demonstration that the findings are credible to those involved. Thus I invited the participants in my study to examine my findings and interpretations and provide feedback as to their accuracy and credibility (Appendix Q, p. 771), as recommended by Stake (1995).

Mishler (1990) takes the idea of respondent validation further. He proposes that the ultimate test of trustworthiness of a study is whether the findings of the study are considered so truthful that they are acted upon by other researchers and practitioners. I hope to make by study available to researchers and practitioners working in this field and if they use the findings and find them useful, this will provide a further test of trustworthiness to my study.

Rich, thick description

Erlandson et al. (1993) argue that rich, thick description enables readers of the study to make decisions regarding transferability of information and findings to other settings "because of shared characteristics" (p. 32). This can only be achieved if the researcher provides rich, descriptive detail of the participants and their experiences as well as the topic under study. I have tried to do this by telling the young people's stories through the eyes of the people most closely involved with them – their family carers and by using quotations from the interviews in the research report in order to give the reader a better understanding of the participants' feelings, thoughts, actions and meanings.

External audits

Merriam (1988) and Miles and Huberman (1994) advocate the use of an external auditor, who has no connection with the study, to examine whether the findings, interpretations and conclusions are supported by the data. It is proposed that my study be assessed by external examiners, who have no connection with the study. This should further help to establish the verification and accuracy of my study.

Having described the ways in which I tried to verify my findings, the next section provides a detailed account of the methods and methodology of my study. By methods I mean the techniques and procedures used in the process of data gathering – the tools of research. My aim in describing the methodology of my study is to help the reader understand the inquiry process (Kaplan, 1973) by providing a description of the methods used, discussing their advantages and limitations and the rationale for choosing these particular tools of research.

RESEARCH TOOLS

As already stated the philosophic assumptions I made about the nature of reality, knowledge and humankind influenced my choice of methods (Table 12, p. 97), as did the aims and objectives of my study. The methods employed in my study are described below.

Policy discourse analysis

Definitions of discourse are difficult, because the word has different meanings within different disciplines. Moreover, these definitions vary depending on whether a formal (Chomsky, 1957, 1965) or a functional (Halliday, 1973, 1978) paradigm is adopted (Table 21, p. 134). For formalists, discourse is "language above the sentence or above the clause" (Stubbs, 1983, p. 1) and analysis involves focusing on the way in which different units function in relation to each other. In contrast, functionalists define discourse as language use:

> ...the analysis of discourse, is necessarily, the analysis of language in use. As such, it cannot be restricted to the description of linguistic forms

> independent of the purposes or functions which these forms are designed to serve in human affairs.
>
> (Brown & Yule, 1983, p. 1)

Table 21. Formal and functional approaches to the nature of language

Formal approach	Functional approach
Regard language as a mental phenomenon	Regard language as a societal phenomenon
Linguistic universals derive from a common genetic linguistic inheritance of the human species	Linguistic universals derive from the universality of the uses to which language is put in human society
Explain children's acquisition of language in terms of a built-in human capacity to learn language	Explain children's acquisition of language in terms of the development of the child's communicative needs and abilities in society
Study language as an autonomous system	Study language in relation to its social function

Adapted from Leech, 1983, p. 46

However, Schiffrin (1997) defines discourse as utterances. This definition allows discourse to be viewed "not as a collection of decontextualized units of language structure, but as a collection of inherently contextualized units of language use" (Schiffrin, 1997, p. 39). Thus this definition encompasses both the functional emphasis on how language is used in context and the formal emphasis on extended patterns. Schiffrin argues that approaches to discourse should incorporate both formal and functional analyses. She maintains that the identification of units and the relationships between them can be combined with a focus on actions and purposes and the interpretation of social and cultural meanings. She argues that formalist approaches face problems surrounding the identification of units, whilst functionally-based approaches encounter problems of subjectivity and uncertainty with regard to the identification of functions. Therefore combining both types of analyses helps to "balance the weaknesses of one mode of analysis with the strengths of another" (p. 361).

In her book "Approaches to Discourse", Schiffrin (1997) identifies six approaches to discourse analysis – speech act theory; interactional sociolinguistics; ethnography of communication; pragmatics; conversational analysis and variation analysis.

Wetherell, Taylor and Yates (2001) also identify six approaches to discourse analysis, some of which are similar to Schiffrin's – conversation analysis and ethnomethodology; interactional sociolinguistics and the ethnography of communication; discursive psychology; critical discourse analysis and critical linguistics; Bakhtinian research and Foucauldian research. However, Cameron (2001) identifies five approaches to spoken discourse analysis – ethnography of speaking; pragmatics; conversation analysis; interactional sociolinguistics and critical discourse analysis. The above illustrates that the study of discourse is a contested field – "a global migration of hybridisation" (Threadgold, 2000, p. 41). Gee (1999) maintains that there are many approaches to discourse, none of which are "right". He argues that researchers need to adapt tools of research to specific issues, problems and contexts of study.

My study was concerned with uncovering the theoretical underpinnings of national and local policy documents. It was not just concerned with surface meanings of policy documents, but with how rhetorical devices are used to "manage meaning" and control power relationships (Sullivan, 2000). Thus my approach was influenced by Foucauldian ideas concerning power (Foucault, 1980). In Foucauldian terms power is not something that one person or powerful group has, rather it is:

> ...a more sinuous and insinuating mechanism that works its way in a "capillary" fashion into the "very grain" of individuals, inhabiting their bodies, their beliefs and their self-hood, and binding them together as institutional subjects (Foucault, 1980: 39). Power, in this sense, is both coercive and enabling. It is not imposed from "outside" or "above", but circulates within institutions and social bodies, producing subjects who exert a "mutual "hold" on one another. Foucault called it, memorably, "a mutual and indefinite "blackmail", which binds superiors and subordinates in "a relationship of mutual support and conditioning" (p. 159).
>
> (MacLure, 2003, p. 49)

Thus my study drew on the ideas of critical linguistics (Mills, 2003). This approach not only describes discursive structures:

> ...but also [shows] how discourse is shaped by relations of power and ideologies, and the constructive effects discourse has upon social identities, social relations and systems of knowledge and belief, neither of which is normally apparent to discourse participants.
> (Fairclough, 1992b, p. 12)

Critical linguists, such as Fairclough (1989, 1992a, 1992b) and Hodge and Kress (1988), analyse texts for political purposes. They maintain that the close analysis of the language of texts can reveal ways in which people are oppressed within current social structures. They regard language as instrumental in creating people as individuals and social subjects because language and ideology are closely intertwined. By using this approach, I hoped to identify power relations.

However, my study was also concerned with uncovering the political character of the documents and to question common sense stances. By "politics" I mean:

> ...anything and anyplace where human social interactions and relationships have implications for how "social goods" are or ought to be distributed. By "social goods" I mean anything that a group of people believes to be a source of power, status or worth...
> (Gee, 1999, p. 2)

Therefore my study was also influenced by Jacques Derrida's (1996) ideas about deconstruction. Shapiro (2001) states that deconstruction has the power to show how "every social order rests on a forgetting of the exclusion practices through which one set of meanings has been institutionalised and various other possibilities... have been marginalised" (p. 321). Therefore my approach is what MacLure refers to as an "impure" one. It draws on different discourse traditions and adapts specific tools and strategies to address issues. As Derrida (1996) maintains:

> Deconstruction is not a method, nor is it a set of rules or tools... if you want to "do deconstruction"... then you have to perform something new, in your own language, in your own singular situation, with your own signature, to invent the impossible and to break with the application, in the technical, neutral sense of the word.
>
> (Derrida, 1996, pp. 217-218)

As my study was concerned with analysing policy documents related to people with learning disabilities, I drew on Gale's (1999) ideas concerning policy discourse analysis. He argues that when analysing policies it is essential to look at the connection between policies and their contexts. Burton and Weiner (1990) maintain that policies are "ideological and political artefacts which have been constructed within a particular historical and political context (p. 205). Gee (1999) concurs with this, arguing that:

> ...the present is, indeed, partly an artefact of a very specific past. The present is an outcome of previous situated meanings and cultural models, meanings and models which continue to inhabit the present in more or less overt ways.
>
> (Gee, 1999, p. 57)

Therefore Codd (1988) stresses the importance of researchers beginning their analysis by recognising the importance of the context. Therefore I began my analysis of the documents by looking at the historical development of policies and services for people with learning disabilities in an attempt to identify some of the material and social circumstances which influenced policy-making.

I then analysed the documents using Kenway's (1990) and Gale's (1999) framework which looks at the "what", the "why" and the "how" of policies. The "what" of policy is concerned with the text. Fairclough (1997) defines text as "the written or spoken language produced in a discursive event" (p. 135). Analysis of text involves looking at both the content of the texts and the texture of texts, that is their form and organisation, as well as the values and beliefs they promote. The "why" of policy is concerned with ideology. Thompson (1984) defines ideology "as meaning in the service of relations of domination" (p. 4). According to Fairclough (1997), ideologies arise in class societies characterised by relations of domination. However, he maintains that people can and do resist and reject ideologies (Abercrombie, Hill & Turner, 1980) He sees ideology, text and discourse as being inter-connected. He argues that features of texts can be ideological in so far as they affect power relations. However, ideologies are also generated and transformed in texts. He further argues that ideologies can be come neutralised – they become common sense. MacLure (2003) argues that discourse can:

> ...interrogate, or at least to "interrupt", the flat pronouncements of common sense or polemic offers a new kind of agency to teachers, students and researchers, by providing resources for asking how particular interests and views are stitched up in texts.
> (MacLure, 2003, p. 79)

This brings us to the "how" of policy which is concerned with discourse. As stated previously, definitions of discourse vary and overlap because of various theoretical and disciplinary viewpoints. However, I have used Schreiber and Moring's (2001) definition in my study. They define discourse as "a specific way to talk about and understand the world – or parts of the world" (p. 4). According to Gale (1999), discourses appeal to ideologies, as well as being informed by them. Moreover, discourses also produce texts and interpret them. In Ball's (1994a) words policy text and policy discourse are "implicit in each other" (p. 15).

From this discussion it is clear that text, ideology and discourse are inter-related. As Gale (1999) states there is no one simple directional flow, although discourse is centrally positioned in relation to text and ideology (Figure 11, p. 139). Whilst Kenway's (1990) and Gale's (1999) way of analysing policy documents provides a way of questioning policy, it is important that researchers recognise the interconnections between these policy levels, as well as the relationship between policies and their contexts.

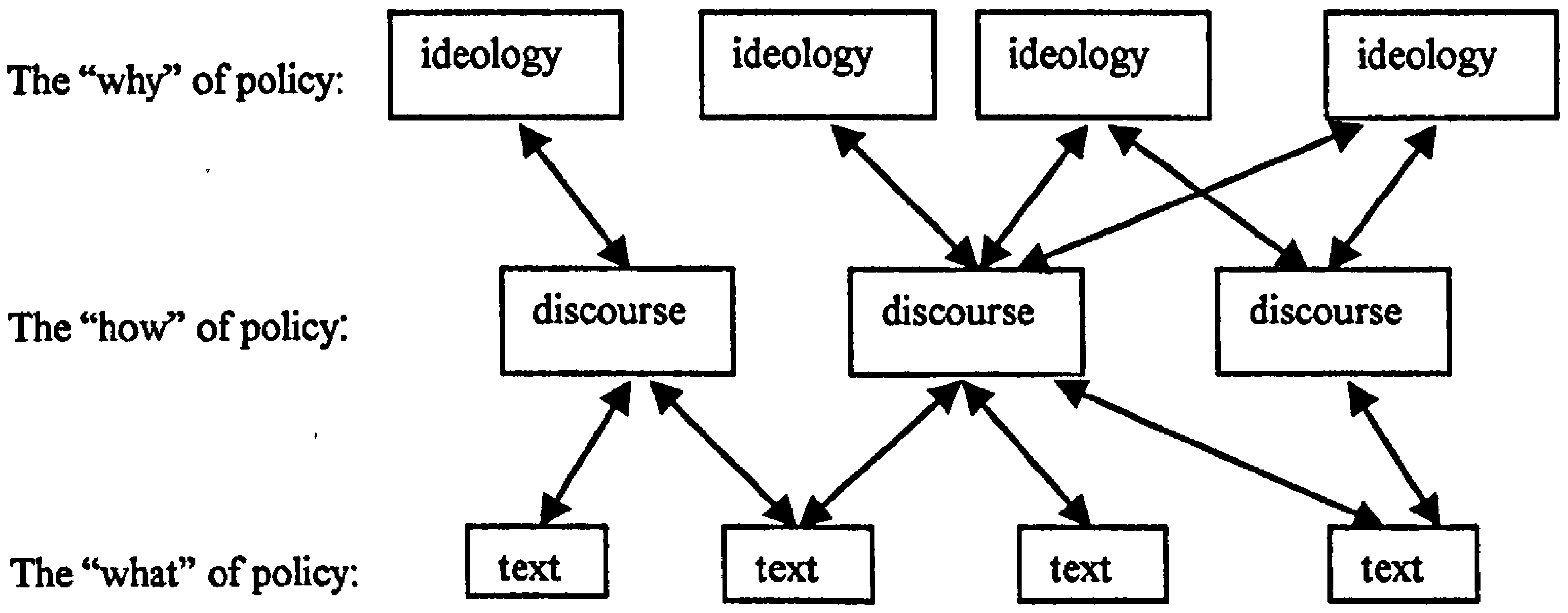


Figure 11. Policy as text, discourse and ideology
Source: Gale, 1999, p. 397

I used discourse analysis to examine the rhetorical devices used in the policies – metaphorical representation, rational and emotional language and binary oppositions. In her book, "Discourse in educational and social research", Maggie MacLure (2003) discusses examples of ways to unravel texts. She argues that in order to "disarticulate" texts it is necessary to look at the way in which they are "articulated" – that is "joined or stitched together" (p. 9). She states that one of the most common ways in which articulation is achieved is through the setting up of binary oppositions. She argues that oppositions such as nature/culture; language/reality; mind/body are deeply embedded in Western culture and philosophy. Indeed, Derrida (1998) maintains that this oppositional logic has been practised from Plato onwards (p. 93). According to MacLure (20003), oppositions are found everywhere – in everyday language, in the Press, in academic communities and in the fundamentals of philosophy. She argues that these binary oppositions are one of the main ways in which meaning and knowledge are produced:

> One "side" achieves definition – comes to meaning – through its *difference* with respect to a (constructed) "other" which is always lacking, lesser or derivative in some respect.
> (MacLure, 2003, p. 10)

I also drew on the work of Morgan (1997) which looked at metaphorical representation. Humes (2000) argues that the use of metaphors help to "manage meaning" and influence people's perceptions. He argues that although this can be well-intentioned – it can motivate people and give them a sense of unity and purpose – it can also discourage people from thinking about aims and values and questioning policies. Humes (2000) argues that concepts such as "community", "empowerment", "participation" and "ownership" disguise the power dimension of organisations and strengthens their legitimacy. In this way policy-making is seen in terms of democratic consultation, partnership and consensus. Thus it makes it difficult for people to challenge authority. Fairclough (1997) refers to this as "discoursal democratization". He maintains that discoursal democratization is linked to political democratization and "to the broad shift from coercion, incorporation and pluralism in the exercise of power" (p. 80).

I also drew on the work of Hartley (1999) and Humes (2000). These writers have examined texts in terms of their usage of emotional and rational language. Hartley (1999) views rational language as reflecting the strategic objectives of an organisation, its structure and bureaucratic processes. The emphasis is on rational strategic and operational planning (Humes, 2000). In contrast, emotional language refers to social processes and human qualities and is designed to appeal to the emotions rather than reason. Fairclough (1989) refers to this as "synthetic personalisation" (p. 80) and Humes (2000) describes it as the "rationalisation of emotions" (p. 45). Hartley argues that this shift from rational to emotional language "may serve as the new legitimacy rhetoric" (p. 317) and Fairclough (1997) regards it as part of a state process to break down divisions between public and private, political society and civil society, "as the state and its mechanisms (especially ideological) of generating consent expand into private domains" (p. 80).

Mestrovic (1997) and Blase and Anderson (1995) describe this appeal to the emotions as creating a culture of "niceness" which leads to the "institutional silencing" of criticism (Blase & Anderson, 1995, p. 138). This "niceness" discourages the voicing of concerns which might be seen as a challenge to authority. In addition, Humes argues that:

> ...if meaning is managed effectively, the majority of staff internalize the professional and organizational vocabulary through which work is defined by officialdom. Dissent is silenced by representing it as straying beyond the boundaries of acceptable professional discourse. Descriptions such as "troublemaker", "negative", "not a team player" and "over the top" are used to label those who refuse to play by the (linguistic) rules of the game.
>
> (Humes, 2000, p. 45)

However, both Humes and Fairclough argue that discourse analysis can raise awareness of dominant ideologies and that "from awareness and critique arise possibilities of empowerment and change" (Fairclough, 1997, p. 83).

Procedure

National documents related to people with learning disabilities were identified and collected by consulting the Scottish Executive's list of recent publications, the Scottish Consortium for Learning Disability and PAMIS. Local documents were identified by liaising with managers in the social work and education departments, the health board and family carers.

Interviews

The research interview is a two-way process which allows the researcher to interact with the participants. It enables data to be gathered through direct verbal interaction:

> ...an interview is a form of discourse. Its particular features reflect the distinctive structure and aims of interviewing, namely, that it is a discourse shaped and organised by asking and answering questions. An interview is a joint product of what interviewees and interviewers talk about together and how they talk with each other.
>
> (Mishler, 1986, vii)

The research interview moves beyond surface talk to a discussion of thoughts and feelings. It allows a more in-depth investigation than would be possible with a questionnaire (Table 22) as the interviewer can follow-up ideas, probe responses and investigate motives and feelings:

> By providing access to what is "inside a person's head" [the interview] makes it possible to measure what a person knows (knowledge or information), what a person likes or dislikes (values and preferences), and what a person thinks (attitudes and beliefs).
> (Tuckman, 1972, cited in Cohen & Manion, 1994, p. 272)

Table 22. Summary of relative merits of interview versus questionnaire

Consideration	Interview	Questionnaire
1. Personal need to collect data.	Requires interviewers	Requires a clerk
2. Major expense	Payment to interviewers	Postage and printing
3. Opportunities for response-keying (personalization)	Extensive	Limited
4. Opportunities for asking	Extensive	Limited
5. Opportunities for probing	Possible	Difficult
6. Relative magnitude of data reduction	Great (because of coding)	Mainly limited to rostering
7. Typically, the number of respondents who can be reached	Limited	Extensive
8. Rate of return	Good	Poor
9. Sources of error	Interviewer, instrument, coding, sample	Limited to instrument and sample
10. Overall reliability	Quite limited	Fair
11. Emphasis on writing skill	Limited	Extensive

Source: Tuckman, 1972, cited in Cohen & Manion, 1994, p. 285

This is possible because interviews usually last one and a half to two hours, thus allowing prolonged engagement with the interviewee. Thus the lengthy duration of the interview allows the interviewer to establish a rapport with the respondent and to foster a climate of trust. In my study some of the family carers were interviewed individually and also took part in the focus group discussion and the nominal group discussion. Similarly, some of the professionals were involved in individual interviews, the focus group discussion and the nominal group technique discussion. According to Maykut and Morehouse (1994), this prolonged engagement with the interviewees increases the likelihood that the researcher will come to understand the participants' perceptions of the phenomenon in greater depth. As well as being a method for gathering information in relation to research objectives, the interview can also be used to test or propose hypotheses, identify variables and relationships and validate results from other research methods (Cohen & Manion, 1994).

Types of interviews

Interviews can be conducted with individuals (Bart & O'Brien, 1984), dyads (Daly, 1992) or groups (Douglas, 1990). They range from completely formalised interviews to non-directive interviews. The formal or structured interview consists of set questions with the answers being recorded on a standardised schedule. The interviewer has little freedom to make modifications. The data from this type of interview is relatively easy to analyse, however, it is the researcher who decides which questions to ask and the questions asked may not be the important ones from the participants' viewpoints (Bell, 1993).

The guided or focused interview uses no questionnaires or checklists. Instead the researcher uses a framework which allows certain questions to be asked but also permits the interviewees to talk about the topic and express their views in their own time. In this kind of interview the researcher is free to modify the questions, change the wording and alter the sequence of questions. This allows the interviewees to talk about what is of significance to them rather than to the researcher. It also gives the interview a more conversational feel and hopefully relaxes the participants.

However, its loose framework also ensures that all topics crucial to the study are covered (Kitchin, 2000).

In the informal or unstructured interview, the interviewer has a number of key issues which s/he raises in a conversational style instead of having a set questionnaire. In this kind of interview the researcher asks questions pertinent to the study as opportunities arise, then listens closely to the interviewees' responses for clues as to what questions to ask next or whether it is important to probe for additional information (Maykut & Morehouse, 1994). Such interviews can provide valuable data but they require a skilled interviewer and a great deal of time to analyse.

In the non-directive interview, the interviewer takes on a subordinate role and the interviewee is allowed to express their subjective feelings in a spontaneous way, free from interviewer bias. This method has been used successfully in therapeutic settings (Rogers, 1945). However, Cohen and Manion (1994) question the usefulness of this type of interview in educational and social research. They argue that in the therapeutic setting, the interviewer is a source of help and the purpose of the interview is to change the behaviour of the person. In contrast, in educational and social research the role of the interviewer and purpose of the interview are different. Here the researcher is seeking out information therefore s/he needs to be in control of the questions asked and needs to limit discussion to certain areas of the interviewee's experience, if results are to be obtained.

After careful consideration I decided to use guided or focused interviews in my study, both for the individual, dyadic and group interviews.

Focused or guided interviews

This decision was based on various reasons. Firstly, in line with participatory research, I wanted the participants to be actively involved in the research and construct their own data. This way of interviewing enabled the participants to play an active role rather than a passive one, with myself acting as facilitator, rather than director or controller (Knox, Mok, & Parmenter, 2000). In addition, Denzin (1994) and Knox et al. (2000) claim that this form of interviewing allows:

> ...the inquirer and the informant [to] develop, from their individual meaning systems, a unique shared meaning system in their collaboration [which allows] the expertise of the informants to emerge, to be recognised and to be valued.
> (Knox et al., 2000, pp. 55-56)

Thus interviewing in this manner avoids control of others, develops mutual understanding, a sense of connectedness with people (Reinharz, 1992) and helps to develop "egalitarian research methods" (James, 1985, p. 3).

Secondly, the focused interview complements the emergent design of my study and grounded theory. Merton and Kendall (1946) contend that the focused interview is a useful tool in helping the researcher uncover the subjective experiences of the participants (Table 23). The data produced can then be used to test the validity of hypotheses, propose new hypotheses and explore unanticipated responses, which in turn may give rise to further hypotheses. This cyclic process fits in well with an emergent design (Figure 10, p. 125) and the generation of theory based or inductive reasoning.

Table 23. Characteristics of focused interviews

The persons interviewed are known to have been involved in a particular situation.
Elements in the situation which the researcher deems significant have previously been analysed by him/her.
Using his/her analysis as a basis, the investigator constructs an interview guide.
The actual interview is focused on the subjective experiences of the people who have been exposed to the situation.

Thirdly, Merton and Kendall's (1946) criteria for using focused interviews seemed to match my study in terms of participants and researcher characteristics. They suggest that the people being interviewed in focused interviews need to have been involved in a particular situation (Table 23, p. 145). In my study the participants who took part in the individual and dyadic interviews all had either experience of going through the transition period with their offspring, or had experience of the transition period in the course of their work. In the group interview, all the participants had been involved in the transition period for this group of young adults, either as family carers or professionals. Merton and Kendall (1946) also suggest that in focused interviews the researcher should acquire knowledge of the situation in which the participants have been involved so that s/he can gain insight and knowledge into the topic to be investigated. This, they argue, will enable the researcher to identify areas of inquiry so that relevant data can be obtained from the interview (Table 23, p. 145). As I have undergone similar experiences to the family carers in my study and have researched the topic previously, this increased my understanding of the topic and helped me devise interview guides (Appendices B & D, pp. 484 & 490).

Finally, I felt that the structured interview would not have provided me with the in-depth information about the participants' thoughts and feelings that the aims and objectives of the study required, or have enabled me to view the problem from the participants' perspective. Therefore I rejected this form of interview. Similarly, I felt that the unstructured interview would require more time than I had available and that some of the topics, crucial to the study, might not be covered. Moreover, I felt I was not sufficiently skilled as an interviewer to carry out this technique successfully. In contrast, through my work as a part-time fieldworker, I have had considerable experience of conducting both individual and group focused interviews.

Thus the focused interview technique fitted in with the design of my study, its theoretical framework, the nature of its participants and my experience and skills as a researcher. However, there are a number of problems surrounding the use of this kind of interview as a research technique.

Interviews are not merely a means of extracting "pure" information from someone, or eliciting their "real" beliefs and attitudes. What the interviewees reveal depends on their perceptions of the researcher (Delamount, 1984), the nature of the study, how they interpret the questions and on how they wish to present themselves (Cannell & Kahn, 1968). In addition, interviews are prone to bias and subjectivity on the part of the interviewer. Selltiz, Jahoda, Deutsch and Cook (1962) point out that "interviewers are human beings and not machines" (p. 583). Thus their attitudes, opinions and manners may all have effects on the respondents. Indeed, research (Nederhof, 1981; Shosteck, 1977) has shown that an interviewer's sex, age, race, religion or class may influence the participants' responses. In my study I have provided information about my background and tried to be aware of how my behaviour and personal experiences influenced the data collection process.

My background as a parent of a young adult with profound physical and intellectual disabilities may have been valuable in helping me to gain intimate knowledge as I was seen by the family carers as a friend, as someone who could empathise with them. Indeed, Finch (1993) and Whitmore (1994) maintain that it is often the characteristics of the researcher, rather than his/her research skills which gains them entry into the participants' worlds. Hammersley, Gomm and Woods (1994) also stress the importance of the interviewer having an understanding of, and empathy with, the interviewee if s/he is to access people's ideas, thoughts and feelings. In addition, the family carers trusted me, which Bernard (1982) found to be essential especially if the aim of the study is to contribute to social change through conscious-raising and specific policy recommendations. However, Reinharz (1992) points out that although a researcher's identity can enhance empathy with the participants, it can also impede it. The researcher may see the respondent in his/her own image, seek answers that support his/her preconceptions or misunderstand the participants' responses. Therefore I had to be careful not to substitute my experiences for that of others or refrain from asking questions that challenged my assumptions. Whilst it is impossible to eliminate researcher bias completely, Gavron (1966) comments that "an awareness of the problem plus constant self-control can help" (p. 159). Therefore after each interview I recorded my feelings, reflected on ways in which I might have influenced the respondents' answers and how I could try to prevent this in subsequent interviews (Appendices C, F & J, pp. 487, 499 & 504).

However, Kitwood (1977) points out that there will always be a conflict between reliability and validity in the interview situation. This is because the researcher functions as the data collection instrument – "the human-as-instrument" (Lincoln & Gruber, 1985). Kitwood maintains that it is the human element in the interview that increases its validity as in an interpersonal situation people are more likely to reveal their thoughts, feelings and values. However, if reliability is increased by greater control in the form of a rational, calculating and detached interviewer, then validity decreases as the interview is no longer regarded as a friendly encounter. Thus responses are more likely to be calculated or dishonest. In an attempt to increase the reliability of my interview data, I interviewed five family carers (three individual interviews, one dyad), thus hoping to gain insight into the problem from a variety of perspectives. Moreover, as already seen, I also introduced provisions of trustworthiness into my study to try to increase the validity and reliability of the methods used and the data collected. In addition, I tried to be constantly aware that my research is a construction and affected by personal reactivity and I tried to make this explicit throughout my study and to reflect on how this influenced the collection and analysis of the data.

Another problem surrounding the use of the interview is that it requires considerable skills on the part of the researcher and the respondents. Reinharz (1992) suggests that researchers require interviewer skills of restraint and listening as well as interviewees who are verbal and reflective. Regarding the former, as already mentioned I have had experience of interviewing both individuals and groups. With regard to the latter, some of the family carers whom I interviewed have been involved in working groups with the statutory authorities and consultative committees with government agencies and were known to be articulate and to have reflected on their experiences.

As well as having empathy with the interviewees, Hammersley et al. (1994) stress the importance of the interviewer actively listening to the respondents, focusing them on the topic, clarifying ambiguous material, identifying clues and indicators and using probes effectively (Patton, 1990). In addition to this I also tried to put the participants at their ease by asking them for information which was well known to them at the beginning of the interview (Appendices B, D & I, pp. 484, 490 & 502). Yeandle (1984) argues that the first part of an interview is important as it acts as an "ice-breaker" which enables participants to "relax and talk about themselves... convincing them that the interview had relevance to them as individuals" (p. 39). I also tried to make the interviewees feel as if they were collaborators in the research process as according to Mishler (1986) this kind of empowerment helps participants in "their efforts to construct coherent and reasonable worlds of meaning and to make sense of their experiences" (p. 118).

Another problem to be considered when using the interview technique is how to record responses. There are several ways of doing this. For example, replies can be summarised in the course of the interview or at the end of the interview. The former can affect the continuity of the interview and may result in interview bias as the interviewer may unconsciously emphasise responses that support his/her preconceptions and ignore those which do not. With the latter method, the interviewer may forget important details. Therefore I decided to record the interviews using a tape recorder in order to overcome these problems. Although taping the interviews might have influenced the data gathering process, I felt that taping the interviews had several advantages. Firstly, taped interviews can be re-analysed and evaluated by other researchers for bias and subjectivity. Secondly, taping left me free to observe and record non-verbal behaviour. Thirdly, it speeded up the process and gave the participants freedom to talk about the topic in a naturalistic setting and express their views in their own time. Lastly, taping the interviews and transcribing them gave me the opportunity to study the data more thoroughly.

Another problem with interviewing is that it is time consuming. Interviews have to be set up, tapes transcribed and large amounts of data categorised and analysed. Despite these disadvantages I used individual, dyadic and group interviews in my research as I regard this method as a good way of exploring people's views of reality, their emotions, experiences and feelings.

Individual and dyadic interviews with the family carers

Sample

As already discussed, purposive sampling was used to locate four sets of family carers of young adults with profound physical and intellectual disabilities (Table 24), who were willing to share their expertise and act as participants in the study. The participants were selected to provide a richness and diversity of information, rather than as representatives of a wider group (Patton, 1990; Morse, 1994). Ideally the size of the sample should have been determined by the saturation point i.e. when newly collected data is redundant by previously collected data (Glaser & Strauss, 1967) but for practical reasons and time limitations the sample was restricted to four families. As already mentioned, due to the severe communication impairments of the young people, their family carers were chosen to recount their experiences. This method has been used by other researchers (Morris, 1999b) when the young person's level of communication impairment was such that it was not possible to ask him/her about their experiences.

Table 24. Sample of family carers for individual and dyadic interviews

Pseudonym	Young person (age)	School provision	Post-school provision
Helen	Faye (27)	Westfield	Fraser Centre
Maureen	Simon (21)	Hollywell	Lemington Court
Joyce	Kylie (21)	John Harvey	Gordon House
Catherine and Roger	Geri (19)	Garefield, Mudwood, Dunness, Kogan	Lemington Court

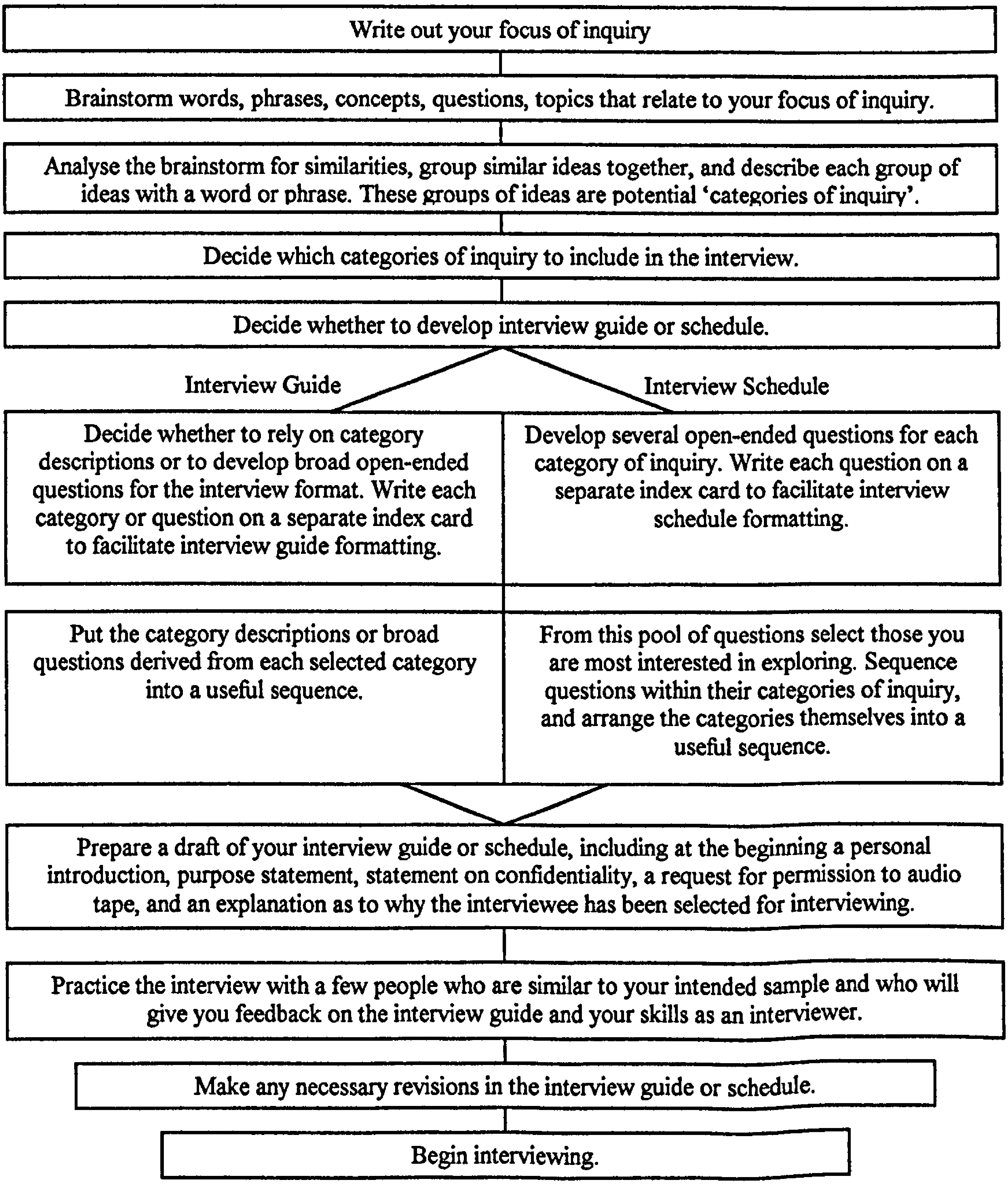
Procedure

An initial framework for the interviews was developed using procedures identified by Maykut and Morehouse (1994) (Figure 12, p. 152 & Appendix A, p. 483). This method not only helped me to generate ideas but provided a record of my work which can be evaluated by other researchers, thus increasing the trustworthiness of my study. I decided to use an interview guide consisting of broad, open-ended interview questions, supplemented by probes and cues (Appendix B, p. 484). This gave me the opportunity to ask questions in my own way, to alter the sequence of questions or go deeper into topics which seemed important to understanding the participants' experiences. Moreover, Maykut and Morehouse (1994) argue that the interview format guide is particularly useful for exploring phenomena through interviewing when little is known about the problem. I also used Patton's (1990) six types of questions to help me formulate my questions (Table 25).

Table 25. Patton's (1990) topology of interview questions

Question	Description
Experience/behaviour questions	Asks questions about what people do or have done e.g. Tell me about your job.
Opinion/value questions	Asks questions which are cognitive in nature e.g. What is your opinion of the 5-14 guidelines?
Feeling questions	Asks questions about affective states e.g. How did you feel when you were told you were going to loose your job?
Knowledge questions	Asks interviewees to tell what they know about a particular topic e.g. What is the school's policy on bullying?
Sensory questions	Asks questions about what the interviewees see, hear, smell, touch and taste e.g. What do you notice first when you walk into a classroom?
Background/demographic questions	Asks interviewees information about age, marital status, residence e.g. How old were you when you started teaching?

I began the interview by using non-controversial questions, framed in the present, and focusing on the interviewees' experiences in order to put the participants at their ease. Gradually as the interview progressed and rapport was established, I introduced opinion/value questions, feelings questions and knowledge questions. The interview was brought to a close by inviting the interviewee to raise any points they thought had not been covered and by thanking them for their participation. The interview guide was piloted using a family carer who was not included in the research sample and feedback was given on the contents and format of the interview and my skills as an interviewer.



Write out your focus of inquiry

Brainstorm words, phrases, concepts, questions, topics that relate to your focus of inquiry.

Analyse the brainstorm for similarities, group similar ideas together, and describe each group of ideas with a word or phrase. These groups of ideas are potential 'categories of inquiry'.

Decide which categories of inquiry to include in the interview.

Decide whether to develop interview guide or schedule.

Decide whether to rely on category descriptions or to develop broad open-ended questions for the interview format. Write each category or question on a separate index card to facilitate interview guide formatting.

Develop several open-ended questions for each category of inquiry. Write each question on a separate index card to facilitate interview schedule formatting.

Put the category descriptions or broad questions derived from each selected category into a useful sequence.

From this pool of questions select those you are most interested in exploring. Sequence questions within their categories of inquiry, and arrange the categories themselves into a useful sequence.

Prepare a draft of your interview guide or schedule, including at the beginning a personal introduction, purpose statement, statement on confidentiality, a request for permission to audio tape, and an explanation as to why the interviewee has been selected for interviewing.

Practice the interview with a few people who are similar to your intended sample and who will give you feedback on the interview guide and your skills as an interviewer.

Make any necessary revisions in the interview guide or schedule.

Begin interviewing.

Figure 12. General procedure for developing an interview guide or an interview schedule

Source: Maykut & Morehouse, 1994, p. 84

The family carers were contacted by telephone and told the nature and purpose of the study and asked if they would be interested in taking part. If they agreed I offered the participants the option of meeting at their house or mine and arranged a mutually convenient time. Participants were given a copy of the interview guide in advance, if they so wished. I also asked the participants for their permission to tape the interviews. The interviews themselves were conducted following the interview guide (Appendix B, p. 484) and when completed I made notes about non-verbal behaviour, my feelings and the interview process itself (Appendix C, p. 487).

Individual interviews with the professionals

Sample

The four professionals involved in the individual interviews (Table 26) were selected using snowballing sampling – "identifies cases of interest from people who know people who know what cases are information rich" (Miles & Huberman, 1994, p. 28).

Table 26. Sample of professionals for individual interviews

Pseudonym	Job description
Margo	Education liaison officer, focuses on people with additional support needs. One aspect of her job is supporting the transition of young people to post-school provision. Attends meetings in school and offers advice to schools, parents and young people about the moves to the next stage. Links with social work colleagues and represents education services on the social work post-16 group.
Pauline	Team leader in social work in community care, works with people from 16+ and school leavers with disabilities. Oversees social workers who care manage the care packages of people over 16 who have disabilities.
Tina	Community learning disability nurse, part of a community team for people with learning disabilities. Assesses healthcare needs, the planning and giving of care and treatment and the evaluation of services. Also looks at inclusion to mainstream services, accessing primary healthcare services. Sees her role in terms of an "enabler".
Jillian	Local co-ordinator for a voluntary agency which is concerned with the needs of children and adults with "profound and multiple learning disabilities" (PMLD). Provides families with information, training and support. Facilitates groups of families to get together to discuss issues, campaign, raise money, organise social events. Works in partnership with family carers to influence both local and national policies.

Procedure

The procedure followed was similar to the one used in the individual interviews with the family carers.

Group interviews

Watts and Ebbutt (1987) describe group interviews or focus groups as useful tools for generating discussions and a wide range of responses. Participants have an opportunity to listen to each other's contributions, which may spark new insights, or help them to develop their ideas more clearly. Thus information not thought of, or shared, in the individual interview, may emerge in the group interview. Usually people enjoy group interviews because they are given an opportunity to express their viewpoints and sometimes they come to a new understanding of the issues through their interactions with other group members. From the researcher's viewpoint, the group interview enables him/her to observe the participants discussing a topic which interests the researcher. From these interactions the researcher often gains new insights into how people construct their worlds and why they think as they do (Morgan, 1988). Furthermore, group interviews are also useful for helping the researcher explore a topic for which little information is available (see also Table 28, p. 159).

However, Watts and Ebutt (1987) claim that group interviews are of little use in allowing personal matters to emerge or in circumstances where the researcher has a series of follow-up questions for specific group members. As I used individual and dyadic interviews to cover these aspects, these disadvantages were not applicable to my study. Nevertheless, Mulford, Watson and Vallee (1980) warn that groups are more than the sum of their parts and that group dynamics have to be taken into consideration. They suggest that groups need to "form, storm, norm, perform and mourn" to be successful. For the group to "form" everyone needs to feel that they are included in the group. Then follows a period of "storming" in which the group works out the issues and personalities begin to emerge. At this stage it is essential that individuals are not allowed to dominate the group and that everyone is encouraged to participate in the discussion. At the "norm" stage, people settle down and recognise that it is permissible to hold different opinions. When an atmosphere of trust is established within the group, the "performing" stage is reached and questions are addressed. Towards the end of the interview a stage of "mourning" is reached and the interview is brought to a close. Faulkner, Swann, Baker, Bird and Carty (1993) argue that an understanding of these stages is essential if focus group discussions are to be successful.

With the above in mind, I decided to conduct a group interview as I wanted to explore with the family carers how the problems they and their offspring had encountered during the transition period between school and adult provision might be overcome. At this point I widened my sample to include professionals, from a variety of backgrounds (Table 27, p. 156), involved with young adults with profound physical and intellectual disabilities. The purpose of the group was to bring different perspectives into contact and allow people to express their thoughts, ideas and feelings about the problems surrounding the transition period in an open and emergent way.

Sample

I had planned that the group would consist of the family carers whom I had interviewed previously and four professionals from the three main statutory agencies involved with the young people – health, social work and education, as well as a representative from a voluntary service set up to support people with "profound and multiple learning disabilities". Once again I used the snowball technique to locate the professionals involved in the discussion. The group was limited to eight participants as research (Krueger, 1988; Morgan, 1988) has shown that groups need to be small enough to ensure that everyone will take part in the discussion, yet large enough to ensure diversity of opinion. Unfortunately, due to illness on the part of one of the professionals and two of the young people involved in the study, only three professionals and two family carers took part (Table 27, p. 156). Thus there was no professional representative from the education department. The short notice provided by these participants meant that I was unable to contact other representatives.

Table 27. Sample for group interview

Pseudonym	Profession
Jillian*	Co-ordinator of a voluntary service specifically involved with people with "profound and multiple disabilities" (PMLD) and their family carers
Pauline*	Team leader in social work – community care
Angela	Resettlement manager for health board
Helen	Family carer of Faye
Maureen	Family carer of Simon

* Also participants in the individual interviews

Procedure

A covering letter detailing the study was sent to the managers of the "Same as You?" (SAY) Project and the advisor of special educational needs inviting them to attend, or send representatives, to the focus group discussion (Appendix E, p. 493). I then met with the managers of the SAY Project to give them more information about my study and they identified participants, from both the health board and social work department, who had experience of working with young adults with profound physical and intellectual disabilities and their families during the transition period. I also had a telephone conversation with the advisor in special educational needs and she agreed to take part in both the focus group discussion and the nominal group technique. Having identified participants, letters were then dispatched to arrange mutually convenient times. The four professionals were also sent copies of Chapter 5. (The family carers had already received a copy for respondent validation purposes). The first batch of letters proved unsuccessful in establishing a mutually convenient time and a second batch of letters had to be sent out (Appendix E, p. 493). I then sent out letters informing participants of the date of the focus group and since two dates had been identified, the second was used for holding the nominal group technique discussion. Participants were also sent a copy of the interview guide and a summary of the problems and difficulties identified by the family carers during the transition period (Appendix D, p. 490).

The group met in my house in the morning and the interview was taped with the consent of the participants. The information provided by the family carers in the individual and dyadic interviews was used to devise an interview guide (Appendix D, p. 490). The interview guide consisted of broad questions and sub-topics. It was loosely structured so as to encourage conversation. The participants were seated around a dinning room table on which the tape recorder was placed. From the beginning I tried to encourage the group to "form" by serving refreshments, by getting everyone to introduce themselves and telling the other group members about their involvement with young adults with profound physical and intellectual disabilities. I also tried to present the questions in an unbiased way and be aware that my non-verbal behaviour could influence responses. I then started with questions I thought the interviewees would find easy to answer, with more sensitive and difficult questions being asked later. In addition, I strove to foster a positive atmosphere of trust and support. I encouraged involvement by showing interest in the topic through verbal and non-verbal behaviour, by inviting and encouraging all members of the group to participate and by using probes to clarify and elaborate ideas. When I felt that the discussion was moving away from the topic, I used deferring statements to focus the group on the task (Robson, 1986) so that all aspects of the area for discussion were covered. At the "mourning" stage I asked the participants if there was anything else they wanted to say or whether there was anything else they wanted to ask about the study or the interview itself. The group was thanked for their help, the meeting was closed and a light lunch served. Immediately after the interview was completed I reflected on the process and content of the interview (Appendix F, p. 499).

Nominal group technique

Strengths

The nominal group technique (NGT) is a structured procedure for gathering information from a group of people who have insight into a particular area of interest. It facilitates group decision-making and allows a balanced participation of all group members (Delbecq, Van de Ven, & Gustafson, 1975). This is achieved by allowing individual members of the group to generate ideas independently in response to a carefully formulated question. These ideas are then shared with the other members of the group who discuss the ideas and explore them further until finally a group judgement is made about the important ideas. The group is "nominal" to the extent that it is highly controlled and discussion is allowed only during the later stages of the process. The group is therefore a group in name only, or nominally.

Gallagher, Hares, Spencer, Bradshaw and Webb (1993) describe the NGT as being a useful tool for eliciting from participants their concerns and priorities concerning a particular topic. They contend that it allows problems to be approached from a variety of perspectives and encourages participants to recount incidents which illustrate problems and solutions. Delbecq et al. (1975) argue that one of the strengths of this method is that it helps to increase the quality of decision-making by encouraging participation of all the group members by providing an environment in which everyone's concerns and ideas may be effectively voiced. The NGT was originally designed to overcome some of the problems associated with traditional interacting groups such as dominant personalities (Dalkey & Helmer, 1963) and the "focusing effect", where groups pursue a single train of thought for a long period (Torrance, 1957). Gallagher et al. (1993) have compared the NGT to other group processes which aim to generate new ideas and encourage expression (Table 28, p. 159).

One of the techniques which they looked at was brainstorming. This process aims to produce as many ideas as possible, with the hope that some of them will be useful. They found that whilst participants involved in such groups enjoyed the group interaction, some of the group members felt that the group had not concentrated on the task in hand, which resulted in non-completion of the task and feelings of dissatisfaction. In contrast, Van de Ven (1974) found that the NGT maintains a good balance between participants enjoying the interaction during the discussion period and the group remaining focused on the task.

Table 28. The relative strengths of NGT, brainstorming, Delphi and focus groups

Advantages	NGT	Brainstorming	Delphi	Focus
Difficult for dominant participants to control	Yes	No	Yes	Possibly
Avoids "quick decision making"	Yes	No	Yes	Possibly
Generates a high number of comments/ideas	Yes	Possibly	Yes	Possibly
Provides support to allow identification of personal problems and self disclosure	Yes	No	No	Yes
Allows measurement of importance of ideas/items to individuals	Yes	No	Yes	Possibly
Avoids pursuit of a single train of thought ("focus effect")	Yes	No	Yes	Yes
Encourages minority concerns/options to be voiced	Yes	No	Yes	Possibly
Participants value social interaction i.e. group cohesiveness	Possibly	Yes	No	Yes
High degree of task completion	Yes	No	Yes	Possibly
Ease of administration	No	Yes	Yes	Possibly
Need for experienced leader	Yes	No	No	Yes

Source: Gallagher et al., 1993, p. 78

The second technique that Gallagher et al. looked at was the Delphi groups. In this technique a group of "expert" participants are sent a postal questionnaire about the topic. Their responses are then collated by a panel who assess the participants' views which are then fed back to the participants in the form of a structured questionnaire. The participants then return this second questionnaire to the panel and the process is repeated until either a consensus is achieved or a comprehensive understanding of the differing perspectives is accomplished (Linstone & Turoff, 1975). Unlike the NGT the participants never meet. In this way the Delphi method ensures anonymity and avoids the social pressures, which may exist in groups which meet face-to-face, to conform. Furthermore, it is a useful technique to employ if participants are geographically distant and cannot meet. This method also produces a high number of ideas. However, the Delphi method also has disadvantages (Table 28), the main one being that the participants do not interact with each other and thus there is no opportunity for verbal clarification of ideas and terms.

The third technique that Gallagher et al. looked at was focus groups. As this technique has already been fully discussed, I intend to limit the discussion here to a comparison of this technique with the NGT. Gallagher and his colleagues point out that in a focus group it is the sole responsibility of the facilitator to ensure that the group remain focused on the task, whereas with the NGT the structure of the technique greatly assists the facilitator to achieve task completion. Moreover, with the focus group technique there is more chance that participants may feel pressurised to conform by vocal and high status participants. This may lead to a limited range of issues being explored, or a reluctance to express different viewpoints. Although trained facilitators can help overcome these problems, group pressures may still suppress subordinate or minority views (Reynolds & Johnson, 1978). In contrast, the structure of the NGT ensures the involvement of all participants:

> It [NGT] provides the detail of qualitative information supplied by focus groups, whilst avoiding an over-reliance on the skills of a moderator to secure participation. Group dynamics are structurally controlled in a supportive environment.
> (Gallagher et al., 1993, p. 81)

Another problem with focus groups is that analysis of the results is time consuming, whereas the NGT produces results which can be used to provide instant feedback to the participants. In addition, the NGT provides data which can be analysed both qualitatively and quantitatively.

Having discussed the strengths of this technique, I will now go on to look at some of the difficulties surrounding it and the ways in which I tried to overcome them.

Weaknesses

The question for discussion in nominal groups is crucial to the whole process (Flanagan, 1954). Delbecq et al. (1975) comment:

> NGT is like a microscope. Properly focused by a good question, NGT can provide a great deal of conceptual detail about a matter of concern to you. Improperly focused by a poor or misleading question, it tells you a great deal about something in which you are not interested.
> (Delbecq et al., 1975)

Furthermore, studies (Musico, 1916; Payne, 1951; Speak, 1967) show that a slight change in the wording or the grammatical structure of a question can influence the nature of the data generated. Thus in my study I developed the question in consultation with my supervisors and other researchers. I did consider testing the question on a pilot group, however, research (Crutchfield & Gordon, 1947; Heller 1969; Weitz, 1950; Wells, 1963) has indicated that difficulties may continue to surround the intended interpretations of questions by participants. For example, Dean (1958) and Campbell (1945) found that respondents interpreted the same question according to different frames of reference. In addition, Thorndike and Gallup (1944) found that the average person's knowledge of commonly used words varied and therefore responses to questions differed. In an effort to overcome some of these problems, I tried to develop a simple and easily understood question. One which was specific and avoided ambiguity but was sufficiently broad to elicit varied responses.

With the NGT care must also be taken to ensure that the facilitator does not dominate the group or coerce participants into making responses. Horton (1980) stresses that the facilitator's role is to carry out the various stages of the procedure. Therefore it is important that s/he is someone who is familiar with the process and can explain the process with sensitivity. I have attended two training courses on the NGT technique and have facilitated a number of groups. In addition, my performance as a facilitator has been observed and monitored by other professional researchers.

Another concern surrounding the NGT is that it can be very time consuming to write down all of the items generated by the group. Thus the participants may loose interest, even when the ideas are recorded in a round robin fashion, especially if duplication of ideas occurs repeatedly. Therefore to speed up the process and maintain the group's interest I allowed the participants to link and group ideas at the initial reporting stage. Peter, Horobin and Hamil (1993) have found that this not only saves time and maintains group interest but allows each item to be clarified and a natural discussion of issues to take place as items are suggested. Peter et al. have also modified the original NGT by omitting the ranking of items stage. A comparison of their methods with Gallagher et al.'s is outlined in Table 29.

Table 29. Comparison of Gallagher et al.'s (1993) and Peter et al.'s (1993) stages in nominal group technique discussions

Gallagher et al.'s (1993) stages	Peter et al.'s (1993) stages
1. Introduction	1. Introduction
2. Silent generation of ideas in writing	2. Silent generation of ideas in writing
3. Listing of ideas on flip chart	3. Listing of ideas on flip chart with discussion of items to clarify, modify and link ideas
4. Discussion of ideas on flip chart	4. Full discussion of ideas on flip chart
5. Ranking to select the "top-ten" ideas	5. Voting for x items (the actual number of items chosen depends on the overall number of items generated)
6. Voting on "top ten" ideas	6. Break
7. Break	7. Discussion of vote
8. Discussion of vote	8. Stage 5 is repeated until the required number of items are selected, with the number of choices made at each repetition set appropriately by the facilitator
9. Re-ranking and rating revised "top ten" items	9. Discussion of choices made by the group
10. Conclusion of nominal group	10. Conclusion of nominal group

Peter et al.'s method also omits the ranking stages as they have found that whilst people usually have strong opinions about ranking their most and least important items, there is often uncertainty or ambivalence about the middle rankings. In addition, as the facilitator records the amount of votes given to each item on the flipchart, for all to see, in Gallagher et al.'s method, Peter et al. argue that some participants may feel pressurised to vote for the popular items in the next round of voting. Therefore I favoured Peter et al.'s method of running a nominal group.

As already mentioned the NGT is time consuming. It is not a flexible technique as it requires prior planning, structure, time and needs the active involvement of all the participants. However, it is a useful tool to research in that it:

- allows target groups to single out critical problem dimensions by means of a group process which is unthreatening and depersonalized.
- clarifies the meaning of critical items for both researchers and participants through discussion.
- can be used to explore both the "objective" and "subjective" dimensions of a problem area.
- identifies the priority foci of differentiated reference groups on an exploratory problem by means of a voting procedure.

(Adapted from Van de Ven & Delbecq, 1972, pp. 341-342)

Therefore I have used it in my study to generate ideas for good quality provision and services for young adults with profound physical and intellectual disabilities.

Sample

The members of the focus group discussion were also invited to take part in the nominal group technique. Once again the participants were chosen to reflect the full range of professionals and non-professionals who have experience, expertise and insight into post-school provision for young adults with profound physical and intellectual disabilities. Research (Hoffman & Maier, 1961; Hoffman & Smith, 1960; Wagner, 1950) suggests that a valid assessment of a problem area is facilitated by the involvement of different target groups. Therefore I used different target groups, with experience directly related to the problem, but from different perspectives in order to gain a more comprehensive understanding of the problem (Smet, 1952; Van de Ven & Delbecq, 1972). The sample of family carers consisted of the three family carers interviewed previously (Table 24, p. 150). Unfortunately, Joyce was unable to attend because of the continuing ill health of her daughter, Kylie. The sample of professionals was designed to encompass the various disciplines involved with this group of young people and as with the focus group discussion, the participants were recruited using the snowball technique. Unfortunately two were unable to attend, one due to continuing ill-health, the other due to her required attendance at an emergency meeting. Thus the group had no representatives from the health board and education department (Table 30). The short notice provided by these participants meant that I was unable to contact other representatives.

Table 30. Membership of nominal group

Pseudonym	Profession
Jillian	Co-ordinator of a voluntary service specifically involved with people with PMLD and their family carers
Pauline	Team leader in social work – community care
Roger	Family carer of Geri
Helen	Family carer of Faye
Maureen	Family carer of Simon

Procedure

Following on from information received about dates for the focus group discussion, an invitation was sent to all participants inviting them to attend the following week for the nominal group technique discussion. The group members were also reminded at the focus group discussion of the date of the nominal group technique discussion. The group members, who were unable to attend the focus group discussions, were reminded of the nominal group technique discussion by telephone. The group was held during the morning at my home. The discussion was audio-taped with the consent of the participants.

The group members were seated around a table and the following structure, based on Peter et al.'s (1993) method, (Table 29, p. 162) was used. I welcomed the participants and introduced myself. The participants were then asked to introduce themselves, giving brief information about their jobs and/or involvement with young adults with profound physical and intellectual disabilities. I then explained my interest in the subject and the part the participants would play in examining the topic. Next I handed out an A4 sheet of paper, with the question to be discussed on it, and a pen to each person (Appendix, G, p.500). I then read out the question to the participants.

The group members were asked to spend the next 10-15 minutes independently writing down, in silence, their own ideas in response to the nominal group question. I stressed that no discussion or communication between members was to take place at this stage of the procedure. When every member was finished writing, individual group members were invited to feed back their ideas in a round-robin fashion. Each person in turn was asked to share one item which they had written down with the group. The contribution was written in black felt-tip pen on a flip chart using the words spoken by the participant and numbered. This procedure was repeated until all the group members had exhausted their individual lists. Identical ideas were recorded only once and group discussion was encouraged in order to clarify, modify and link ideas. Then a free discussion took place in which group members were encouraged to express their opinions, clarify, elaborate, reword and amalgamate items, or add any new items that might have arisen from the discussion. The participants were then handed out a small piece of paper and asked to choose 5 items from the list on the flip chart which they felt were the most important. The number of votes allowed on each ballot was determined by myself and depended on the number of ideas generated. The participants were then asked to record secretly the numbers of the items on their ballot paper, in any order they wished, fold their paper in half and return it to me. I then shuffled the papers to ensure that anonymity was preserved and the scribe recorded the items voted for on the flip chart by circling the numbers of the items chosen with a green felt-tip pen. The participants were not told the number of votes for each item so as not to influence further voting. However, no second ballot was required as ten items were identified. These items were discussed and feedback about the process obtained from the participants. The group was then thanked for their help and the meeting closed with a light buffet lunch. After the meeting I made notes about my feelings and the process itself (Appendix H, p. 501).

Documents

Travers (1964) defines a document as "an impression left by a human being on a physical object" (Travers, 1964, cited in Bell, 1993, p. 68). Therefore the term encompasses films, videos, slides and other non-written sources as well as written and printed sources. Bell (1993) describes three uses for documentary evidence in social and educational research – to supplement information obtained by other methods, to be the central or only source of information and to provide information where access to participants is difficult or impossible. In my study I used written sources in the form of minutes of the young people's Future Needs Assessment (FNA) meetings to supplement information obtained by interviewing the family carers. These minutes are primary sources, that is they "come into existence in the period under research" (Bell, 1993, p. 68). They are also what Bell calls "inadvertent sources" – "used by the researcher for purposes other than that for which they were originally intended" (Ibid.). Although inadvertent sources are less likely to be biased than "deliberate sources" which are produced for the attention of future researchers, Bell warns that sometimes inadvertent documents can be attempts to justify actions to future generations (Elton, 1967). Therefore researchers need to analyse them critically.

Procedure

When interviewing the family carers I asked them if they had copies of the minutes of the FNA meetings and if I could borrow them for study. Unfortunately only one family had retained copies of the FNA minutes.

Having discussed my methods of data collection, the next section looks at how I analysed the data.

ANALYSING DATA

Before beginning analysis of the data, I engaged in the "Epoche" process (Patton, 1990; Moustakas, 1990). This enabled me to reflect on my own bias and preconceptions surrounding the topic:

> Epoche is a process that the researcher engages in to remove, or at least become aware of prejudices, viewpoints, or assumptions regarding the phenomenon under investigation. Epoche helps enable the researcher to investigate the phenomenon from a fresh and open view without prejudgement or imposing meaning too soon. This suspension in judgement is critical in phenomenological investigation and requires the setting aside of the researcher's personal viewpoint in order to see the experience itself.
> (Katz, 1987, pp. 36-37)

I felt this was essential due to my personal involvement with the topic. Whilst my personal involvement with the topic helped me to gain the understanding of an insider, I also wanted to be able to adopt an outsider perspective. Adopting this perspective helped me to describe relationships, systems and patterns, which the insider might not be aware of, through rigorous and systematic analysis of the data.

Analysis of policy documents

As my study was concerned with analysing policy documents related to people with learning disabilities, I drew on Gale's (1999) ideas concerning policy discourse analysis. He argues that when analysing policies it is essential to look at the connection between policies and their contexts. Therefore I began my analysis of the documents by looking at the historical development of policies and services for people with learning disabilities in an attempt to identify some of the material and social circumstances which influenced policy-making. Then I read the four national documents. Next I examined each document using Kenway's (1990) and Gale's (1999) framework of analysis – the "what", the "why" and the "how" of policy. I also examined the rhetorical devices used in the policies – metaphorical representation, rational and emotional language and binary oppositions. This technique was also applied to the local documents.

Interviews

One of the concerns of my study was to reconstruct the interview data into a "recognisable reality" for the participants. Thus I had to select an approach which was capable of describing, selecting and interpreting the data, as well as enabling me to arrive at research outcomes. Therefore I chose the approach known as "interpretative-descriptive" research (Belenky, 1992 October). This approach to analysing data has description as its primary aim but also recognises the importance of interpretations which may lead to theory development or grounded theory. I also chose a method of data analysis based on Creswell's (1998) data analysis spiral (Figure 13, p. 169) and Glaser and Strauss's (1967) constant comparative method (Figure 14, p. 170) as I was interested in developing propositions or "statements of fact inductively derived from a rigorous and systematic analysis of the data" (Maykut & Morehouse, 1994, p. 126) which reflected the participants' feelings, thoughts and actions. Furthermore, this method allowed an ongoing, inductive analysis of the data and fitted in with the emergent design of my study (see Figure 10, p. 125).

Therefore the procedure for analysing the individual and dyadic interviews were as follows. Firstly, the interview tapes were transcribed and note was taken of any non-verbal behaviour (Appendix K, p. 506). The interview transcripts were then coded to identify the interviewee and page number and subsequently photocopied (Figure 13, spiral 1). Next I listened to the tapes, read through the transcripts and my notes in order to obtain a sense of the overall data (Tesch, 1990; Agar, 1980), its meaning and themes (Hyncer, 1985). The next step involved "unitizing the data" (Lincoln & Gruber, 1985). I read through the transcript copies and when I identified a unit of meaning, I drew a line across the page to separate it from the next unit. These units of meaning were then labelled according to source and given a word or phrase to describe the unit's meaning (Appendix L, p. 691). Once the units of meaning had been noted I reduced them to units of meaning relevant to my study (Hycner, 1985). The units of relevant meaning were then cut out and taped to index cards for ease of working (Figure 13, spirals 1 & 2) (Appendix L, p. 691).

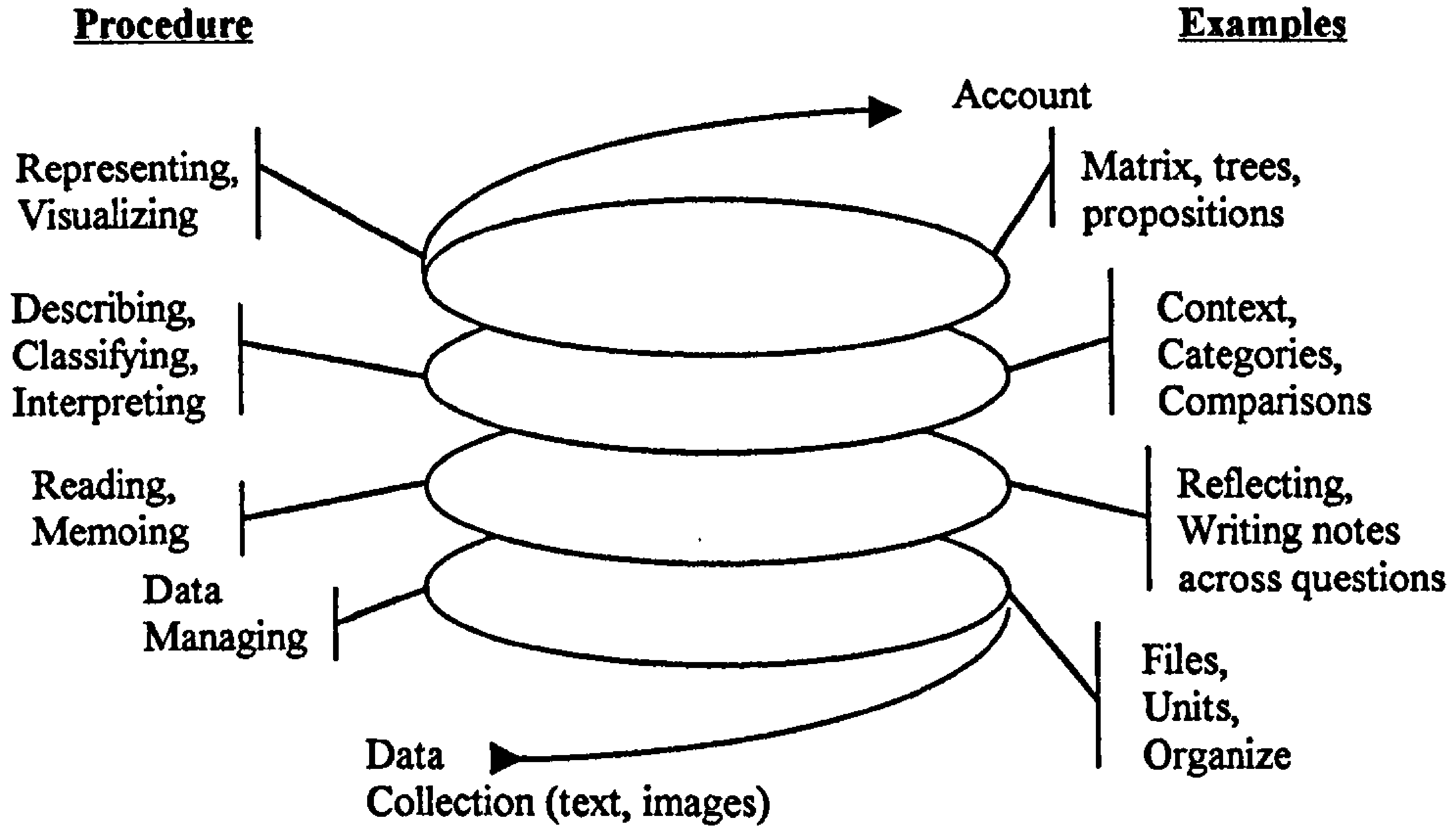


Figure 13. The data analysis spiral
Source: Creswell, 1998, p. 143

The next step involved "inductive category coding" (Figure 13, spiral 3 & Figure 14, p. 169). I now tried to see if any of the units clustered together under a central theme or category. If one unit of meaning on one card seemed similar to the unit of meaning on another card or cards, I grouped them together under a provisional category derived from my initial findings on reading over the transcripts. If I felt that the data card fitted more than one category, I copied it and taped it to the appropriate categories. If the data card did not fit any of the provisional categories, I made a new category. Lincoln and Guba (1985) claim that by using this "look/feel-alike" criteria the researcher can inductively derive salient categories of meaning. Next I began the process of refining the categories (Figure 13, p. 169, spiral 3 & Figure 14, p. 170). Firstly, I wrote rules for each category, in the form of propositional statements, which I used as a basis for including or excluding data cards. Maykut and Morehouse (1994) describe a propositional statement as "one which conveys the meaning that is contained in the data cards gathered together under a category name" (p. 139). They argue that propositions help researchers to understand the topic they are investigating and identify research outcomes. I then re-read each data card to see if it fitted with the category rule, required transfer to another category or required a new category.

When all the data cards had been categorised on the basis of rule inclusion, I reviewed the cards for overlap and ambiguity and adjusted and refined categories and rules if necessary. Lastly, I coded the data cards to their rule-based categories for ease of working.

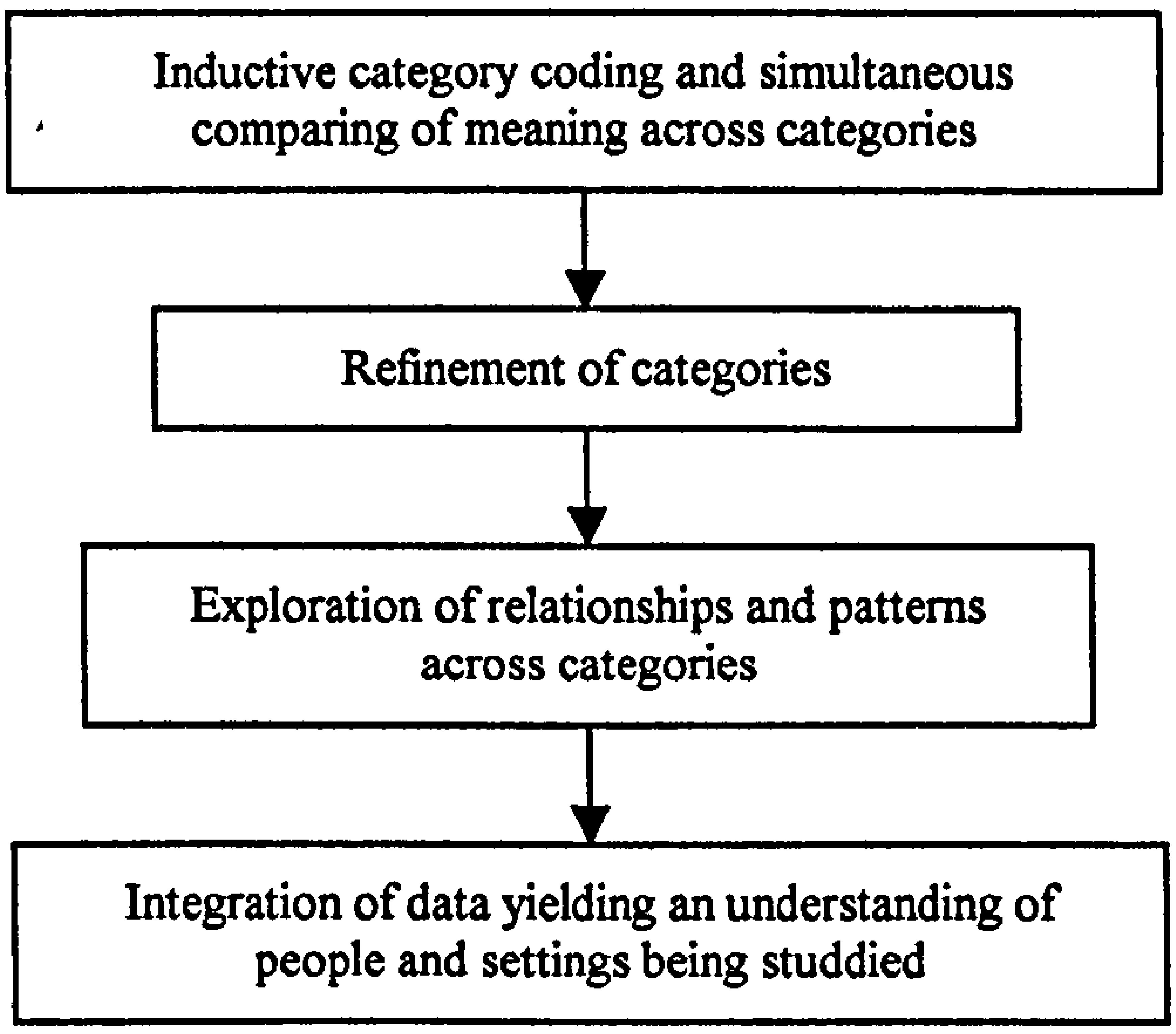


Figure 14. Constant comparative method of data analysis
Source: Maykut & Morehouse, 1994, p. 135

Next I studied the propositions to identify those which stood alone and those which formed patterns or relationships (Figure 13, p. 169, spiral 3 & Figure 14, p. 170). These outcome propositions were then prioritised by considering their relevance to the study and their prominence in the data. I then re-read the data cards and highlighted quotations that best illustrated each proposition in preparation for writing the outcomes section (Figure 13, p. 169, spiral 4 & Figure 14, p. 170).

Each of the individual and dyadic interviews were analysed in this way. I then looked at the outcome propositions for all the interviews and noted common themes as well as individual variations.

The group interview was also transcribed and note was taken of non-verbal behaviour (Appendix M, p. 692). The data from the group interview was also analysed using the method above.

Nominal group technique

The nominal group technique yielded data which was analysed both qualitatively and quantitatively. Firstly, I recorded the items generated by the group on the flip chart in a tabular form (Appendix N, p. 734). The numbers in the left-hand column indicated the items generated by the group members in a "round robin" fashion and were the numbers used to facilitate the voting process. The items generated by group members and recorded on the flipcharts verbatim were written in normal text in the table. I used italic text to indicate an addition to the original idea by other group members. If underlined text was used for emphasis on the original flipchart record, it was also recorded in this way in the table. Strike through text (e.g. ~~strike through text~~) was used to indicate words or phrases removed from the original item by the participants in the later "discussion" sections. I used the symbol X on top of the item number to indicate items that the group had decided to amalgamate or disregard as they felt it was covered by another item. The number of votes received for each item was recorded on the right-hand side of the table.

The items were ranked and then inductively categorised into themes (Chapter 7, Table 39, p. 366) to show the range of issues that were considered important (Hares et al., 1992). Although the induction of categories from the raw items generated by the nominal group discussion is largely subjective, Flanagan (1954) and Van de Ven and Delbecq (1972) suggest a process for the content analysis of data and this I followed. Van de Ven and Delbecq suggest three decision rules which can guide the researcher in the classification of the data:

> 1. Search for nominal items that are observable over wide variations.
> 2. Search for nominal items that seem to explain a large number of related phenomenon.
> 3. Search for nominal items that are easiest to measure and lowest in cost. (Hage, 1971).
>
> (Van de Ven & Delbecq, 1972, p. 341)

I chose the second decision rule and sorted items generated from the nominal group technique into piles related to each other. I then developed tentative categories which I re-defined and modified until all the data items were classified. In order to reduce classification bias, I submitted a tentative categorisation of the data to three members of the group.

I also listened to the taped "discussion" sections (Appendix O, p. 737) to gain further insight into any differences/similarities in priorities between the professionals and the family carers and the underlying logic used by the group to include or exclude items.

Documents

I read the documents and noted down points of interest. I used the method recommended by Faulkner et al. (1993), recording notes about what the document said in the left-hand column and my responses in the right-hand column (Appendix P, p. 767). This allowed me to distinguish between the content of the documents and my interpretations and comments about them. It also helped me analyse the documents critically and relate them to my study. As my purpose in analysing the minutes of the FNA meetings was to provide information about events which took place before my study began and to supplement information obtained by interviewing the family carers, I decided to use an open-ended note-taking method to analyse the documents. This method provides qualitative data in contrast to the categorisation of documents which produces quantitative data (see Table 31, p. 173 for advantages and limitations of both methods).

Table 31. Advantages and limitations of the open-ended note-taking and categorisation methods

	Open-ended note taking	Categorisation
Advantages	Provides a general impression of the content, style, approach, etc. of the document. Allows the researcher to take account of anything of interest to the study. Useful if the researcher does not know what specific features to look out for or does not want to use specific categories of information. Notes provide summary of document.	Allows the researcher to look out for specific features of the document that are relevant to the research questions. Provides numerical information about a document. Allows numerical comparison between different documents. Some category systems can be applied reliably so that two researchers will produce a similar analysis of the same document.
Limitations	Note-taking is selective, two researchers with the same research question may note down different things about a document. Note-taking subject to bias.	The researcher may miss anything of interest which does not form part of the category system. Assigning information to categories abstracts the information from its context

SUMMARY

In this chapter I have provided a detailed account of my research design, so that the reader can see how I have arrived at my findings. By making the research process transparent, I hope I have provided a basis for judging the credibility of my findings, thus increasing the trustworthiness of my study,

In the next four chapters I present the outcomes of my study. Chapter four looks at the nature of local service provision and the theoretical underpinnings of national and local policies and services. It also explores implicit and explicit theories and assumptions about disability and impairment held by the family carers and professionals. Chapter five tells the young people's stories. Chapter six looks at the difficulties encountered by the young people, their family carers and professionals involved with this group, during the transition stage and suggests how these problems might be overcome. Finally, Chapter seven looks at the young people's current post-school provision, suggests criteria for good quality post-school provision and examines the family carers' hopes and aspirations for their young people.

Chapter 4 The dream?

This chapter consists of two parts. The first part looks at national and local documents related to people with learning disabilities, with a particular focus on people with profound physical and intellectual disabilities at the transition stage from school to post-school provision. It uses what MacLure (2003) describes as an "impure" approach to discourse analysis in an attempt to open up policies to further questioning. In order to do this, Gale (1999) argues that researchers must firstly consider the relationship between policies and their contexts. As Codd (1988) states "the task of deconstruction begins with a recognition of context" (p. 244). Therefore the first section of this chapter looks at the historical development of policies and services for people with learning disabilities in an attempt to illustrate how material and social circumstances influence policy making. The following section examines national policies on three levels. Firstly, it focuses on what Gale (1999) describes as the "what" of policy – the text, and the "why" of policy – the ideology and theoretical underpinnings. Then it examines the "how" of policy – discourse. Finally, the third section looks at the policies of one local authority.

The second part of this chapter begins by looking at the nature of local service provision. It concludes by considering the underlying assumptions of both professionals and family carers about the nature of impairment and disability.

THE HISTORICAL DEVELOPMENT OF POLICIES AND SERVICES

Possessive individualism and collectivism

Dalley (1988) argues that social welfare policies in the United Kingdom have been characterised by a pull between two different ideologies – possessive individualism and collectivism. She (Dalley, 1996) provides evidence to show that the United Kingdom has a long tradition of collective forms of support (e.g. Poor Law provision before the New Poor Law of 1834 and more recently, the development of the welfare state). Similarly, MacFarlane (1978) traces possessive individualism back to the Middle Ages in England. Indeed Dalley (1996) claims that its ideas influenced community care policies in the 1980s.

Lukes (1973) describes possessive individualism as offering:

> ...a private existence within a public world, an area within which the individual is or should be left alone by others and able to do and think whatever he chooses.
> (Lukes, 1973, citied in Dalley, 1996, p. 106)

Possessive individualism favours a model of the private, nuclear family and this, according to Dalley (1996), underpins many of the principles which inform current social policies. This model proposes that when care or support is needed, then the nuclear family should provide it. When immediate family is unable to do so, then the service provided should resemble the family model as closely as possible. Therefore this model's values and norms involve independence, privacy and living in small units with a limited number of carers (the surrogate family). Its emphasis is on individual competence and self-reliance.

In contrast, collectivism favours social responsibility, seeing it as society's duty to provide support for all citizens according to their need. Its principles are equity and egalitarianism – everyone should have equal access to support, regardless of race, gender, class, disability/ability. Its values are based on fellowship, sharing, altruism and co-operation. The collectivist view sees care for dependent people as broadening their opportunities and reducing dependence on privatised, family-based care. Such care should aim to encourage autonomy, be responsive to individual needs and choices, help the person to develop wide and varied personal relationships, provide economic security and encourage acceptance and responsibility for care amongst the wider community (Dalley, 1996). This view does not favour institutional settings, instead it proposes collective settings based on group concern, shared care and mutual support, involving both the dependent person and their carers. This approach values difference and diversity. Both these ideologies have influenced the formulation of policies and the development of services for people with learning disabilities in this country.

Prior to the nineteenth century, services for people with learning disabilities were scarce, most lived with their families. However, with the coming of the Industrial Revolution, segregated provision began to be developed. The 1886 Idiots Act required authorities to establish asylums for the care, education and training of people with learning disabilities. Early institutions were small and based on an educational model. Their aim was to educate people with learning disabilities so that they could return to society, however, this view began to change. Gradually people with learning disabilities were perceived as being unable to cope with the demands of the newly industrialised society. Therefore they were viewed as needing care in protective, safe environments. By the early twentieth century, socio-economic factors and eugenic ideologies resulted in this group being perceived as an increasing burden and a possible danger to society. This led to institutions becoming larger, repressive and custodial (Tyne, 1996). Moreover, the group were now viewed as "ineducable"; therefore educational and training services were not required. The focus of legislation, as exemplified by the 1913 Mental Deficiency Act, became the protection of society from this perceived threat.

McIntosh (2002) maintains that the 1913 Mental Deficiency Act also established the role of physicians in the field of learning disability and classified and regulated both institutional care and the condition of mental subnormality, resulting in depersonalisation. He likens this medical and custodial method of segregation to Foucault's (1991c) argument that there is a dual role to societal regulation:

> Two ways of exercising power over men, of controlling their relations, of separating out their dangerous mixtures.
> (Foucault, 1991c, p. 198)

Firstly, "dangerous mixtures" are separated out through purification – people labelled as "idiot", "imbecile" and "morally defective" are admitted to institutional care. Secondly, they are controlled through surveillance – people are observed, supervised and their movements are recorded. This pattern of service provision did not change significantly until the middle of the twentieth century. However, the work of Michael Kennedy (1990), a self-advocacy co-ordinator, who has lived much of his life in institutional care, suggests that Foucault's "controlling relations" is still applicable to-day:

> For a person living in a home regulated by some bureaucratic agency, quality assurance is reliant on the people in the agency. Unfortunately, the people who oversee those homes tend to perceive quality assurance in terms of laws and regulations, and they tend to see people with disabilities as objects rather than as people. Laws and regulations are very necessary and serve a purpose; however, the manner in which those laws and regulations are written and put into use is sometimes dehumanising. For instance, when one lives under the state, regulations such as keeping records of toileting and food consumption are applied to everyone. While some people may require this, others do not, and for some it infringes on their privacy and rights.
> (Kennedy, 1990, cited in McIntosh, 2002, p. 69)

The work of Foucault is referred to later when considering normalisation.

The Depression of the 1930s and the abhorrence felt at Hitler's atrocities towards minorities led to a determination that the rights of minority groups should be protected (United Nations Declaration of Human Rights, 1950; European Convention on Human Rights, 1950; Declaration on the Rights of Mentally Retarded Persons, 1971). However, although the rights of people with learning disabilities were recognised in the United Kingdom, services mainly remained within an individualistic medical model framework. This model, based on personal tragedy theory (see Chapter 2), views people with disabilities as requiring some form of intervention or help, such as medical treatment, professional help, custodial or day care, charity and state benefits. Clare and Cox (2003) argue that this model is based on implicit judgements about people's economic and moral value to society. If people are seen as valuable, they are worth treating; if they are regarded as a threat or of no value to society, they are segregated. They see the model as being rooted in patriarchal power structures and based on the assumption that experts know best. The latter is reinforced by the objectivity of scientific discourse which views the person as a "subject" to be studied rather than an individual who actively constructs his/her own reality and meaning. They contend that these assumptions help to maintain the roles of professional expert and compliant, accepting "patient", thereby preventing professional dominance from being challenged. It also results in failure to consider the emotional and relational needs and subjective experiences of people with learning disabilities. Thus services based on the individualistic medical model do not take into account the views of people with learning disabilities, neither do they work collaboratively with them.

In the 1960s civil rights movements; new theories in sociology, such as labelling theory (Goffman, 1961) and deviancy theory (Becker, 1964; Cohen, 1971; Lemert, 1967); government reports, (see the Howe Report of 1969), which highlighted the neglect and abuse in long-stay institutions; acceptance of the ideas of normalisation (Wolfensberger, 1972) (discussed later) and the belief that all people are capable of learning (see the Education Acts of the 1970s), gradually resulted in a movement away from institutions towards community care (Walker, 1982). In 1971 the government published "Better Services for the Mentally Handicapped" (DoH, 1971) which set out clear targets for the development of residential and day services in the community. However, Bayley (1973) contends that in the 1970s, providing "community care" largely involved the setting up of state controlled segregated services, such as hostels and day centres, as alternatives to long-stay institutions or hospitals. Moreover, although the early seventies did witness a rapid expansion in local authority services, this expansion was delayed by economic constraints which resulted in local services having to review their priorities. During this period Whitehead (1996) claims that departments and agencies became "obsessed with systems approaches to service development" (p. 55). They focused on large-scale reorganisations rather than the effect of their services on the lives and wishes of people with disabilities. Dalley (1989) describes this approach to community care as the managerial-planning model:

> The managerial-planning model is more concerned with the process of implementing community care policies than defining underlying philosophy and principles ... The model is one of logistics and operational strategies... and accomplishing this under conditions of resource scarcity.
> (Dalley, 1989, p. 201)

In 1979, the Jay Committee Report proposed a new model of care based on the following principles:

> 1. Mentally handicapped people have a right to enjoy the normal patterns of life within the community.
> 2. Mentally handicapped people have a right to be treated as individuals.
> 3. Mentally handicapped people will require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individuals.
>
> (University of Central England, 2004)

Around the same time a new way of looking at disability was emerging. The social model of disability (see Chapter 2) challenged the individualistic medical model, asserting that the problems faced by people with disabilities emanated from society and social organisations, rather than from within individuals. It took account of the social context in which people with disabilities lived and supported human values and rights, viewing people with disabilities as oppressed by social organisations and structures. This view of disability as being socially constructed, allowed for change through collective action (Oliver, 1990) and therefore had implications for service planning and provision.

At this time too, the "Ordinary Life" movement was developing in the United Kingdom (King's Fund, 1980; Poterfield & Gathercole, 1985; Towell, 1988). This movement recognised the rights of people with disabilities to live "ordinary" lives. It claimed that people with learning disabilities could, and should, live their lives in the community like everyone else – in ordinary houses, in ordinary jobs with ordinary friends, neighbours, social and leisure opportunities. According to this movement, services should meet the needs of people with learning disabilities, rather than be service-led. These ideas are consistent with what Dalley (1989) describes as the client-focused model of community care. This model is concerned with the principles, quality and standards of service which people with learning disabilities receive. Around this time too, the concept of normalisation was also beginning to influence the field of learning disability in the United Kingdom and by the 1990s most services for people with learning disabilities in this country claimed that their underlying philosophy was based on the tenets of normalisation or social role valorisation (SRV) (University of Central England, 2004). Normalisation emphasises the social stigma experienced by people with disabilities and is not as concerned with the economic structuring of oppression which underpins the social model of disability. However, both are concerned with removing social barriers to inclusion. Normalisation is discussed in the next section.

Normalisation

The development of normalisation

The concept of normalisation was developed in Scandinavia and reflected the liberal trends of Western countries to recognize the rights of disadvantaged and minority groups. In Denmark the Mental Retardation Act of 1959 stated that the aim of services should be:

> ...to create an existence for the mentally retarded as close to normal living conditions as possible.
> (Bank-Mikkelsen, 1980, p. 56)

This implied the acceptance of people with learning disabilities, with their disability, within "normal" society. Moreover, it offered this group the same rights, responsibilities and opportunities as other members of society – including treatment, education and training for optimal development, as well as opportunities to exercise personal preferences and freedom of choice. In the 1960s the normalisation principle influenced both the development of services and legislation for people with learning disabilities in Scandinavia (Bank-Mikkelsen, 1980; Nirje, 1969) and was redefined as:

> ...making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society.
> (Nirje, 1980, p. 33)

Both Bank-Mikkelsen and Nirje's definitions emphasise the basic rights of people with learning disabilities to enjoy the same quality of life as non-disabled members of society. However, such equality did not necessary require integration:

> ...while normalization is the objective, integration and segregation are simply working methods.
> (Bank-Mikkelsen, 1980, p. 56)

In other words, equality could be achieved in an environment that was equal but separate.

A decade later in North America, Wolfensberger, in an attempt to "North Americanize, sociologize, and universalize the Scandinavian formulations" (Wolfensberger, 1980a, p. 7) defined normalisation as:

> ...utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible.
> (Wolfensberger, 1972, p. 28)

According to Walmsley (2001), although both the Scandinavian model and Wolfensberger's model draw upon human rights and deviancy theories, the former emphasises human rights, whereas Wolfensberger's model derives more from deviancy theory. Wolfensberger viewed deviance as the outcome of societal reaction or labelling by official bodies of control.

In 1983 misunderstandings and misapplications of the principles of normalisation, led Wolfensberger to replace the term normalisation with the concept of social role valorisation (SRV). This term reformulated the aims of normalisation in terms of socially valued roles rather than culturally normative practices:

> ...people could be cast into specific social roles and could provide a challenge to a defensive response to the presence of individual pathologies.
> (McIntosh, 2002, p. 68)

Initially, Wolfensberger described SRV as incorporating:

> ...the most explicit and highest goal of normalization... the creation, support, and defence of valued social roles for people who are at risk of devaluation.
> (Wolfensberger, 1983a, p. 234)

More recently he defined SRV as:

> The application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people.
> (Wolfensberger, 1995a, cited in Osburn, 1998, p. 7)

This emphasis on SRV was designed to prevent people with disabilities from being cast in damaging social roles by enabling them to establish positive or culturally valued social roles in all areas of life (Brown & Smith, 1996). SRV makes the assumption that if a person holds valued social roles in society, other desirable things will be accorded to that person, at least within the resources and norms of his/her society. In addition, if that person holds valued social roles, attributes of theirs that might otherwise been viewed as negative, are more likely to be overlooked or dismissed as relatively unimportant (Osburn, 1998). There are two ways of achieving this goal. Firstly, by enhancing people with disabilities' social image in the eyes of others and secondly, by enhancing their competencies. Osburn (1998) argues that this needs to take place at the four levels of social organisation – the individual; the individual's primary social systems, such as the family; the intermediate level, such as neighbourhood, community and the services the person receives; and the larger society, including the entire service system (Thomas, 1999).

Wolfensberger also developed normalisation training and a series of evaluation tools – Program Analysis of Service Systems (PASS) (Wolfensberger & Glenn, 1975) and Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING) (Wolfensberger & Thomas, 1983) to assess the extent to which services were implementing the principle of normalisation. Lindley and Wainwright (1996) argue that although most services for people with learning disabilities claim that their service development is based on the principles of normalisation/SRV, there is some doubt as to whether these services really have incorporated normalisation/SRV, or simply incorporated it into their rhetoric. This is endorsed by Wolfensberger who states:

> Contrary to common claims, few human services have really embraced social role valorization, or are likely to do so. If the rhetoric about it is an ocean, then its committed implementation is a drizzle, and even that often turns into a frizzle.
> (Wolfensberger, 1989, p. 184)

Indeed Deeley's (2002) study into the beliefs and views of various professionals working with people with learning disabilities in Scotland, found unresolved issues surrounding the interpretation and application of normalisation philosophy. This in turn affected their working practice, as well as those with whom they worked. She concludes that "theoretical ideas have developed faster than the attitudes of professionals" (p. 22). Even in cases where normalisation/SRV has been accepted, Lindley and Wainwright (1996) contend that acceptance of the term may also be due to:

> ...a coincidence of political and social agendas between those who wished to legitimise the closure of large institutions (now widely acknowledged to be a cost-saving exercise venture) and those who were genuinely committed to developing better lives for people with disabilities.
> (Lindley & Wainwright, 1996, p. 27)

In a similar vein, Szivos (1996) argues that the principles of normalisation/SRV have sometimes been used to push through policies which have hidden agendas and insufficient funding; to give credence to bad practices and to justify a non-interventionist approach (McGill & Emerson, 1996; Tyne, 1996).

The principles of normalisation have been criticised and defended by various writers. This ongoing debate is outlined below.

Debates surrounding normalisation

Barnes, Mercer and Shakespeare (1999) argue that normalisation:

> ...does not challenge the legitimacy of the professional role in the lives of disabled people, but guarantees its continued authority... Moreover, Wolfensberger's technological determinist approach contains little explanation of the historical relationship between industrial capitalism, the state, professions and disability.
> (Barnes et al., 1999, p. 74)

Thus they maintain that normalisation fails to address the interaction between corporeal and cultural factors that "precipitate, undermine and maintain professional policies towards disabled people" (McIntosh, 2002, p. 70). McIntosh also contends that power relationships between able bodied people and people with disabilities are maintained through political and economic factors, as well as through the individualistic medical model of disability. He cites as examples the process of applying for Disability Living Allowance and employment opportunities for people with disabilities, both of which he argues, create a sense of "self-disablement" and force people to adopt a disabled identity. Similarly, Riddell and Banks (2001) describe how the Disability Discrimination Act of 1995, with its emphasis on "normal functioning" and the individual, rather than on their physical or socio-cultural environment, can be described as an individualistic medical model approach. They point out that the state has an interest in defining what counts as "disability", so that access to benefits are restricted to a limited section of the population. Usually access to these benefits is obtained by demonstrating deficiency in normal daily functioning through a medical examination and the classification of impairment. These examples illustrate that although professionals and agencies espouse a philosophy of holism, issues about service delivery and state benefits still centre around medical versus developmental versus functional models. This offers few solutions to social factors contributing to individual needs.

Drawing on Foucault's (1991c) work, "The examination", McIntosh (2002) claims that Wolfensberger's normalisation principle results in the lives of people with learning disabilities being played out publicly, whereas "we the seeing cannot be seen, our lives played out in the shadow of privacy" (p. 74). He argues that normalisation requires people with learning disabilities to undergo assessment of their strengths, capabilities and weaknesses. The results are then recorded and discussed in "open" forums, plans are then drawn up and the process is monitored and evaluated. He claims that assessments, such as care plans, nursing and community assessments and medical consultations lead to the objectification of people with learning disabilities. In addition, they increase professional control and domination. He contends that:

> As much as the NHS and community care reforms were about consumerism and user participation, they were also about accountability, responsibility and leadership. The professions of nursing, social work, medicine, psychology and all others related are entangled within this construct. Consciously or not, these disciplines are contributors to the diagnosis, classification and politicisation of the human condition of learning disabilities. From whichever disciplinary perspective, the individual is codified into a set of signs, which may have recourse to inter-disciplinary conflict with regard to control and domination.
> (McIntosh, 2002, p. 74)

He concludes by suggesting that this medico-social surveillance both enables and disables people with learning disabilities. They are encouraged to develop personal competence and access culturally normative activities but the examination of personal competence and the relationship between medicine and the welfare system leads to "self-disablement".

However, there is no doubt that both Scandinavian definitions of normalisation and particularly Wolfensberger's formulation of the principle of normalisation and SRV, have influenced service provision and the attitudes of service providers in the United Kingdom (Centre on Environment for the Handicapped, 1972; O'Brien & Tyne, 1981). Moreover, most writers acknowledge that normalisation has improved services for people with disabilities and placed the issue of "disabling" services on service providers' agendas. Even to-day these concepts play an important part in the ongoing debates surrounding the most effective ways of developing and providing services for people with disabilities:

> (Normalisation) was closely associated with deinstitutionalisation, the introduction of community care, small residential units (group homes) in ordinary streets, the use of integrated rather than segregated facilities – schools, health services, leisure facilities – the move away from contract

> work in day centres to more leisure orientated social education centres, and "social integration" (Kings Fund, 1980). One of the most significant implications of normalisation was the emphasis on association with "valued" others, people without disabilities.
> (Walmsley, 2001, p. 191)

Nevertheless, Wolfensberger's theorising has been criticised for being conservative – supporting the current status quo of individualism; for being morally authoritarian – the responsibility for change is in the hands of others, not in the hands of people with learning disabilities; for neglecting issues of gender, class and ethnicity (Brown & Smith 1996; Ferns, 1996) and for its emphasis on conformity rather than diversity and difference (Dalley, 1996; Szivos, 1996). However, some of these arguments have been refuted by Wolfensberger (1995). As mentioned previously, he contends that, with the exception of Scandinavian countries, services have not really embraced the principle of normalisation or SRV, as witnessed by evidence from his PASS and PASSING tools of evaluation. He further argues that his principle of normalisation and social valorisation theory emphasise:

> ...*both* capitalizing upon cultural values, *and* the need to change at least some of them; therefore, any *unnuanced* criticisms that normalization/SRV are allied to the status quo, or that they are subversive of it, are both faulty.
> (Wolfensberger, 1995, p. 366)

Osburn (1998), in a defence of SRV theory, develops this argument further. He asserts that:

> SRV is not a value system or ideology, nor does it prescribe or dictate value decisions. Decisions about whether to implement SRV measures... are ultimately determined by people's higher order (and not necessarily conscious) values which transcend SRV and come from other sources, such as their personal upbringing, family influences,

> political and economic ideas, worldviews, and explicit religions... SRV is descriptive rather than prescriptive.
>
> (Osburn, 1998, p. 4)

Other writers criticise normalisation-based services, challenge Wolfensberger's assumptions and argue that he has deviated from the original concept of normalisation.

Normalisation-based services have been criticised by Dalley (1988, 1996) for incorporating an essentially individualistic approach to care which is linked to possessive individualism. She maintains that this ideology is damaging to many people with disabilities and that collectivist values might offer a greater source of support for this group. She claims that family forms of care often result in isolation and ignore people's needs and desires for affiliation. This argument is developed further by Szivos:

> Dispersal within the community does not guarantee that people will learn to behave in a way which will overcome intolerance towards them. Instead people may feel increasingly stigmatized and cut off by social distance from non-disabled people while being physically separated from others who share their difficulties.
>
> (Szivos, 1996, p. 125)

In addition, Szivos also challenges some of Wolfensberger's assumptions. She argues that psychological processes, such as social comparison (Festinger, 1954) and affiliation (Coleman, 1983; Oliver, 1986) challenge Wolfensberger's assumptions about role modelling, social acceptance and physical and social integration. However, Osburn (1998) refutes this, arguing that SRV theory is based on well-established social science theory, research and empiricism from a variety of disciplines, such as sociology, psychology, education and pedagogy and draws upon multiple bodies of inquiry.

Perrin and Nirje (1989) also criticise Wolfensberger for deviating from the original concept of normalisation. They claim that Wolfensberger's version of normalisation is:

> ...built upon a fundamentally different value base and conception of people, with quite different implications for how we view and treat handicapped people.
>
> (Perrin & Nirje, 1989, p. 224)

They argue that Nirje's (1980) original concept of normalisation advocates that people with learning disabilities should be given the opportunity to live a life as similar in nature as possible to that of others with similar rights and responsibilities. This includes the same rights as non-disabled people to "engage in unpopular, non-conformist or even 'deviant' behaviours" (Perrin & Nirje, 1989, p. 224) – "the right to be different" (Dybwad, 1982, citied in Perrin & Nirje, 1989, p. 224). They contend that Wolfensberger's (1980a) principle of normalisation specifies various standards of behaviour to which a person with learning disabilities must conform. This can be achieved by "eliciting, shaping, and maintaining normative skills and habits" (Wolfensberger, 1980a, p. 17). Although Wolfensberger includes self-determination as one of his ratings in PASS, he states that sometimes the person with learning disabilities' choices may be in conflict with what is defined as normal, appropriate behaviour. In such instances the person with learning disabilities must conform to the values chosen by others. In contrast, Nirje's concept of normalisation encourages people with learning disabilities to express their own preferences and make their own choices by the creation of opportunities and the provision of training in decision-making processes.

Perrin and Nirje (1989) further contend that Wolfensberger's evaluation tool, PASS, is not suitable for measuring what they describe as the "reality of normalisation". They argue that Wolfensberger's concern to minimise deviancy results in an emphasis on appearance rather than reality. For example, Wolfensberger and Glenn (1975) argue that a person with learning disabilities should not wear a visible hearing aid (p. 31). This is contrary to self-help groups of people with disabilities, such as People First, who are now demanding equipment and services to enable them to participate in society in the same way as non-disabled people. This has led to some writers arguing that if normalisation is to survive it needs to incorporate the issue of empowerment into its thinking by:

> deriving good service practices from the experiences of user groups and learning from them how best to work in ways which do not disable them further... [It] has much to learn from people with disabilities, about what it would take to support them in living a life of their own choice.
> (Brown & Smith, 1996, p. 177)

This is what my study aimed to do by investigating the experiences of young people with profound physical and intellectual disabilities and their families during the transition period from school to post-school provision. This enabled me to identify the problems they faced and suggest solutions, based on joint discussion, involving both family carers and professionals (Chapter 6). My study also generated criteria for good quality post-school provision and services for this group (Chapter 7), from both family carers and professionals involved with the group.

However, Osgood (2003) argues that to truly empower people with learning disabilities, organisations have to change – they have to become person-orientated and listen to people with learning disabilities. He maintains that empowering working groups are not the answer but that "person-centred action and attitudes might be" (p. 2). The next section looks at person-centred planning.

Person-centred planning

The origins of person-centred planning

O'Brien and O'Brien (2000) define person-centred planning as:

> ...a systematic way to generate an actionable understanding of a person with a developmental disability as a contributing community member.
> (O'Brien & O'Brien, 2000, p. 2)

Person-centred planning developed in North America between 1973 and 1986. According to O'Brien and O'Brien (2000), several factors influenced its development – the struggle for human rights; the growth of community service systems; legal work aimed at social change for people with disabilities; disabled activists; parent advocacy groups; research practitioners, such as Bellamy, Horner and Inman (1979) and Gold (1972) and the adoption of a phenomenological approach and qualitative methods to understanding the lives of people with learning disabilities (Bogdan & Taylor, 1975; Taylor & Bogdan, 1977). Person-centred planning was developed by normalisation teachers, such as Mount (1984) and Brost and Johnston (1982). Early originators were concerned with how the principle of normalisation could be applied to improve the quality of services to people with learning disabilities. They found PASS helpful in identifying the relationship between disability, service policy and practice and community life. They also recognised that PASS could help them look at a programme from the point of view of the person experiencing it. The first approaches to person-centred planning shared common themes which reflected the originators' involvement in the principle of normalisation. They believed in viewing people with learning disabilities as people first, rather than in terms of their diagnostic labels. Their emphasis was on gifts and capabilities in the context of community life and focused on building relationships. They also stressed the importance of listening to the person with learning disabilities and those who know the person best in accounting for their history, evaluating their present situation in terms of valued experiences and defining desirable changes in their lives (Mount, 1992). Their aim was to increase choice and provide individualised supports based on high expectations from the person's development. To achieve this they suggested that agencies would need to adopt new forms of services and organisation. In addition to these themes, person-centred planning also chose to use ordinary language and images, rather than professional jargon, and frequently graphic facilitation was used to guide discussions and gather information (O'Brien, 1981; Sibbert, 1977). These ideas began to spread and influenced practice in the United Kingdom in the late 1970s (Sanderson, Kennedy & Ritchie, 1997) and more recently, person-centred planning has influenced national policies related to people with learning disabilities.

Although person-centred planning had its roots in normalisation, the practitioners, working to promote its principles and ways of working, divided into two groups in 1986 – those who affiliated themselves with Wolfensberger and continued to provide training in SRV and those who became involved in person-centred planning. These two groups emerged as a result of disagreements over the role of services in society and in people's lives; the significance of innovations, such as supported employment and supported living; the aims of methods and teaching and Wolfensberger's re-conceptualisation of the principle of normalisation as social role valorisation. In person-centred planning, people have rights and control over the services they receive and the lives they lead. It aims to enable the individual to play as central a role as possible in planning for their present and future.

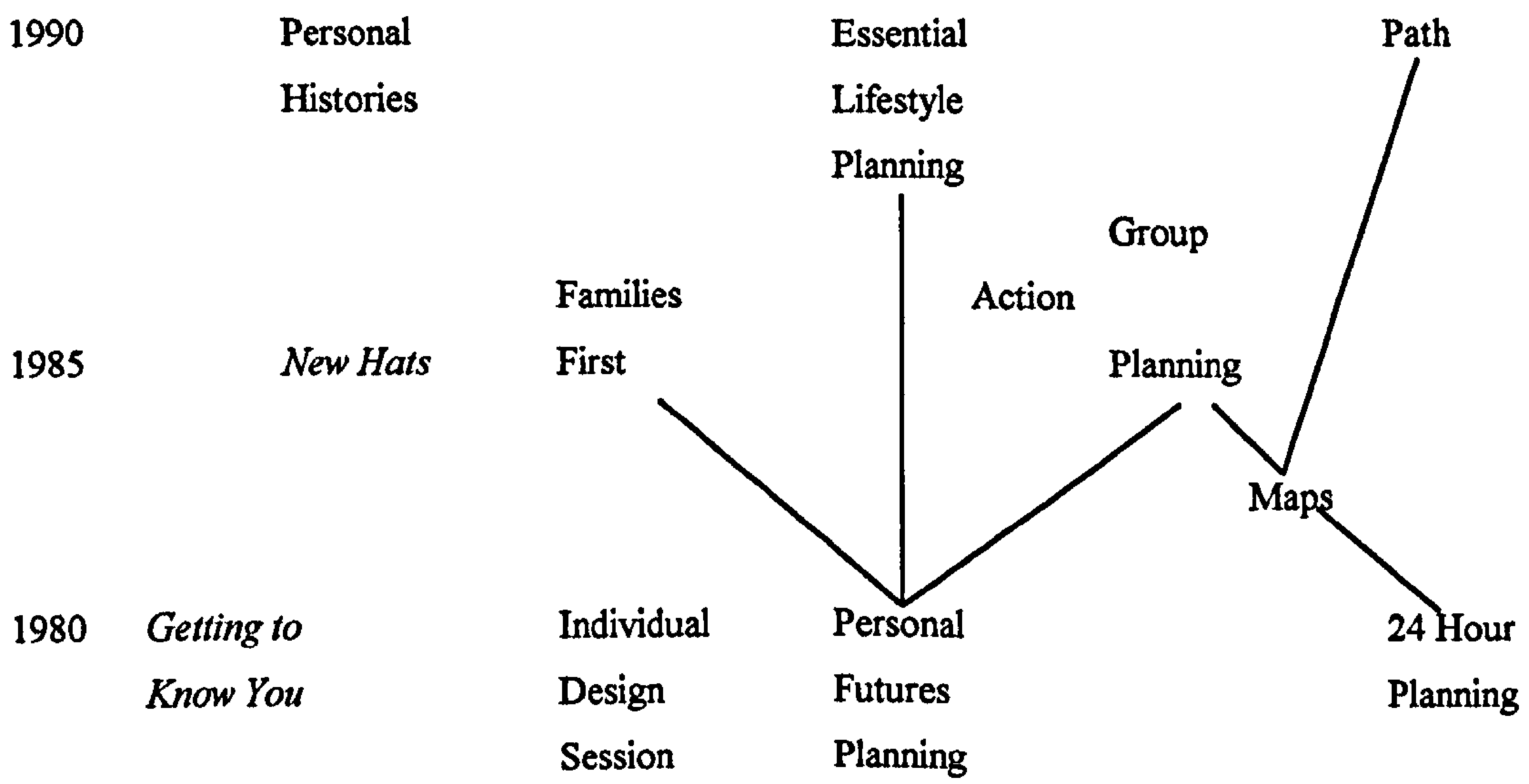


Figure 15. Early approaches to person-centred planning
(Source: O'Brien & O'Brien, 2000, p. 4)

Between 1979 and 1992, eleven approaches were developed (Figure 15) to aid understanding and to explain the relationship between disability, community and organised services. To-day some approaches, such as Essential Lifestyle Planning, are widely practised, whilst others, such as Getting to Know You, have nearly dropped from use. These different approaches to person-centred planning emerged because practitioners were concerned about different issues and worked in different settings. For example, Twenty-four Hour Planning grew from a concern for people whose chances for effective community services were reduced because of the complexity and severity of their disabilities (Green-McGowan & Kovaks, 1984). MAPS was developed to assist the inclusion of children with disabilities in mainstream schools (Forest & Lusthaus, 1989). Practitioners also drew on different theories and tools and this resulted in different approaches. For example, Individual Service Design stayed very close to its roots in PASSING training. Getting to Know You combined normalisation and a needs assessment process to specify services which responded holistically to an individual's needs (Brost & Hallgren-Ferris, 1981). Twenty-four Hour Planning adopted nominal group techniques to ensure equality of involvement and a balance of influence on the group's results.

Person-centred planning emerged because of a growing concern to support people with learning disabilities to discover their gifts and capacities in the context of community life, as well as a desire to use resources and services to help this group live better lives:

> Person-centred planning can invite, align, and direct shared efforts to create positive community roles for people with disabilities. It allows people to exercise their practical wisdom to work for more inclusive, more just communities.
> (O'Brien & Lovett, 1992, p. 20)

Putting person-centred planning into action

Person-centred planning is seen by policy-makers as a tool for guiding community development, for challenging the culture of services and agencies and as a means of promoting self-determination and social inclusion (Towell, 1997, 2000). Indeed, Valuing People (Department of Health, 2001) places person-centred planning centre stage in service delivery for people with learning disabilities and in Wales, "Fulfilling the Promises" (National Assembly for Wales, 2001a) views person-centred planning as an essential planning process. Similarly, the Scottish Executive has committed itself to person-centred ways of working through documents, such as the Education (Additional Support for Learning) (Scotland) Bill and the Same as You? Report. The latter calls for significant changes in policy and practice and sees person-centred planning as playing an important role in bringing about organisational change. However, O'Brien (1989) cautions that developing quality services for people with learning disabilities demands:

> ...active engagement in complex, emotionally charged, ambiguous situations. It calls for reallocation of service resources, working outside traditional boundaries, and renegotiation of the service's position in community life. This essential work calls for the motivation arising from a vision of inclusive community, the boundaries set by a clear and realistic sense of organizational purpose, and the focus offered by well defined service accomplishments. It requires effective leadership from service workers, people with disabilities, and their families and friends...
>
> (O'Brien, 1989, p. 25)

O'Brien and Towell (2003) argue that for person-centred planning to succeed, action needs to take place at four different levels – the personal, the service, the local authority level and the national level. At the personal level, the focus is on "increasing individual opportunity through person-centred planning and action (p. 10). This involves the development of creative solutions to long-term problems (Sanderson et al., 1997) with the individual and the people who love and support them. For this to happen a shift in the balance of power towards people with learning disabilities is required. Both generic and specialist services need to recognise that people with learning disabilities have the same rights as everyone else in society and that having control of one's life and services used, is as important to people as their need for practical help. Moreover, in order for social inclusion to be achieved, professional boundaries need to be crossed and broken down. This is also an important goal at the service level for both mainstream and specialist services. O'Brien and Towell contend that both services "need to negotiate their respective roles in ways which make it possible" for people with learning disabilities "to cross the boundaries between specialist and mainstream services" (p. 10). At this level, emphasis is on "building capacity for personalised supports" (p. 10). This requires services to be more flexible and to provide assistance which gives people with learning disabilities more control over their lives. People with learning disabilities and their families have an active role to play in what O'Brien and Towell describe as "operational leadership":

> …considering not just their personal circumstances but the capacity of specialist and mainstream services to effectively support and include bigger and bigger numbers of people whose interests and needs may differ from their own.
> (O'Brien & Towell, 2003, p. 10)

Recent research in Scotland (Gillis & Weston, 2004), supports O'Brien and Towell's study. Gillis and Weston found that both families and organisations have little knowledge of person-centred planning. Like O'Brien and Towell, they also found that there is still an unequal power relationship between service providers and people who use services, resulting in little joint working between professionals and parents. Their study also revealed a lack of cross-departmental and cross-agency support of person-centred planning. They argue that more research is required to identify what needs to happen to organisations so that they can work in a person-centred way. They suggest that some of these factors might be commitment, backed by action; designated funding and personnel; networks of multi-disciplinary working and buddying of professionals and non-professionals. In addition, their study also found a lack of support from senior management to colleagues who had attended person-centred planning training and wished to implement their training at work. They point out that there is often no "top-down" approach. They suggest that professionals should be given more support to take their training forward through the resourcing of person-centred support groups and local "banks" of independent facilitators. They also advocate that service managers, people who use the services and staff all need to train together in order to provide mutual support which will help them to implement their training. They stress that:

> Person centred planning has to happen in a person centred environment.
> (Gillis & Weston, 2004, p. 3)

> Person centred planning is not a solution in itself, without services that are organised and work in a person-centred way.
> (Ibid., p. 2)

These arguments are similar to those espoused by researchers in England (Mansell & Beadle-Brown, 2004) and in Wales (Felce, 2004) (see pp 200-201).

O'Brien and Towell argue that specialist services need to change the ways in which they work with generic services; whilst mainstream services need to ensure what they offer is available appropriately to more people with learning disabilities.

At O'Brien and Towell's local authority level, the focus is on implementing strategies for social inclusion. Once again, people with learning disabilities and their families play an active role in administrative and policy decision-making at this level. However, relocating power and control to people who use services presents major challenges to traditional service systems. As Holburn and Vietze (1999) note:

> ...for person-centred planning to survive in an agency, it needs support from the very system that it views as detrimental and seeks to change [and] the painless alternative is to proclaim person-centredness while adhering to the usual practices.
> (Holburn & Vietze, 1999, p. 118)

Gillis and Weston's (2004) study also suggests some ways of supporting person-centred working at the local authority level. They advocate the setting up of multi-disciplinary steering groups, which include people who use services, to develop policies and action plans to take person-centred planning forward in their area. They also recommend that local authorities provide financial and organisational support for local person-centred support groups and support national and international networking.

At O'Brien and Towell's (2003) national level, the focus is on "implementing inclusive national policies" (p. 10). Its aim is to encourage strong national leadership so that government investments join up to "promote social inclusion and build personal capacities" (p. 11), as well as enabling local authorities to implement inclusive local strategies. Once again people with learning disabilities and their families are seen as playing an active part in administrative and policy decision-making.

Each of these levels are inter-connected and performance at one level influences performance at other levels:

> Higher levels do create conditions for performance at lower levels, and performance will be strengthened to the extent that different levels align around investing in social inclusion and the creation of greater personal capacity. However, even while higher levels are learning, there is plenty of room for action closer to people with learning disabilities. No one has an excuse to opt out of taking some action...
> (O'Brien & Towell, 2003, p. 12)

However, O'Brien and O'Brien (undated) admit that whilst more and more people with learning disabilities are in communities, they do not as yet "belong" to communities. They argue that, at present, work to build communities is "small in scope, with many more people debating it than people working to learn how to do it" (O'Brien & O'Brien, undated, p. 1).

Moreover, Osgood (2003) expresses doubts about applying the principles of person-centred planning to large organisations. He argues that person-centred planning focuses on people, gifts and community. It is about people, not organisations:

> Person-centred planning is an idiographic qualitative approach. Large services are nomothetic quantitative beasts, lumbering heavily, dealing with conceptions of groups of people as homogenous classifications. PCP developed within "communities of practices", not formal institutionalised organisations such as the NHS or Social Services, and in a culture different from the United Kingdom. How do we generalise bespoke tailored provision in large services used only to providing off-the-peg solutions?
> (Osgood, 2003, p. 3)

He suggests that whilst it is easy for organisations to adopt the language of person-centred planning, it is much more difficult for them to put person-centred planning into action. This requires changes in values, relationships, finances, functions and structures. Moreover, research (Holburn & Vietze, 2002) suggests that small organisations, with fewer traditionally trained staff, are more likely to put person-centred planning into action than larger systems, with hierarchical chains of command. He claims that person-centred planning creates uncertainty and ambiguity for managers of large organisations. Seeing people with learning disabilities in terms of individuals, each with their own gifts, preferences and aspirations and not as a homogenous group with deficits requiring professional intervention, demands flexibility of resources and roles, becoming "user" orientated, surrendering power and professional interests and listening to people who use the services, their families and direct care staff (Iles, 2003). Large organisations have been used to certainty, control and uniformity. They have focused on financial security, budgets and protecting themselves from liability, quality of life for people with learning disabilities is secondary. Both Kinsella (2000) and Osgood (2003) fear that services will be tempted to adopt a single model to "roll out" across services, at the cheapest price:

> ...one size fits no-one. Hearing stories of success should not encourage us to repeat verbatim the formula. The formula may be for a totally different context and disease. Don't put pile cream on acne!
> (Osgood, 2003, p. 4)

They argue that this indicates a superficial understanding of person-centred planning and an obsession with being seen to be doing the right thing, rather than making changes in culture and attitudes. Osgood asserts that services should not adopt person-centred principles and mission statements if they cannot action person-centred planning; resources need to focus on action not language. This is echoed by Smull (1996):

> Person-centred planning should be done with everyone only where there is the willingness to make the investments and changes necessary... we should not make the promise unless we believe we can keep it.
> (Smull, 1996, cited in Osgood, 2003, p. 11)

Mansell and Beadle-Brown (2004) consider the effectiveness of person-centred planning and conclude that there is no good-quality, systematic evidence to justify it. They refer to Kinsella's (2000) study which found almost no evidence of the effectiveness of person-centred planning compared to other approaches, and to Rudkin and Rowe's (1999) review which found no statistical significant outcome differences for people receiving person-centred planning. They contend that evidence in support of person-centred planning comes mainly from individual case studies. They draw on literature from other forms of individual planning which show that individual planning only reaches a minority of people with learning disabilities (Felce, Grant, Todd, Ramcharan, Beyer, McGrath, Perry, Shearn, Kilsby & Lowe, 1998), is often a paper exercise (Social Service Inspectorate, 1989) and rarely relates to, or changes the lives of, people with learning disabilities and their families (Cummins, Jauernig, Baxter & Hudson, 1994; Cummins, Baxter, Hudson & Jauering, 1996; Stancliffe, Hayden & Lakin, 1999). They suggest that putting scarce resources into the implementation of person-centred planning might not be justified. Furthermore, they argue that often budgetary constraints undermine individualised planning and the motivation to take planning seriously, as well as preventing implementation of achievement goals.

However, Emerson and Stancliffe (2004) dispute this. They argue that Holburn and Vietze's (2002) study demonstrates the effectiveness of person-centred planning and that studies in the United Kingdom and the United States of America indicate the impact of person-centred planning in medium-to-large sized institutional environments (Rea, Martin & Wright, 2002), agencies (Coyle & Moloney, 1999) and whole states (Butkus, Rotholz, Lacey, Abery & Elkin, 2002). They also cite studies in which individualised planning has produced results which benefit people with learning disabilities (Lucyshyn, Dunlap & Albin, 2002; Jones, Felce, Lowe, Bowley, Pagler, Gallagher & Roper, 2001; Felce, Jones & Lowe, 2002). However, Felce (2004) supports Mansell and Beadle-Brown's (2004) arguments. He maintains that:

> Policy-makers, senior managers and leaders in our field are embarking on PCP not out of evidence that people receive better support and live enhanced lives as a result, but because they have convinced themselves, or been convinced by persuasive campaigners, that PCP is a logical and necessary approach to knowing people well enough so as to be able to make support arrangements that meet their individual requirements and take account of their preferences and lifestyles choices.
> (Felce, 2004, pp. 27-28)

Whilst acknowledging that person-centred action requires focusing on people with learning disabilities and their representatives in order to determine preferred lifestyles, for him, the question is not whether person-centred planning can improve people's lives but whether "policy has identified the conditions under which its widespread implementation would be possible without degradation of the process and its impact" (p. 28). He argues that wide-spread implementation of person-centred planning will be a long-term process which will require the restructuring of service policies and practices related to authorising, paying, contracting and financing supports and services – the system architecture. Mansell and Beadle-Brown (2004) and Emerson and Stancliffe (2004) both endorse this, but Mansell and Beadle-Brown also emphasise the importance of changing practice directly through work with front-line staff on achieving real change in the lives of people with learning disabilities (see Felce, 1988). These writers all imply that making services more person-centred will not be accomplished by the introduction of a new model of individual planning in the form of person-centred planning. They argue that attention also has to be paid to the way services are funded, to staff training and to power relationships:

> Positive change is likely to emerge from the interplay between dynamic processes in which person-centred planning... is intrinsic inter alia to the growing empowerment of people with disability, specialist service development, greater access to the opportunities and resources in mainstream provision, and to the development of staff with the attitudes and skills required to promote all three of the preceding objectives.
> (Towell & Sanderson, 2004)

This section has demonstrated the importance of considering the relationship between policies and their contexts. As Burton and Weiner (1990) state policies are "ideological and political artefacts which have been constructed within a particular historical and political context" (p. 205). Therefore failure to acknowledge that policies are influenced by material and social circumstances and to recognise that policy changes within and across contexts, misses the basic premise of policy as process (Gale, 1999).

The next section looks in detail at the theoretical underpinnings of recent national documents. Dworkin (1979) sees good theory as being essential to good practice:

> The purpose of theory is understanding. Understanding is energizing. It energizes to action. When theory becomes an impediment to action, it is time to discard the theory and return naked, that is without theory, to the world of reality.
> (Dworkin, 1979, citied in Brown & Smith, 1996, p. xii)

For Dworkin, theory influences the way in which we endeavour to bring about, and maintain, change in services. However, as shown above, theories do not appear from nowhere, they reflect personal attitudes and socio-political trends prevalent at the time. The next section also attempts to uncover the political character of official policies. After all, as Hume (2000) writes:

> This is an age of public relations experts, spin doctors whose function is to present "reality" in a particular way, an exercise that involves the skilful manipulation of language and media images, the leaking of information and mis-information, the promotion, destruction and rehabilitation of political and professional reputations.
> (Humes, 2000, p. 46)

NATIONAL DOCUMENTS

Having considered the relationship between policies and their contexts, the second part of this chapter looks at what Gale (1999) describes as the "what" of policy (the text), the "why" of policy (the ideology) and the "how" of policy (the discourse). The "what" and "why" of policy are considered in the next section.

The "what" and "why" of policy

The Scottish Executive has produced a number of documents relating to people with learning disabilities in the last five years. They have been produced within a policy framework committed to ensuring equality, fairness and opportunity for all through social inclusion. From one perspective, these documents can be regarded as a necessary step aimed at challenging conservative ideas and the self-interests of professionals, as well as empowering people with learning disabilities. From another perspective, there is a danger that practitioners will be so caught up in implementing the recommendations of these documents, ensuring systems, structures and processes are in place that they will have little time and energy to reflect on aims and principles or:

> ...challenge policy-makers to live up to their ideals contained in policy documents – by, for example, providing adequate resources to ensure effective implementation.
> (Humes, 2000, p. 38)

Time will tell.

Unsurprisingly, the Scottish Executive's principle of inclusion is found in a range of policy documents relating to people with learning disabilities, such as "The same as you? A review of services for people with learning disabilities" (Scottish Executive, 2000). Indeed some policy documents contain the theme in their titles – the Beattie Committee Report (Scottish Executive, 1999) is entitled "Implementing Inclusiveness: Realising Potential" and the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities is entitled "Promoting Health, Supporting Inclusion" (Scottish Executive, 2002). Four national documents are analysed in the following sections – the Beattie Committee Report (1999), the SAY Report (2000), "Promoting Health, Supporting Inclusion" (2003) and the Health Needs Assessment Report (2004).

Implementing Inclusiveness: Realising Potential, The Beattie Committee Report

In 1998 The Advisory Committee on Post-school Education and Training of Young People with Special Needs was set up to look at the range of needs among young people who need additional support to take part in post-school education and training or employment. This group became known as the Beattie Committee, named after its chair, Robert Beattie. The Committee made several recommendations concerned with improving transitions, provision and employability. The central recommendations include:

- The appointment of a keyworker for each young person to see them through the transitional period
- The establishment of Area Support groups to oversee the activity of keyworkers and to co-ordinate the work of different agencies

- An emphasis on employment and employability
- More coherent and consistent approaches to assessment

  (Riddell & Banks, 2001, p. 19)

The report (Scottish Executive, 1999) states that:

> The single, unifying principle at the core of all the Beattie Committee's proposals and recommendations is Inclusiveness. It is central to our vision that all young people on leaving school – whatever their circumstances – should have access to adequate and appropriate learning provision within a learning environment matching their needs, abilities and aspirations. The principle of Inclusiveness is essential for an effective transition from school to further education or training and for later transitions. It should encompass personal development as well as formal skills and qualifications. Inclusiveness should also underpin the policies and practices of the agencies and institutions which offer guidance, education and training. The Committee believes that Inclusiveness is essential to help young people reach their full potential.
> (Scottish Executive, 1999, para. 2.1)

The Committee admits that it was drawn to the principle of inclusiveness by the Tomlinson Report (1997) in England entitled "Inclusive Learning" and by a desire not to perpetuate a "deficit" model. Their definition of inclusiveness above demonstrates an adherence, at least in part, to the concept of normalisation. It acknowledges the human rights of people with learning disabilities to have access to a range of post-school provision and attempts to move away from an individualistic medical model of disability by focusing on needs, abilities and aspirations. However, it is more akin to the Scandinavian model of normalisation as it accepts that in some instances a separate learning environment may be necessary in order to provide the best and most appropriate provision to meet the young person's needs (para. 2.3, 2.13 & 2.14). This emphasis on provision being tailored around the needs, abilities and aspirations of the individual rather than the convenience of the service provider, reflects Dalley's (1989) client-focused model (see p. 181). It also mirrors the values underlying person-centred planning by advocating that the individual should be at the centre of policies and practices (para. 2.7, 4.4 & 12.1); by acknowledging the diversity of people's needs and abilities (para. 2.9); and by recognising that an inclusive approach requires a continuum of learning opportunities, flexible provision (para. 2.15) and clear routes for progression (para. 2.16).

The report also places an emphasis on identifying, adapting and dismantling barriers to learning (para. 4.6) and on valuing people with learning disabilities as whole persons, in terms of their abilities and potential, not just their problems and difficulties (para. 2.10 & 2.11). This adheres to both the principle of normalisation and to the social model of disability. Wolfensberger's SRV model stresses the importance of valued social roles for people at risk of social devaluation by enhancing their social image and their social competencies (Osburn, 1998). The Beattie Committee sees employment as increasing young people's self-esteem, providing opportunities for personal growth and giving young people disposable income (para. 9.8). This implies that it is through employment that people with learning disabilities will achieve socially valued roles and social inclusion:

> Young people not in any form of education, training or employment are at risk of social exclusion. This has effects on society as well as the individual.
> (Scottish Executive, para. 3.19)

I would argue that the latter sentence suggests a hidden agenda. The social and economic costs of life-long dependency are costly to the state and labour intensive in relation to care. Therefore, it is in the interests of society to reduce the cost. One way of doing this is to encourage people with disabilities to gain employment and lead an independent life:

> The purpose of the Area Strategy Group should be to ensure that all young people receive the support that they require to meet their identified learning and support needs; and to make the transition from school to post-school provision, and into employment.
> (Scottish Executive, para. 4.16)

This emphasis on employment as the main factor in ensuring social inclusion is driven by market forces. Social and health factors, well-being, choice, social prejudice and inaccessible environments are rarely considered (Kitchin, 1998; O'Brien, 1990). Employment is seen as the panacea for social inclusion.

However, it must be remembered that the Committee's remit was to make recommendations "geared towards helping young people to improve their skills and capabilities to obtain and sustain employment" (para. 9.1). Despite this, the report also recognises that for some young people post-school learning is not about gaining employment but rather "improving the quality of life experience" and "satisfying . . continuing learning needs" (para. 9.2). Nevertheless, it only devotes one chapter to the consideration of continuing learning opportunities for people in resource centres and those who have "profound and complex needs" (para. 9.8). Furthermore, it states that:

> The wider range of social support and health care offered by Resource Centres falls outwith the Committee's remit.
> (Scottish Executive, para. 9.8)

However, my study shows that it is often society's failure to meet these young people's healthcare needs that leads to them being excluded from continuing learning opportunities (see Chapters 5 & 7).

The Beattie Committee Report claims to be based on the principle of inclusiveness, which is related to the social capital perspective and the social model of disability. However, the report's focus on education for employment, with little discussion about education and training to promote quality of life, social networking and citizenship, suggests to me that it is more in line with the human capital perspective. Education and employment for this group are linked to economic factors. It is not difficult to argue that if the Scottish Executive was truly committed to equality for all, it would tackle the poverty experienced by people with disabilities who cannot work by encouraging the United Kingdom government to increase state benefits for this group. The report justifies its focus on employment by referring to data obtained in focus group discussions involving young people with learning disabilities. This data suggested that people with learning disabilities want to participate in society and that "for most "employment" is the key to realising this aim" (para. 3.4). However, there are difficulties surrounding consultation and genuine involvement of people with learning disabilities. Firstly, did the young people set the agenda? What was the motive for the consultation? Often the agenda is set by non-disabled people who make assumptions about people's best interests. Clare and Cox (2003) maintain that genuine attempts to consult people with learning disabilities necessitates a shift in the balance of power between professionals and those who use their services:

> This requires a commitment to a set of values and ethical principles that acknowledges the rights of all individuals to be treated with respect, to have their views heard and acknowledged, and have their needs and wants met.
> (Clare & Cox, 2003, p. 943)

Secondly, there is a danger that people with learning disabilities will express a desire to be employed because professionals see it as an appropriate goal for them (Riddell et al., 1997). Thirdly, was the group representative? It is fairly common practice to discount or ignore the views of people with cognitive impairments and/or communication difficulties. The views of the former group tend to be regarded as invalid or unreliable, whilst the latter group's views are often ignored as they are deemed to be unable to express their views. The problem is located firmly with the individual and not regarded in terms of society's inability to overcome the obstacles to effective communication. Yet it is this group of people who use services extensively. If policies and services adopt the principle of inclusiveness then they need to include all groups. They must ensure that the voice of people with profound physical and intellectual disabilities is heard and acknowledged. Furthermore, although some of the Beattie Committee's recommendations will benefit people with profound physical and intellectual disabilities, its focus on employment and its failure to consider social support and healthcare marginalises this group. They are once again "the forgotten people". I feel that an individualistic medical model still tends to be used when it comes to the provision of services for this group. Whilst there are many situations in which healthcare and medical knowledge are essential for this group, an individualistic medical model does not provide the best foundation for promoting inclusion.

However, as commented upon earlier, the report does make an attempt to move away from what it calls a "deficit" model towards the social model of disability. It stresses the importance of involving young people and their families in decision-making and assessment processes (para. 7.29) at individual, service and strategic levels. As well as encouraging empowerment, the report also contains other elements of social model thinking. It seeks to offer choice to people with disabilities and provide provision based on their needs and wishes rather than on professional judgements and imperatives:

> It (assessment) must be focused on the young person and not designed to accommodate the organisational structures or administrative practices of an institution or agency.
> (Scottish Executive, Appendix 1, p. 94)

> An Inclusiveness approach requires that this should not mean simply allocating the young person to the "best fit" which is available. In some cases suitable provision may already be in place. In other cases, it will mean drawing together strands of provision and other support into a "package" of provision. This is the challenge of Inclusiveness.
> (Scottish Executive, para. 7.38)

The above shows a desire to move away from what Dalley (1989) describes as managerial-planning and professional practice models towards a more client-focused model.

With reference to new packages of provision, the Beattie Committee recommends that Area Strategy Groups should develop and co-ordinate enhanced learning opportunities for young people attending resource centres and those with "profound and complex needs" (para. 9.15). In addition, it suggests that the Scottish Further Education Funding Council (SFEFC) should offer learning opportunities in colleges to meet the needs of young people with a "high level of learning and support needs" (para. 9.10) This is in line with the Beattie Committee's desire to see inclusiveness as applying to all young people (para. 9.13). However, the report recognises that not all colleges will be able to provide this level of support as it will be costly. Instead the report recommends that colleges "collaborate to provide a better level and quality of support" (para. 10.11). This suggests to me that the policy-makers are only prepared to live up to the ideal of inclusiveness for all if it is not too costly. Furthermore, there is the danger that the proposal in paragraph 10.11 will result in one college being designated to provide provision for this group, thus limiting choice.

To conclude, although the principle of inclusiveness underpins the Beattie Committee Report and inclusiveness is seen as applying to all young people, I would argue that young people with profound physical and intellectual disabilities have been marginalised by the report's focus on employment, its failure to consider within its remit young people who require "social support and healthcare" (para. 9.8) and by sacrificing its ideal of inclusiveness for all if providing resources and services becomes too costly (para. 10.11). The latter supports Trent's (1995) and Simpson's arguments that:

> ...the fundamental determinant of the conditions in which concepts thrive or fail is the economy.
> (Simpson, 1999, p. 153)

The same as you? A review of services for people with learning disabilities

The same as you? Report (SAY) was Scotland's first major review of services for people with learning disabilities for decades. The main message of the report is that people with learning disabilities have the right to be supported to have the same opportunities as everyone else to live a full life, including employment and meaningful day activities, leisure activities, access to both generic and specialist healthcare services, opportunities to make choices and establish friendships and relationships. The report made twenty-nine specific recommendations designed to improve the lives of people with learning disabilities and their family carers. Some of these recommendations involve new initiatives, such as the closure of long-stay hospitals; the establishment of Partnership in Practice Agreements (PiPs); the setting up of the Scottish Consortium for Learning Disabilities (SCLD); the development of local databases, the establishment of direct payments; the introduction of local area co-ordinators and personal life plans. Others focus on particular groups of people with learning disabilities, such as those with autism, "profound and multiple learning disabilities" and challenging behaviour, whilst others look at issues concerning funding, information, therapy services, advocacy, employment and so on. An Implementation Group has been established by the Scottish Executive to take forward the report's recommendations. The focus for the first three years is on the closure of long-stay hospitals, employment and local co-ordination.

As with the Beattie Committee Report, social inclusion also lies at the heart of the SAY Report. It defines social inclusion as "helping people to feel and be part of the society in which they live" (Scottish Executive, 2000, p. 131). The ministerial foreword also emphasises the principles of social inclusion. Its emphasis is on people with learning disabilities leading normal lives, being included in the community and having more say and control over their lives. With the latter in mind, the SAY Report included people with learning disabilities and their family carers on its steering group, unlike the Beattie Committee who only consulted with this group. The SAY Report also included people with "profound and multiple disabilities" in its remit and recommended that local authorities should look at the extra needs of this group and those of their carers (p. 99, recommendation 29). It defines "profound disability" and "complex needs" as follows:

Profound disability needs	A term used to describe someone who has a very severe degree of learning disability which may be associated with complex needs. For example, this could include feeding difficulties, physical disabilities or sensory impairment.

(Scottish Executive, 2000, p. 130)

Complex needs	This describes the needs a person has over and above their learning disability. For example, extra physical or mental problems, challenging behaviour or offending behaviour.

(Scottish Executive, 2000, p. 128)

The use of these terms have already been criticised in Chapter 2. I have also argued throughout my thesis that the SAY Report has failed to set a framework for the delivery of practical services for people with profound physical and intellectual disabilities and their family carers.

The Say Report identifies seven principles which it sees as essential to helping people with learning disabilities "lead full and active lives" (p. 11, para. 27). These principles are akin to the concept of normalisation and the social model of disability. They stress the importance of people with learning disabilities being seen as individual people and valued members of their communities. As regards service provision, they envisage people with learning disabilities being able to access both generic and specialist services which are age-appropriate and take account of abilities and needs. This is in line with the client-focused model and indeed the report recognises that people with learning disabilities have a range of needs which constantly change (p. 4, para. 7-8). There are also several references, both in the ministerial foreword and the report itself, which emphasise the need to shift away from professional practice and managerial-policy models towards a more client-focused model:

> Professionals need to acknowledge their limits and the rights of others.
> (Scottish Executive, 2000, p. iv)

> The review offers an opportunity to change from thinking which is led by services to thinking which is led by people's needs.
> (Scottish Executive, 2000, p. 10, para.26)

However, the ministerial foreword also provides a note of caution which supports the managerial-policy model:

> We have to be realistic and recognise the many pressures there are for resources both nationally and locally.
> (Scottish Executive, 2000, p. v)

However, too much emphasis on this model could lead to a playing down and devaluing of individual needs. Whilst Emerson and Stancliffe (2004) admit that operating within an assigned budget is a requirement of publicly funded services, they argue that funding needs to be linked to individuals rather than services, a point re-iterated by the focus group in my study. Emerson and Stancliffe further maintain that if funding is linked to services, then the choices open to planning teams are limited to available services from existing service providers. They point to studies conducted in the USA in which authorities have significantly changed features of the system architecture to support person-centred action. These include a shift to individual need-based funding under the control of an individual planning team, which is budget neutral from the disability services budget as a whole (Fortune, Smith, Campbell, Clabby, Heinlein, Lynch & Allen, 2004) and a change in evaluating services on the basis of service performance standards concerned with processes, to one based on outcomes and the goals identified in each individual's person-centred plan (Butkus et al., 2002).

The SAY Report was accompanied by the change fund which was designed to help local authorities implement its recommendations (Scottish Executive, 2000, recommendation 4). Unfortunately, the report did not fully take into account major epidemiological change, which indicates significant improvement in the longevity of people with disabilities (Emerson, Hatton, Felce & Murphy, 2001). This has major financial implications for future services and provision. For example, focusing on the group involved in my study, the SAY Report suggests that the Scottish Consortium for Learning Disabilities should "set up a national network of support to local providers offering advice and training on the needs of people with profound and multiple learning disabilities" (recommendation 29) but it fails to recognise the increasing numbers of people within this group who will require costly packages of support, as well as new forms of support. Felce (2004) argues that strategic planning needs to take into account epidemiological changes to the population of people with learning disabilities, both in terms of numbers and nature of disability. I would suggest that these changes highlight the inadequacy of the change fund monies. Felce (2004) also contends that the failure of British national policies to quantify provision targets, apart from targets to close institutions (see Scottish Executive, 2000, recommendation 12) does little to "safeguard the interests of those who depend on service support" (Felce, 2004, p. 27). This is particularly relevant to the young people who are the focus of my study.

Although the report espouses the principles of normalisation, like the Beattie Committee Report, they are more in line with the Scandinavian model of normalisation. The SAY Report states that nursing homes or residential care are appropriate forms of care for some people, stressing that:

> Individual solutions, based on individual needs and choices, should always be the aim.
> (Scottish Executive, 2000, p. 51, para. 33)

Similarly, the report also sees special schools as being necessary "for a small number of children whose needs are too great for most ordinary schools to meet, such as those with profound and multiple disabilities" (p. 80, para. 22). Once again this group is being excluded and marginalised. This seems to me to be more in line with what Clare and Cox (2003) describe as the rehabilitation model, rather than on person-centred planning (Table 32).

Table 32. The rehabilitation and independent living views of disability

	Rehabilitation	Independent Living View
Terms for defining the problem	Impairment/skill deficiency	Dependence on professionals, relatives and others who take over control of your life.
Where is the problem located?	In the person	In the environment & the way services do their work
What's the solution?	Professional intervention	Removal of barriers, advocacy, consumer control, & self-advocacy
Who is the person?	Patient/client	Person/citizen
Who's in charge?	Professional	Citizen
What defines results?	Maximum possible individual functioning as judged by professionals	Living independently (being in control of your life regardless of how much assistance you need to do so)

Source: O'Brien & O'Brien, 2000, p. 7

They argue that the former model is often used in the development of services for "people with complex needs". The model aims to:

> ...help the individual experience optimal physical health, psychological well-being, living skills and social relationships, taking into account the impairments resulting from injury or illness, and should form a collaborative and individually-tailored process in which the person and

> his or her helpers work together towards agreed goals, with the person engaging in rehabilitation being a full and equal partner in this process. (Clare & Cox, 2003, p. 939)

The model provides not only a collaborative framework for looking at the development and provision of services for people with profound physical and intellectual disabilities, but also recognises the importance of social context. Nevertheless, it has been criticised for retaining a focus on individual difficulties, maintaining the power base of professionals and for neglecting the need for societal change (Clare & Cox, 2003). Although the importance of social factors are acknowledged, "the focus tends to be on enabling the person and the family to adapt and cope within the context of a disabling society" (Clare & Cox, 2003, p. 939).

The views expressed by the family carers in Chapters 6 and 7 of my study, suggest that whilst they value practical, rehabilitation-orientated attempts to help them in looking after their young people, they also recognise that action is required at political and social levels. For this to happen, people with profound physical and intellectual disabilities and their family carers need to be genuinely involved in the planning and delivery of services and this requires a shift in the balance of power and control, away from the professional provider towards the young people and their families. This the SAY Report endeavours to do by encouraging the use of person-centred planning, advocacy and direct payments.

As already discussed, some writers argue that the use of person-centred approaches have been justified on the basis of technocratic and ethical reasons, rather than on good quality, systematic evaluations (Mansell & Beadle-Brown, 2004; Trent, 1995). Moreover, Mansell and Beadle-Brown point out that adopting a person-centred planning approach for all people with learning disabilities is an enormous undertaking, not only because of the numbers of individuals involved, but because of the nature of people's disabilities. They argue that people with major communication difficulties, impaired social interaction and severe challenging behaviour, present considerable difficulties for staff when it comes to person-centred planning. For example, there is evidence that staff often misjudge this group's non-verbal communication (Bradshaw, 2001), limit their choices and decisions (Murphy & Clare, 1995), find it difficult to empathise with them and help them find the means to achieve their goals (Emerson & Hatton, 2000). Whilst many of these difficulties can be overcome (see O'Brien & Mount, 1989), this group tend to be socially isolated and have limited social networks – they are in danger of being socially excluded. Moreover, Emerson and Stancliffe (2004) point out that person-centred planning, done properly, requires considerable time and effort, as well as changes in the architecture of the system. They propose the incremental introduction of person-centred planning and individual need-based funding. However, resources are scarce and there is the danger that plans will be notational or aspirational rather than being real working documents which guide practice, are regularly reviewed and make a real difference to the lives of people with learning disabilities (Felce, 2004). As regards people with profound physical and intellectual disabilities, it is likely that the difficulties outlined by Mansell and Beadle-Brown, refereed to above, along with scarce resources, will result in this group either not being involved in person-centred planning or having plans which are unlikely to produce person-centred action. However, Simpson (1999) cautions against viewing person-centred planning as being the only way through which people with learning disabilities can lead better lives:

> ...the danger of such an exclusive orientation to the discourse of community care is that it generally fails to recognize regimes of power and discourse, and to acknowledge that the main need of people with learning difficulties is for society to stop oppressing them.
> (Simpson, 1999, p. 155)

This is recognised in the SAY Report and in the ministerial foreword. In fact the report itself stresses the need for the general public and communities to have a greater understanding of people with learning disabilities, to recognise their rights, needs and their contribution to the community and to respond more positively to them (p. 5, para. 8). Indeed recommendation 21 (p. 98) aims to increase public awareness and understanding of people with learning disabilities and to include them in their communities. The above is more in line with the social model of disability than the normalisation model. Although normalisation recognises that a change in public attitudes is necessary, its main area for promoting change is services. In contrast, the social model is concerned more with disabling social and economic structures, rather than services issues:

> The (social) model calls for the individual and collective responsibility of all societal members to dismantle disablement and to promote a socially aware, active and inclusive culture.
> (Brett, 2002, p. 830)

As argued in Chapters 2 and 3, the social model does not give a full explanation of the experience of people with profound physical and intellectual disabilities. Moreover, its emphasis on self-advocacy and collective action ignores the reality that this group is heavily reliant on other people, especially when it comes to having a voice. Often self-advocacy for this group is replaced by well-intentioned people who nevertheless make assumptions about the person's best interests and views. At other times their views and interests are assumed to be represented by speakers from within the disability movement who claim to represent <u>all</u> people with learning disabilities (Corker, 1999).

The report also recognises the role of family carers:

> ...it is striking that family carers are often given the responsibility for (and expected to provide) social and nursing care that many professional agencies refuse to offer
> (Scottish Executive, 2000, p. 7, para. 16)

The report suggests that family carers be given training and advice to look after people with learning disabilities. It also recommends that people with learning disabilities should be "supported to lead a full life with their families or in their own homes" (p. 9, para. 5). This emphasis on family care is akin to what Dalley (1989) describes as the informal care model. This model stresses the importance of the role of informal care. It places individual and family responsibility for caring at the centre of community care and down plays the importance of services provided by professionals. Whilst family care is attractive to service providers in that it is relatively inexpensive and cost-effective, it places additional burdens and stress upon family carers (see Chapters 5 & 6). Greater emphasis is now being placed on the role of individuals and families in the provision of care. Mansell and Beadle-Brown (2004) point out that person-centred planning endorses the idea of informal care and possibly implies that it is preferable to formal service provision. They argue that this offers service agencies the opportunity to define activities, which they would previously have funded, as the responsibility of the "circle of support". Thus person-centred planning might be used to shift more of the costs of disability to individuals, their families and friends. The role of the state is increasingly being seen as one of enabling private and voluntary action, rather than as service provider. This reflects a concern with economic issues which demand efficiency and value for money. Once again this supports Trent's (1995) and Simpson's arguments that acceptance or rejection of concepts and models are largely determined by economic conditions.

From the above discussion it can be seen that the SAY Report expresses ideas which fit more than one model and that some of its elements are contradictory. Fairclough (1997) suggests that contradictory or inconsistent elements are often found in texts and usually happen when innovations occur which go against conventions and expectations. Perhaps possessive individualism and collectivism are beginning to be replaced by a new ideology, described by Johnson (1987) as 'welfare pluralism'. Welfare pluralism involves plural provision whereby a greater proportion of social care is provided by voluntary agencies, private organisations, community initiatives and informal sources of care. State provision is minimal and reserved for areas where no-one else is providing. It also recognises the expertise of consumers and service users and sees their participation in decision-making processes as essential. Furthermore, it emphasises the importance of regular monitoring, inspection and review processes. According to Parton (1994), this has led to a concern "with assessment, planning, care management, negotiating, co-ordinating, using information technology, and operating the laws and procedures" (p. 26). Thus more and more time is spent on administration and liaison, rather than direct work with service users.

The SAY Report, however, does attempt to improve the lives of people with learning disabilities and their families based on a recognition of their rights as people, social inclusion in local communities, choice in their daily lives and real opportunities to be independent. It is based on principles of normalisation, the "ordinary life" approach, the client-focused model and the social model of disability. However, I would argue that these underlying philosophies do not always extend to people with profound physical and intellectual disabilities. The SAY Report, although recognising this group, fails to provide a framework for the delivery of practical services to this group and their family carers. At the moment, it seems unlikely that society is prepared to tackle its shortcomings in terms of service provision and environments for people with profound physical and intellectual disabilities and this is reflected in policy documents.

Although my study did not focus on the healthcare needs of young people with profound physical and intellectual disabilities at the transition stage, this was an important issue for the parents involved in my study (see Chapter 7). Therefore recent legislation concerned with the healthcare needs of people with learning disabilities are considered below.

Promoting Health, Supporting Inclusion: The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities

"Promoting Health, Supporting Inclusion" (Scottish Executive, 2003) arose as the result of one of the recommendations made by Caring for Scotland: The Strategy for Nursing and Midwifery in Scotland (Scottish Executive, 2001). It makes twenty-four recommendations designed to ensure that all nurses and midwives recognise the needs of people with learning disabilities and work towards "promoting and improving their health" (page 7).

The report is based on the seven principles of the SAY Report and encompasses the principles of normalisation and social inclusion:

> Children and adults with learning disabilities are people *first,* and have needs, dreams and aspirations like everyone else. They also have health needs like everyone else. To lead full and active lives as valued members of the community, they need to receive the services and support that will keep them healthy and enable them to participate fully in society. This means that where possible, people with learning disabilities should be able to use the same local services as everyone else, with some children and adults also benefiting from the provision of specialist social, health and education services.
> (Scottish Executive, 2003, p. 4)

Unsurprisingly, it differs from the Beattie Committee Report in that it sees good health as enabling social inclusion, whereas the Beattie Committee Report stresses employment as the key to social inclusion.

The report aims to move away from an individualistic medical model of disability towards a social model. Disability is no longer viewed as an "illness" (p, 2) and the problems that people with disabilities face are seen in terms of societal barriers, not individual pathology:

> ...there are many barriers and issues that prevent people from having their needs met effectively. Some of the barriers within health services are cultural, value-based, system-based and organisational. Others arise as a result of lack of knowledge, limited clinical experience and inadequate understanding of health needs.
> (Scottish Executive, 2003, p. 4)

The report focuses on the needs, concerns and difficulties of people with learning disabilities and their family carers. It stresses that planning and practice must be needs-led and that management should not be medicalised (p. 36). In fact the report's first recommendation calls for the Public Health Institute of Scotland to carry out a needs assessment of the health needs of people with learning disabilities to inform the development and commissioning of future services. Similarly, learning disability nurses are no longer seen as working within an individualistic medical model and treating the "symptoms" of disability. Instead, they are seen as health promoters and enablers, using their knowledge and skills to "promote wellbeing and enable and support social inclusion" (p. 20).

Although the report emphasises the need for a client-focused model, it also contains elements of a professional-practice model. The review held a number of focus group discussions involving midwives and practitioners. Not surprisingly, these professionals were anxious to claim key roles in promoting the health and well-being of people with learning disabilities and were prepared to recast their roles (Hill, 1982):

> The need to develop and enhance their role was viewed by many as a priority as it was recognised that there would be an increasing and changing need for their skills, not a diminishing one.
> (Scottish Executive, 2003, p. 15)

Furthermore, the report also seeks to protect the role of nurses from being eroded by social work and educational professionals:

> Whilst some of the relevant nursing skills necessary to support people with complex needs may be transferable to social care and education staff, others require underpinning nursing knowledge, clinical judgement and experience.
> (Scottish Executive, 2003, p. 42)

As seen in Chapter 5, such demarcation disputes have had detrimental effects on the lives of people with profound physical and intellectual disabilities and their family carers. Often this group is excluded from participating in day services and leisure and short break opportunities because of statutory agencies' failure to resolve whether certain tasks and procedures should be carried out by social care or nursing staff. Ironically, as highlighted in the SAY Report, it is often family carers who provide such care (Scottish Executive, 2000, p. 7, para. 16).

This professional concern to establish and maintain dominance is also seen with regard to people with "complex needs":

> As the level of learning disability becomes more severe, so does the likelihood of increasingly complex health needs, and the role of specialists in learning disabilities, including nurses, becomes even more crucial ...specialist nursing interventions may need to be provided within people's normal daily environments.
> (Scottish Executive, 2003, p. 42)

> (Nurses and midwives) working with children and adults who have complex needs must have a range of skills that enable them to effectively assess, treat and provide therapy.
> (Scottish Executive, 2003, p. 6)

For me, this implies the need to keep people with "complex needs" under the province of medicine. "Treatment" and "interventions" are required. There is a danger here that the person with "complex needs" may come to be seen as flexible and "alterable" through interventions by experts. This can lead to the idea that it is the person with "complex needs" who needs to adapt to the environment through individual effort, rather than society changing. Brett (2002) argues that people who are seen as not being able to adapt, are then viewed as not belonging. Thus society is not required to confront its own prejudices.

However, as discussed previously, the report supports the idea of health professionals and services being based on a social model of disability rather than an individualistic medical one. Furthermore, the report recognises the rights of people with disabilities and their families and seeks to empower them. It claims that people with learning disabilities and their families have been "at the very heart of this National Nursing Review" (p. 2). Moreover, recommendation 10 (p. 43) advocates that people with learning disabilities and their carers are involved in the planning and delivery of care. Indeed, the report itself consulted widely with people with learning disabilities and their families and included them in its professional reference group, its user and carers' group and its complex health needs sub-group. However, Wilding (1982) argues that in reality it is professionals who set the agenda for policy debate (O'Hagan, 1993) and research (Walmsley, 2001). Moreover, it is professionals who define and assess needs and control resources and funding. There is still a need to allow people with learning disabilities and their family carers to truly participate and be involved in the planning, delivery and provision of services at national and local level:

> The challenge now is to ensure that this becomes an integral part of service culture and not an occasional, optional feature that only occurs when a special project is initiated and funded.
> (Clare & Cox, 2003, p. 948)

Health Needs Assessment Report: People with Learning Disabilities in Scotland

As mentioned previously, this report was undertaken in response to the first recommendation of "Promoting Health, Supporting Inclusion". "The Health Needs Assessment Report" makes twenty-five recommendations which call for specific actions in five areas – leadership and accountability, infrastructure, interventions, information and education. Its aims are to reduce health inequalities and to promote social inclusion. The report is built around the seven guiding principles of the SAY Report:

> People with learning disabilities are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community.
> (Scottish Executive, 2004, p. 2, para. 1.1)

It is interesting to note that both "Promoting Health, Supporting Inclusion" and this report are built around the seven principles of the SAY Report. Moreover, both also use a tiered model of care. With reference to the seven principles, Humes (2000) would argue that there is a danger here that "certain narratives become dominant and serve as the received wisdom of... institutions and systems" (p. 48). Similarly, there is a danger that the tiered model may come to be regarded as the "accepted" model of healthcare. Aspis (1999) argues that this can lead to other issues, such as the imbalance of power between people with learning disabilities and non-disabled people, remaining unchallenged and unrecognised. He further contends that without knowledge of the thinking behind social structures, people with learning disabilities will find it difficult to challenge practice in a meaningful way. He maintains that in order to really empower people with learning disabilities they need to have:

> ...information about why people are labelled, definitions of oppression, the power of statutory and service agencies, and the legislative framework...
> (Aspis, 1999, p. 181)

He claims that, like everyone else, many people with the label "learning disability" have the ability to learn and understand the nature of relationships and rights, if they are supported in doing so.

In its opening chapter, the report makes reference to the principles of normalisation and SRV. It stresses the importance of people with learning disabilities being regarded as valued members of society and as having the right to access employment and public life, to participate in life-long learning and to be active participants in the community. It argues that this not only improves the lives of people with disabilities, but also increases their worth in the eyes of society, leads to more positive responses from the general public and raises public expectations of what people with learning disabilities can achieve. Moreover, the report sees health improvements in the lives of people with learning disabilities as having a positive impact on both their social experiences and their quality of life. As regards people with "profound learning and multiple disabilities", the report sees health improvements for this group as essential elements in achieving social inclusion for the group, "in helping them to develop communication skills and the ability to make choices, and to participate in other opportunities such as lifelong learning and leisure activities" (p. 3).

However, the report recognises the need for extra support for people with learning disabilities, as emphasised by the Chair of the report reference group:

> Health needs should be met within mainstream services wherever possible, but additional support and supplementary provision is needed... offering mainstream services when appropriate, mainstream with additional support when appropriate, and sometimes offering special provision – we need all these options.
> (Mathieson, 2004, p. 8)

Thus the report acknowledges that the health needs of people with learning disabilities needs to be addressed through a variety of service provision. However, whilst some of its recommendations might be achieved within existing resources, others will require new funding and resources:

> Implementation will require partnership across all organisations and agencies, and recognition and acceptance of the health needs of this group. But most of all, it needs a clear commitment from all stakeholders to addressing these needs over time, otherwise we run the risk of people with disabilities being failed yet again.
> (Brown, 2004, cited in Mathieson, 2004, p. 9)

To conclude, analysis of these national documents, concerning people with learning disabilities, illustrates that they express ideas which fit more than one model. They all contain aspects of the client-focused model which incorporates principles of normalisation and the "ordinary life" approach. However, there is also evidence of the managerial-planning and professional practice models which may lead to a playing down and devaluing of the individual needs of people with learning disabilities and "interdisciplinary conflict with regard to control and domination" (Mcintosh, 2002, p. 74). Nevertheless, there is a consensus amongst the documents that policy should be based on the principles of social inclusion and equality. Moreover, in all of the documents there is a recognition of the importance of the rights of people with learning disabilities in relation to the pattern and design of services.

The documents also contain elements of social modelling thinking. However, research suggests that the social model is only just beginning to have an impact on service delivery (Coles, 2001). Moreover, Oliver's social model has not been universally accepted by professionals:

> ...we have seen a paradigm shift and many professionals have now come to espouse the social model, in theory at least. Whether it has much impact on practice is another question altogether.
> (Oliver, 1996, p. 31)

In addition, I have put foreword the view that there are elements in the documents which imply that there is still a tendency to use individualistic medical model thinking when it comes to the planning, development and delivery of services for people with profound physical and intellectual disabilities. At the moment, services for this group still seem to be based on implicit judgements about their economic and moral value to society and are dependent on society's willingness to target this group in terms of funding and resources. I have also argued elsewhere (Chapters 2 & 3) that both the individualistic and social model of disability are inadequate for understanding disability in relation to people with profound physical and intellectual disabilities. Nevertheless, all of the documents show that there is a will to improve services for people with learning disabilities. There is also a desire to plan services that aim to dismantle barriers, recognise diversity and include people with learning disabilities and their family carers in decision-making processes. Hopefully, these documents will enable people with learning disabilities and their families to truly participate, both within an inclusive policy framework and in society more equitably.

However, as Weatherley and Lipsky's (1985) study shows, national policies are often constrained and distorted by "street level bureaucrats". Often local authorities deal with many priorities for change and frequently in a climate of an overall scarcity of resources, or without a substantial amount of new money to implement policies. Moreover, they can sometimes feel rushed to respond to new requirements. With regard to policies concerning people with learning disabilities, they often encounter additional difficulties because important initiatives for modernising mainstream services do not refer specifically to the inclusion of this group. In addition, implementing these national documents is not solely a matter of adopting new procedures and techniques, it requires a change in culture and systems. Before considering the local documents of one authority, the next section looks at the "how" of policy discourse.

In conclusion, like the previous section, this section has demonstrated the importance of considering the relationship between policies and their contexts. It has shown how policy texts rely on their contexts or surrounding texts to assist in the determination of meaning. For example, both "Promoting Health, Supporting Inclusion" and the "Health Needs Assessment Report" have used the seven principles established by the SAY Report as their fundamental principles and both use a tiered model of care. Thus Gale (1999) claims that "contexts are not just locations where policy prediction happens but they are intricately involved in the production process itself" (p. 399). Moreover, he further argues that:

> ...policy con-texts, as the prefix implies, are "forms of" texts or, to draw on its Latin origins (contextus), are texts which are "woven together" to form "connections".
> (Gale, 1999, p. 399)

For example, the SAY Report "weaves" together concepts associated with normalisation, "ordinary living" approaches, person-centred planning and the social model of disability. Thus policy texts do not stand in isolation, they are influenced by contexts. However, policy texts also influence contexts. As Gale (1999) states "policy texts are implicated in an attempt to discursively create and recreate their own contexts" (p. 399). This is demonstrated in the discussion above – all the national documents strive to create a socially inclusive society. Thus Gale argues that policy contexts are:

> ...domains of interdiscursive struggle amongst discourses which employ strategies to establish and maintain their dominance or challenge the dominance of others.
> (Gale, 1999, p. 400)

Therefore, according to Yeatman (1990) they always contain "contradictions which can be mobilised by readers who are discursively positioned to do so" (p. 165). This is illustrated above as all the national policies considered here express ideas which fit more than one discourse. Although Yeatman's arguments suggest that discourse can be a tool of agency, it can also be a tool of constraint as shown by closely examining the "how" of policies. The following section looks at the strategies employed by discourses to "establish and maintain their dominance or challenge the dominance of others" (Ibid.).

The "how" of policy

Luke (1995) argues that one of the main tasks of discourse analysis is to "disarticulate" or unravel the texts of everyday life as a way of "disrupting" common sense" about the naturalness or inevitability of identities, values and concepts (p. 20). This, he claims, helps to uncover the workings of power and material interests in texts. MacLure (2003) suggests that one way of disarticulating texts is to look for the ways in which texts are "articulated" – that is joined or stitched together (p. 9). She claims that one of the most common ways of articulating texts is through binary oppositions. This device is seen in the SAY Report. The report is structured around the opposition between present and future – where we are now (bad) and where we want to be (good). Living in the community is elevated above institutionalised care. This basic opposition provides the structure onto which a range of other oppositions are mapped. "Hospitals are not places where people with learning disabilities can live full lives" (p. 39) – living with families or in their own homes helps people with learning disabilities to lead a full life. Institutionalised care is equated with little choice, limited social networks, no employment and sometimes abuse. In contrast, living in the community offers people with learning disabilities choice, friendships, jobs. Institutional care is also attacked overtly through ascriptions which insinuate a lack of thought and understanding:

> Sometimes what seemed the best approach has, looking back, appeared lacking in understanding.
> (Scottish Executive, 2000, p. 2)

In contrast, housing in the community is justified through pieces of "scientific" research, carried out by reputable agencies, in this case the Department of Health, on the basis of both cost and quality outcomes. However, MacLure (2003) and Latour and Woolgar (1979) argue that research texts are "fabrications" and use rhetorical and literary devices to persuade readers of the facticity of their arguments:

> Their truths and findings are put together – that is, built or woven... to achieve particular effects and structures – rather than artlessly culled from a pre-existing world Out There.... Texts assemble and deploy the objects and phenomena to which they seem to refer, so as to invest them with particular moral and epistemological significances.
> (MacLure, 2003, p. 80)

All of the documents considered imply that their recommendations are based on a social scientific model of research and enquiry. This assumes a "scientific explanation of physical and social reality" which can provide solutions to practical problems and be used "for social action and improvement" (Pring, 2000, p. 110). However, Hammersley (1995) argues that this kind of approach fails to consider post-structalist arguments:

> It [post-structuralism] insists not just on the relativity of all knowledge claims but also that knowledge is a product of desire or power... Any claim on the part of researchers to be in pursuit of the truth, or to be in possession of knowledge, is treated by post-structuralists as hiding the work of other interests.
> (Hammersley, 1995, pp. 14-15)

This emphasis on evidence-informed policy and practice has also been criticised by Humes and Bryce (2001). They highlight the way in which research evidence intersects with other factors, such as ideological, economic, bureaucratic and professional issues, which influence policy decisions. For example, policy-makers bring a number of perspectives into play when considering the issues they are expected to address. These perspectives are influenced by their education and training as well as financial and managerial pressures. This is seen in the four documents considered in the previous section. In addition, Ozga (2000) expresses concern that this focus on evidence-informed policy may lead to research for policy, resulting in research being subject to political forces. This may influence the kinds of questions it is permitted to ask (Humes & Bryce, 2003), as well as the forms of discourse in which its findings may be expressed:

> [T]he idea that human sciences... stand outside or above the political agenda of the management of the population, or somehow have a neutral status embodied in free-floating progressive rationalism, are dangerous and debilitating conceits.
> (Ball, 1995, p. 263)

Looking more closely at the language employed in the documents, analysis shows that a mixture of both rational and emotional language is used. Hard-edged managerialism is in evidence in the Beattie Committee Report as is shown in its use of terms such as "effectiveness", "quality assurance arrangements" and "quality management systems". The emphasis here is on rationale and strategic planning. Similarly, the SAY Report provides examples of rational management, particularly at the beginning of Chapter 2 where aims and objectives are expressed in terms of "developments". "Promoting Health, Supporting Inclusion" and the "Health Needs Assessment Report" also refer to "standards", "quality" and "accountability".

At other times the reports use a gentler form of discourse designed to appeal to the emotions. They talk of "consulting" and "empowering" people and giving them "ownership". These terms suggest a sense of agency – agency which is equally distributed. In addition, the usage of a lexicon which appeals to emotion highlights the value systems espoused by the documents. Participation conjures up the ideal of social justice which is associated with service user control and leadership (Ryburn, !991a); trust and respect (Ryburn, 1991b; Mittler, 1995); equality between service users and professionals (Mittler, 1995) and mutuality (Shemmings & Shemmings, 1995). However, Healy (1998) argues that:

> ...the ideals of participation have been developed in a political context in which individualism is emphasized, with the often explicit purpose of "winding back" the welfare state... In essence, the participatory ethos embedded in recent legislation is not necessarily reflective of a concern with social justice but, rather, arises from an emphasis on individualism that has become increasingly widespread over the past 50 years throughout much of the Western world.
> (Healy, 1998, p. 900)

Similarly, consulting widely implies that the decision-making is open and democratic in nature. However, family carers of people with learning disabilities often view their participation in the planning and delivery of services as tokenistic. Similarly, people with learning disabilities, who are consulted about policy-making decisions, are far from being equal partners, nor are they representative. In addition, sometimes the people who are asked to participate are people who are known to operate within existing conventions. Thus participation is often an officially managed process. Anderson (1998) argues that this "discourse of participation" reflects administrators' concerns to establish good public relations and create "greater institutional legitimacy" (p. 573). Humes (2000) concurs with this, arguing that often participation is a strategy of "containment designed to disguise the power nexus" (p. 42). In addition, Ban (1992) argues that partnership and participation are meaningless unless practitioners "are comfortable with the practice implications that accompany these ideas" (p. 6). A commitment to these ideas often involves administrative, structural, financial and organisational changes. Furthermore, I would argue that currently, participation is regarded as an unquestionable "good" when it comes to the planning and delivery of services for people with disabilities. As a result, often people with profound physical and intellectual disabilities are taken to decision-making meetings which take little, or no account of their severe cognitive and communication impairments. Their presence is tokenistic. Often the young people become bored with the proceedings, fall asleep, or engage in behaviour which disrupts the meeting, resulting in them being removed from the meeting. Healy (1998) argues that often ideals of participation "have been imported from other disciplines without due regard for...specificities" (p. 897) When this happens, these ideals of participation "establish practice benchmarks that are both unrealizable and inappropriate in this field" (p. 912). Although she is referring to child protection practice, her arguments, I believe, are relevant to the group in my study.

All of the documents considered here have consulted widely and endeavoured to involve stakeholders in order to reach a consensus. However, Humes (1999), speaking from an educational viewpoint, argues that sometimes consensus is more apparent than real. Moreover, frequently the preferred outcome is "invariably a single cost-effective 'solution' to complex educational problems" (Humes, 2000, p. 43). He urges people to challenge the limited participation that officially-managed processes usually permit.

The Beattie Committee Report also contains elements of evangelical language – inclusiveness is "central to our vision" (para. 2.1). Humes (2000) maintains that this use of evangelical terms is designed to inspire and energise people. The SAY Report, "Promoting Health, Supporting Inclusion" and the "Health Needs Assessment Report" also express what Humes (2000) refers to as a "can do" philosophy of positive action and achievement by peppering the reports with examples of good practice. Hartley (1999) suggests that, like the "discourse of participation", this appeal to the emotions may be an attempt to legitimise policy documents. He quotes Mestrovic (1997) who describes the process as:

> ... manipulation of emotions by self and others into a bland, mechanical, mass-produced yet oppressive ethic of niceness.
> (Mestrovic, 1997, cited in Hartley, 1999, p. 319)

Blase and Anderson (1995) also suggest that this culture of "niceness" can lead to the "institutional silencing of criticism" (p. 138). Thus policy documents, even those presented and couched in emotional terminology, are at one level concerned with control.

The documents also make use of metaphorical representation and the discourse of community. Communities are seen as giving people with learning disabilities a sense of identity and self-esteem as well as providing them with a network of support. Moreover, as communities have regulations and conventions connected to a value system intended to protect members' rights, freedoms and interests, it is assumed that becoming a member of the community will be beneficial to people with learning disabilities. However, Reidy (2001) argues that it is not enough for people with learning disabilities to be physically integrated into communities, they also need to be socially integrated. For this to happen, this group needs to be seen as having something to contribute, otherwise they will be met with a lukewarm reception and merely tolerated by other community members. In addition, some communities are negative and destructive. They are incapable of dealing constructively with human diversity or addressing injustice. In such communities people with learning disabilities may be bullied, harassed, face discrimination and experience repeated failures which result in low self-esteem. People often feel resentment that resources have been taken away from their communities in order to support people with disabilities. Some writers would further argue that "the community" no longer exists and that the term "community care":

> ...masks impersonal rationing by joining two words with high appeal, emptying them to content, and filling the hallowed out space with bureaucratic professional activity.
> (O'Brien & O'Brien, undated, p. 9)

Indeed sociological studies (Young & Willmott, 1986) suggest "community", in the sense of a closely knit, mutually supportive neighbourhood, is scarce. In practice Dalley (1988) found that it is the family, and overwhelmingly women, who undertake the role of caring for people with substantial needs. This is also reflected in the profiles of the young people in my study – mothers were the principal care-givers.

It can also be argued that stressing the rights of people with learning disabilities to have access to the opportunities and life-styles of mainstream society, could lead to a failure to recognise their right to be different, as well as an under-rating of their specific needs. The latter particularly applies to the young people who are the focus of my study. Furthermore, although the term "community building" has positive connotations, for example, "the creation of relationships and social structures, that extend the possibilities for shared identity and common action among people" (O'Brien & O'Brien, undated, pp. 1-2), it can also camouflage a desire for control and social engineering. Indeed Morgan (1997) draws attention to both the positive and negative aspects of metaphors:

> ...any given metaphor can be incredibly persuasive but it can also be blinding and block our ability to gain an overall view.
> (Morgan, 1997, p. 347)

The documents also use what Yeatman (1990) describes as "policy genres" and Gale (1999) refers to as patterns or "templates". All of the documents use the template which Bowe, Ball and Gold (1992) refer to as "the language of the general public good" (p. 20), in this instance the "general public" being people with learning disabilities. Indeed the use of binary oppositions in the SAY Report, referred to previously, can be regarded as a way of persuading readers that people with learning disabilities living in the community benefits both people with learning disabilities and society as a whole. According to Fairclough, (1992) these templates point "to various forms of interaction which are structured in particular ways and involve particular sets of participants" (p. 51). As discussed previously, the use of language designed to appeal to the emotions can be used to suggest agency and therefore is likely to appeal particularly to people with learning disabilities and their families. Similarly, the "can do" philosophy found in the SAY Report and the two health documents, is likely to appeal to implementers and service providers. Yeatman (1990) argues that these policy genres can be used to "deny the politics of discourse" (p. 160). They are written in a way which disguises "dominant" discourses (Ball, 1994a) and their "niceness" can silence criticism (Blase & Anderson, 1995).

This discussion has shown that discursive forms can disguise and conceal the power dimension by including appeals to "communities" and "participation" and by the use of "emotional" language. Humes (2000) claims that representing policy in terms of democratic consultation, partnership and consensus, strengthens legitimacy. The discussion has also demonstrated that discourse can be both a tool of agency and a tool of constraint. Moreover, the previous sections have illustrated that discourses are influenced by internal and external pressures coming from economic, political, ideological, institutional and professional factors. Policy text, ideology and discourse are all inter-related and influenced by context.

The following section looks at the documents of one local authority.

LOCAL DOCUMENTS

The first part of this section analyses an authority's community plans, focusing on services for people with profound physical and intellectual disabilities. The second part looks at documents concerned with the transition stage from school to post-school provision, once again focusing on young people with profound physical and intellectual disabilities.

The Community Plan and the Joint Community Care Plan

Echoing national policies and documents, the region's Community Plan (2004) also features inclusion as one of its goals:

> ...To deliver an Inclusive Fogart – to ensure that everyone in Fogart enjoys the full benefits of society. This means tackling the barriers of poverty and discrimination, improving the quality of life for all and ensuring that everyone, whatever their personal circumstances, has access to the opportunities and services they need.
> (Community Plan, 2004, p. 2)

Similarly, in the region's Joint Community Care Plan (2001-2004), both health and social care commit to a "joint vision" which aims to:

> ...provide modern, integrated services for the people of Fogart. We will do this by involving service users, carers, staff and local communities in all future service planning and by fundamentally changing our ways of working together.
> (Joint Community Care Plan, 2001-2004, p. 3)

Its aims expand on this 'vision' and reflect some of the recommendations of "Modernising Community Care: An action plan (Scottish Executive, 1998), such as partnership working and the crossing of traditional boundaries; joint training; the provision of flexible, innovative services which are evidence-based, represent best value and focus on vulnerable groups. It also echoes some of O'Brien and Towell's (2003) suggestions for changes in services so that person-centred planning can be implemented (see pp. 195-196).

The plan also describes health and social services in terms of a client-focused model and follows some of the principles of person-centred thinking – meeting people's needs, being person-centred, inclusive and accessible and "involving citizens/users, patients and staff in agreeing and developing service changes" (p. 53). Humes (2000) would argue that the latter phrase encourages employees to believe that they are agents of change, that they "own" the policies which they are expected to implement. He maintains that this strategy disguises the imbalance of power and "strengthens the legitimacy of the leadership by representing policy and management in terms of democratic consultation, partnership and consensus" (p. 46). This results in employees finding it difficult to complain or voice their concerns. The plan also contains elements of Dalley's (1989) managerial-planning model, emphasising joint working relationships and the development of unified services which "represent value for money" (p. 53).

Focusing on its section about learning disabilities, the plan proposes a move away from segregated provision towards a person-centred service based on inclusive principles "where each person is supported to participate in integrated opportunities within their own community" (p. 121) and "be included in society and, as active citizens, to benefit from lifelong learning" (p. 121). Furthermore, the plan describes how the recommendations of the SAY Report are being implemented by the SAY Project, a joint initiative involving both health and social work. This project held stakeholder events which involved people with learning disabilities, family carers and staff, from both voluntary and statutory services, in discussing and agreeing priorities for the PiP. As a result of these events, eleven working groups were set up, consisting of people with learning disabilities, family carers and professionals to take forward the issues identified at the conferences. Although this may be seen as empowering people, the Scottish Executive had already highlighted three main priorities – the closure of long-stay hospitals, the establishment of local area co-ordinators and employment. This is in line with Humes' (2000) argument that where open forms of participation are permitted, the process is often carefully managed.

Furthermore, although people with learning disabilities attended the events, most were not actively involved in the decision-making processes and the subsequent implementation of the action plans. For example, there was strong support from people with learning disabilities to re-instate day centre holidays but this did not appear in the action plans. As Deeley's (2002) study indicates there is still an imbalance of power amongst people with learning disabilities, family carers and professionals. Frequently the agenda is set by professionals who assume that they are the experts and can make decisions in the "best interests" of people with learning disabilities. Similarly, people with learning disabilities and their families often assume that "professionals know best". As Apis (1999) argues, without knowledge of the thinking behind social structures, people with learning disabilities and their families will find it difficult to challenge practice in a meaningful way. Moreover, they are often uncertain that their voices will be listened to or that anything practical will come out of consultations. Likewise, professionals are frequently uncertain how to respond to what people with learning disabilities and their families have to say. O'Brien and Towell (2003) argue that people need to find effective ways of communicating with each other; to listen to each other and "to work together to make and implement plans to change the culture and systems which contain them" (p. 5).

The Joint Community Care Plan also describes how the Beattie Committee recommendations are being carried forward through the "Inclusiveness Project Involve". This project aims to "help young people at risk of social inclusion access the full range of post-school opportunities" (p. 165). It focuses on "young people with the highest level of support needs" (p. 165) – pupils in transition from behaviour support centres and college students leaving supported provision. Not surprisingly, as with the Beattie Committee, people with profound physical and intellectual disabilities are ignored and forgotten about once again.

The plan also refers to a "rehabilitation service" which aims to "provide assessment and rehabilitation to those with physical disability aged 16-64" (p. 165). Contained within this service is a "Young Disabled School Leavers Service":

> A weekly clinic is held for young people who live with cerebral palsy, traumatic brain injury, muscular dystrophy, spina bifida and other conditions. Key roles of the YDSL service are to smooth the transition from the paediatric service to adult services, provide medical assessment and review, and link with assessments and other inputs from Professions

> Allied to Medicine (PAMS). Part of the process is to assess the individual's functional abilities, the potential for rehabilitation and the possibility of moving on to independent living.
> (Joint Community Care Plan, 2001-2004, p. 165)

The above quote suggests that this service is based on what Clare and Cox (2003) refer to as the rehabilitation model (see p. 215). The focus is on individual impairments and enabling the person to live independently within the context of a disabling society. It is more in line with individualistic medical model thinking than social model thinking.

The Joint Community Care Plan also contains a section entitled "Young people affected by disability – Transition to adulthood". Its "vision" is:

> ...that all young people approaching adulthood will have access to any aspect of community life that has value to us as adults. For some young people who have special needs due to disability this means having access to varying degrees of support and additional and often specialist resources. Every young person with a disability has a number of rights:
>
> This vision is not yet a reality. If inclusion is to become real for all young people with a disability, it is not only service providers who need to review their ways of working, their structures, their funding arrangements, their processes and procedures. Inclusion is also about individual attitudes. We all need to value diversity and difference in people and fully embrace the fact that everyone has value and worth regardless of ability and disability.
> (Joint Community Care Plan, 2001-2004, p. 164)

This 'vision' follows, to some extent, the principles of normalisation and person-centred planning. It is in line with the SAY Report which emphasises the importance of both generic and specialist services. However, its focus is more on physical presence in the community, rather than on uncovering and enhancing people's unique gifts and talents so that their identities can emerge (Reidy, 2001). Reidy (2001) argues that:

> It is not sufficient to merely fill generic valued roles; there also needs to be an active process of discovering and enhancing each individual's personal social roles.
> (Reidy, 2001, p. 2)

Although the 'vision statement' recognises that service providers will need to change, not only their ways of working, but thinking, it does not pay enough attention to the development of relationships between people.

This section also mentions briefly, young people with "very complex needs". Their definition of this term is:

> [People whose] disabilities may include severe learning disability, profound communication needs and physical disabilities, which require hands on care with all aspects of daily living.
> (Joint Community Care Plan, 2001-2004, p. 164)

However, the focus is on the cost of support packages, estimated at "between £3,200 and £56,000 per year" (p. 164) and the setting up of an inter-agency team to focus on life long planning and funding for this group. The danger here is that the focus may only be on the young person's needs and not on their gifts and talents and how these can be developed and recognised by other people in society.

Having looked at the region's community care plans, the next section focuses on documents concerned with the transition stage from school to post-school provision, focusing on young people with profound physical and intellectual disabilities.

Post-school Provision and Respite Care Facilities for Young Adults with Profound and Multiple Disabilities

In May 1995 the secretary of the Parents Advisory Group, a support group set up by the social work department, wrote to the directors of the social work and education departments, as well as the chief executive of the health board, expressing parental concern about the lack of post-school provision and services for young people with "profound and multiple learning disabilities". As a result of this, professionals from social work, education, health and the voluntary sector met with parents of people with learning disabilities to look at how things might be progressed. At this meeting members of the Parents Advisory Group presented their report entitled "Post-school Provision and Respite Care Facilities for Young Adults with Profound and Multiple Disabilities". This document provided a descriptive label for the young people (see Chapter 2), outlined the group's aims and objectives and how they could be translated into practice. It also contained an inventory of post-school current provision, which highlighted the gap in service provision for young people with "profound and multiple learning disabilities", as well as a projection of the number of school leavers in this group between 1995-2002. Their suggestions concerning service provision for this group were based on data obtained from a questionnaire completed by family carers of young people with "profound and multiple disabilities".

In its introduction, the parents stress the rights of their young people to access both generic and specialist services and to be included in the community. Indeed their aim places a heavy emphasis on their young people's rights. However, they want segregated day services for their offspring:

> Whilst recognising and welcoming the principles behind integration, we remain unconvinced that this approach is the best for our young people, some of whom are frail and unable to cope with large numbers of people in the wider environment. Moreover the example of the fortunes of the Disabled Persons Bill and our experiences of looking after our young people in the community suggests, to us, that society is not yet ready for integration. However, we also recognise that our youngsters can, and

> do, benefit from contact with the more able bodied members of our society and would welcome short periods of integration in a controlled environment. We would also hope that the unit would make use of existing community services and promote integration with ordinary people. Nevertheless we, as parents, feel we must ensure an appropriate, and therefore, if necessary, segregated service for our young people.
> (Parents Advisory Group. 1995, p. 1-2)

This is similar to the view espoused in the SAY Report. It is akin to the Scandinavian principle of normalisation, although the document's objectives draw on some of the elements of Wolfensberger's social valorisation theory:

> To promote a sense of self worth, self esteem and respect within the local community
> (Parents Advisory Group, 1955, p. 2, objective 8)

Like Wolfensberger, the parents recognise the two broad strategies for achieving social role valorisation – the enhancement of the young people's social image in the eyes of others and the enhancement of the young people's competence:

> To provide them with appropriate opportunity and real choice so that personal growth and development can continue.
> (Parents Advisory Group, 1995, p. 2, objective 3)

As well as emphasising the rights of their young people, the document also stresses the rights and needs of parents "to feel some "normality" in their lives" (p. 3, objective 10). The parents' objectives also stress the need for services which are flexible, age-appropriate, needs-led and enhance the quality of their young people's lives. Although the document adheres to a client-focused model, the parents also stress the importance of services "giving value for money" (p. 2, objective 2), indicating elements of a managerial-planning model.

Their "Principles into Practice" section sets out a framework for the provision and delivery of post-school services to young people with "profound and multiple disabilities". They include the provision of services which are informed by individual assessments based on needs; services which ensure a smooth transition; provide continuity of school experiences and make use of community services. They favour a segregated provision which adopts a multi-disciplinary approach and has high levels of staffing. This type of provision looks at the young people holistically and provides services to meet their physical and healthcare needs, including therapy, as well as their educational and social needs:

> To maintain our children's existing skills and provide new areas and experiences which will encourage the development of new skills
> (Parents Advisory Group, 1995, p. 2, objective 6)

The parents also stress the importance of services working in close partnership with family carers and involving them in decision-making processes.

The above description of services echoes the aims of the rehabilitation model. Critics of this model (Clare & Cox, 2003) argue that it retains a focus on individual difficulties, supports the power-base of professionals and neglects the need for social change. The parents' emphasis on the impairments of their young people suggests that the individualistic medical model underpins this document and indeed medical interventions and therapies do improve the quality of life for this group. However, the document also reflects some of the ideas underlying the social model of disability. The parents stress the importance of empowering both themselves and their young people by offering choices and opportunities to participate in decision-making processes. They also propose services which are based on their young people's needs and wishes, rather than on professional judgements and imperatives. Furthermore, they call for individual and collective action of all members of society to promote an inclusive culture. However, their recognition of their youngsters' impairments, together with their own experiences of overt and subtle discrimination, leads them to the idea that segregated provision best suits the needs of their young people. This does not mean that they neglect the importance of social change as evidenced in their efforts to obtain services for their young people. They are, however, realistic and, like Llewellyn and Hogan (2000), feel that it is unlikely that society will tackle its shortcomings in terms of service provision and environments for people with profound physical and intellectual disabilities. They would probably regard the social model as visionary but at present unrealistic with regard to their young people.

Transition of Children with Special Needs from Children's Services to Adult Services

At the meeting of professionals and parents referred to above, it became apparent that not only was there a gap in service provision for people with "profound and multiple learning disabilities", but also for other groups of people with learning disabilities. After several meetings, it was decided that three working groups would be set up to identify the different needs of the specific groups:

> a) Young people who are able to access existing facilities with little or no support, who have social and/or health needs.
>
> b) Young people who are able to access existing facilities with support, who have social and/or health needs.
>
> c) Young people with profound disabilities who have social and/or health needs.
>
> (MacArthur, 1997, p.1)

Although it was originally intended to set up three working groups, lack of response from parents to join group A, resulted in group B looking at the needs of the young people in both groups. As the report produced by group C relates closely to my study, I have chosen to focus on this document and analyse its theoretical underpinnings.

Group C consisted of the advisor of special educational needs, two representatives from the local health board and healthcare trust, five representatives from the social work department and seven family carers. The aims and objectives of "Post-school Provision and Respite Care Facilities for Young Adults with Profound and Multiple

Disabilities" were used in working group C's report entitled "Transition of Children with Special Needs from Children's Services to Adult Services" (MacArthur, 1997). The working group also made four recommendations for services for this group:

> 1. Meeting the needs of the group will require special facilities and trained staff
> 2. The development and planning of services should fully involve parents as well as social work and education departments, the health board, community services and colleges
> 3. Services should:
> a) Provide an educational, occupational and leisure facility during day-time or evenings
> b) Provide an opportunity for breaks and holidays at a respite facility
> c). Aim to meet the objectives set out in this report
> 4. A specially adapted base should be found to meet the daily needs of these young people.
> (Adapted from MacArthur, p. 15)

The document then draws on the parents' proposal to outline the services offered by such a base. It concludes that:

> Social Strategy has a responsibility to ensure that <u>all</u> young people have equal access to services which meet their needs regardless of their social class, gender, ethnicity and disability.
> (MacArthur, 1997, p. 17, para. 7.3)

Although written in 1997 both documents make recommendations which have subsequently been endorsed by national documents discussed earlier. Their underlying principles are similar – normalisation, "ordinary lives" approach, a client-focused model. However, there is no mention of social inclusion, although principles of integration, partnership and empowerment are espoused.

Moving On: Transition into Adulthood

Following both working groups' reports, a development worker was appointed to take forward the issues raised in the reports. Her report entitled "Moving on: Transition into Adulthood" and her proposed action plan is based on the philosophy that:

> ...young people with special needs have a right to be included in any aspect of our communities that are of value to us as adults.
>
> (Brown, 1997, p. 2)

This philosophy is emphasised again towards the end of the document. This reflects the principles of normalisation/SRV. However, for me, the use of the word "our" proceeding "communities", instead of "their", implies a distinction between the non-disabled and disabled – the communities belong to able bodied people. The remainder of the document describes current services, identifies gaps in services and suggests ideas for the way forward. In its concluding remarks the document highlights the main themes of the report. These themes contain elements of the principles of social inclusion such as partnership, empowerment and inclusiveness:

> Inclusion of young people with special needs into the wider community is dependent on the skills and commitment of all supporting services.
>
> Young people with special needs should be involved more in the development and evaluation of services.
>
> (Brown, 1997, p. 41)

Unfortunately this initiative, although embarked upon with great enthusiasm by family carers and professionals from a number of different agencies, was never developed further. The action plan was never implemented. A post 16 group was established but the parents who had initiated the work were not invited onto this group. However, the parents from working group C continued to campaign for services for their young people and eventually took their story to the Press (see Chapter 5).

A recent request for policies on the transition period from education, social work and health services, revealed that the health board have no policies concerning the subject, however, the social work department and the education department have a joint policy.

Arrangements for School Leavers who have Special Educational Needs

This document was drawn up by a working group consisting of professionals from education, social work and health in 2002. The language of the document suggests that its aim is to provide "guidance" (p. 2) on transition planning/future needs assessment and review meetings. Its recommendations are couched in words such as "should" rather than "must" and practitioners are encouraged to adopt its recommendations by the use of phrases such as "it is good practice for" and "best practice is achieved". However, the appendices contain information about legislation, examples of letters for parents, a calendar checklist and frameworks for future needs assessment and transition planning, suggesting that this document is concerned with more than just "guidance". Humes (2000) describes this as:

> ...an Orwellian world in which words mean something other than that which they ostensibly denote.
> (Humes, 2000, p. 46)

The document is concerned with the process of implementing transition policies, rather than with defining underlying philosophy and principles:

> This circular outlines transition planning arrangements... (and) describes arrangements for transition planning/future needs assessment and subsequent review meetings.
> (Education Services, 2002, p. 3)

However, it does provide a definition of disability which is used by social work services "for the purpose of future needs assessment":

> Disability is an impairment, whether physical or mental which has a substantial and long term adverse effect on a person's ability to carry out normal day to day activities.
> (Education Service, p. 24, para. 2)

This definition of disability as an impairment is directly opposed to social modelling thinking. Social model theory makes a distinction between disability, which is socially created and impairment, which is referred to as a physical attribute of the body. Impairment is viewed in terms of a biological category and disability as a form of social oppression. The above definition sees disability in terms of an impairment and thus is more akin to individualistic medical modelling thinking. This kind of thinking views the problems faced by people with disabilities in terms of individual pathology rather than in terms of socially constructed barriers. In this sense it is the polar opposite of the principle of inclusion, espoused by the Tomlinson Committee (FEFC, 1996), which sees the system as the problem, not the person with disabilities. It is this principle of inclusiveness which is at the core of all the Beattie Committee's (Scottish Executive, 1999) proposals and recommendations. The definition of disability in "Arrangements for School Leavers who have Special Educational Needs" shows how principles can become diluted or changed when implemented at local levels (Weatherley & Lipsky, 1985). It also supports Oliver's (1996) comment that the social model has not been universally accepted by professionals. Consequently, Coles (2001) argues that everyone involved in service provision for people with learning disabilities should participate in Disability Equality Training which:

> ...challenges assumptions about the cause of disabled people's difficulties and introduces the idea that society, its attitudes and its human and physical structures create such difficulties
> (Coles, 2001, p. 509)

As this document is principally concerned with the process of implementing transition policies, it can be described as a managerial-planning model. As such, it is concerned with logistic and operational strategies and existing resources and funding.

It talks about young people's needs in terms of "resource implications" (p. 21, para. 5.2) and seeks to identify "locally based resources to meet the needs of the young people" (p. 22, para. 5.3), suggesting that services are resource-led rather than needs-led. Again this is in direct contrast to the Beattie Committee Report which states that:

> Inclusiveness means that the needs, abilities and aspirations of young people should be recognised, understood and met within a supportive environment which encourages them to achieve their goals and to make real, measurable progress.
> (Scottish Executive, 1999, p. 10, para. 2.4)

Similarly, there is no mention of an Individual Action Plan, a keyworker, or a mentor, as suggested by the Beattie Committee. Nevertheless, the document does emphasise the importance of empowering young people and their families by encouraging their "active participation" (p. 3, para. 1.1). However, it offers little practical advice on how to achieve this, apart from preparing pupils for meetings, providing parents and young people with information leaflets, keeping meetings and reviews small in size and making them informal and "pupil and parent-centred" (p. 5). There is no mention of replacing FNA meetings with meetings more akin to person-centred planning. However, the document does incorporate some of the Beattie Committee's other criteria for inclusiveness (see Scottish Executive, 1999, p. 15, para. 2.24). It stresses the importance of agencies working together and assessment processes which consult the young person, their family and other professionals involved with the young person.

The document also consists of four information leaflets for the young people and their parents. These leaflets are similar in terms of content and layout and there is no attempt at producing a leaflet which is "user friendly" for the young people. However, in contrast to the rest of the document which is based on rational management (see Chapter 3), the information leaflets adopt an emotional management approach, focusing on social processes and the human qualities of people (Hartley, 1999). They adopt what Humes (2000) refers to as a "listening" mode. The school, the local authority, the professionals involved in the meetings are all portrayed as being open and responsive to the views of the young person and their family:

> It (the FNA meeting)...is held in school to discuss and plan future provision for your son/daughter... All those who are (at the moment) involved with your son/daughter, and those who may be involved in the future, will be invited to this meeting. This means that you, as parents, have the opportunity to meet with all these people at the same time. You can ask questions and express your views about plans for your son/daughter's final years in school and his/her future on leaving school.
> (Education Services, 2002, p. 1)

Blase and Anderson (1995) suggest that such a culture of "niceness" can lead to the silencing of criticism. Standards of politeness, courtesy and civility may discourage parents from voicing their concerns, fearing that they might be seen as a challenge to authority. Furthermore, parents may be reluctant to express views which challenge professional opinion in case they are labelled as "trouble-makers" or "neurotic mothers". Blase and Anderson maintain that:

> The individual is marginalised and pathologised through labelling in order to protect the legitimacy of the institution.
> (Blase & Anderson, 1995, p. 138)

Thus Humes (2000) argues that officially managed processes, "however carefully presented and softened by emotional terminology, (are) at one level concerned with control" (p. 45).

To conclude, analysis of these local authority documents shows that, like the national documents, these documents contain elements of the "what", "why" and "how" of policy. They echo the principles espoused in national policies, however, like their national counterparts, they also express ideas which fit more than one model.

Sometimes, as in the case of "Arrangements for School Leavers who have Special Educational Needs", they appear to be in direct opposition to the principles espoused in national documents. Like the national documents, the local ones also use discourse as a tool of agency and constraint. For example, in the Joint Community Care Plan staff are encouraged to "own" the policies, however, it can be argued that this "discourse of ownership" disguises power relationships and legitimises the Plan. Once again this discussion has demonstrated the inter-relationship amongst policy texts, ideologies and discourse (see Chapter 3, Figure 11, p. 139). Moreover, it highlights how national policies can be constrained and distorted by "street level bureaucrats" (Weatherley & Lipsky, 1985). As Parton (1994) points out:

> ...the exercise of power takes place via an ever shifting set of alliances between political and non-political authorities. Professionals and other 'experts' are crucial to its operation, but they also have their own interests and priorities which means that day-to-day policy and practice are neither unified, integrated or easily predictable.
> (Parton, 1994, p. 12)

THE NATURE OF LOCAL SERVICE PROVISION

In Fogart schools initiate the Future Needs Assessment process and inform the social work department. The process begins when the young person is between the ages of fourteen and a half and fifteen years of age and the final meeting is held two or three months before the young person leaves school. At the initial meetings, the young person and their family are supported by a social worker from the Children and Families Disability Team and this worker also attends the FNA meetings. As the school leaving date approaches, information is passed onto the social work Community Care Team. A member from this team visits the young person and their family, carries out an assessment of their needs and attends subsequent FNA meetings. However, if planning for post-school is:

> ...likely to take some time and require additional support then the case will be referred to the relevant Community Care Team for joint working.

> This referral should take place at least one year before planned school leaving date. At this point the young person will be open to both teams.
> (Education Services, 2002, p. 21)

In such cases, information is then passed on to the Post 16 Working Group whose remit is:

> ...to allocate funding for care and support costs from the Post 16 Working Group budget and to collate information on a Fogart wide basis about needs of service users. This will assist in the planning, development and commissioning of resources for the future.
> (Fogart Council, 2003, p. 6)

The group consists of social work managers and team leaders from both children and adult services, plus the education liaison officer whose role is to feed in information about support requirements, identified by the young person's school, to the post-16 group. By the time of the final review meeting, provision and funding should have been identified "to ensure a smooth transition from school" (Education Service, 2002, p. 22). However, this does not always happen for young people with profound physical and intellectual disabilities:

> Jillian (voluntary sector): ...what tends to happen is that people find out whether or not they are going to have an appropriate day service in the last few months before the young person leaves school... and there tends to be a last minute scramble, a last minute panic and a situation which could have been dealt with in a measured way becomes an emergency and that shouldn't happen. There are various planning groups who are trying very hard to address this and I think the reason why it becomes an emergency is because there is a basic lack of resources.

However, there is specific funding for this group in Fogart:

> Pauline (social work): ...whether or not there is enough I think is the question and whether or not it will remain a separate focus, I think is the question as well, because that will depend very much on... There's going to be quite a significant change in leadership in the social work service in Fogart, so it will depend very much on what their view on that will be.

At present, Fogart has three day service provisions for young people with "complex needs". All of the units are run by voluntary agencies and funded either entirely by the social work department, or using a mixture of Independent Living Fund monies, Direct Payments and social work funding. However, none can meet the needs of young people with "complex healthcare needs" and as seen in Chapter 5, the family carers are "on call" should the young people require nebulisation, suctioning or replacement nasal gastric or gastrostomy tubes.

As regards short break services for this group, there is currently no provision:

> Jillian (voluntary sector): There is a great deal of work going on at the minute, spear-headed by several very active, or a few very active family carers to try and fill this gap and I think the social work department are fully behind this and have in fact invested quite a lot of money on an interim proposal but currently health funding is still uncertain. Hopefully this will resolve itself in the future but it is the situation at present.

Health services for this group post-16 are fragmentary. There is little or no co-ordination of services and families are left to manage healthcare services on their own. Whilst a liaison nurse has recently been appointed, many of the "Promoting Health, Supporting Inclusion" recommendations have not been implemented.

> Tina (health): We're not perfect yet... there's a commitment... I think we do get locked into the political bit where we feel we are sometimes the Cinderella service, you know, we are the bottom of the pile, there's always a more higher profile service expansion going on for other people

> but not generally for people with learning disabilities in particular. But Fogart is not too bad in that respect, it does recognise the need and its got very strong groups as like the SAY group who has done a lot in terms of "here we are, you will pay attention to us" and we've gone a long way to public education...

In terms of developing leisure opportunities for young people with profound physical and intellectual disabilities, there has been some progress. PAMIS have held fun days for people with "profound and multiple learning disabilities", organised music workshops, wheelchair ice-skating and fund-raised for specially adapted bikes at a local country park. Although these developments give people with profound physical and intellectual disabilities a higher profile in the community, they are segregated activities. In addition, a working group under the SAY project have looked at making leisure centres more accessible to people with "profound disabilities" and have provided equipment for this group to enable them to access swimming pools in the region.

Similarly, progress has been made in terms of supported housing. Jillian describes how one young man with "profound learning disabilities" has moved into his own tenancy, supported by a voluntary sector provider:

> Jillian (voluntary sector): That seems to be hugely successful. I think it was funded under the Supporting People Team... the difficulty there was that they had to identify the need by a certain deadline which is now passed and budgets are set now, so it may be more complicated for people coming on from hereon in to get sufficient funding. But certainly there's a lot of work going on there.

There is also a working group in the SAY project which has applied for funding from the Change Fund to compile an information booklet for families about services, particularly for people with "profound and multiple learning disabilities".

From the above, it can be seen that there is a commitment in Fogart to develop services for people with profound physical and intellectual disabilities. Specific funding has been allocated to this group post-16, however, because of the high cost involved in meeting these young people's needs, the amount provided is insufficient and leads to a scarcity of provision and services. In theory there is a commitment to needs-led services but in practice the development of services is resource-led. The statutory agencies have still not managed to work together and pool resources and funding to meet the needs of this group. The development of services for this group seems to depend on the commitment of ground level staff and the existence of strong, pro-active family carer groups. The social work department has recognised this group's needs and dedicated funding and resources to this group but health services have failed to respond, despite such policies as the SAY Report and "Promoting Health, Supporting Inclusion". It remains to be seen what impact the Health Needs Assessment Report will have.

Tregaskis (2000) notes that disability studies have tended to concentrate upon the representation of people with disabilities' experiences within a social context, whereas investigations into non-disabled people's attitudes, beliefs and perspectives surrounding impairment and disability, seem to be missing from disability studies. She argues that disability research should look at the ways in which non-disabled people's attitudes to impairment and disability are constructed and maintained, as this contributes to the exclusion of people with disabilities. She contends that the social model of disability assumes that changes in non-disabled people's attitudes will only come about through social inclusion and the removal of the exclusionary capitalist system (Barnes, 1996; Finklestein, 1980; Oliver, 1990) and that this has led to a neglect of the 'attitudes issue' at a theoretical level. My development of a transactional model takes this 'attitude issue' into account (see Chapter 3). It recognises the effect of non-disabled people's attitudes on people with disabilities' psycho-emotional well-being and its importance in giving people with disabilities an emotional framework within which they can try to make sense of their own personal experiences of impairment and disability (Tregaskis, 2000). Therefore the following section looks briefly at the underlying assumptions of the family carers and professionals involved in my study surrounding the nature of impairment and disability. However, it does not consider the role which attitudes play in helping to construct and maintain the social exclusion of people with disabilities, as this is out with the scope of the study. Nevertheless, it recognises the importance of this issue if change is to occur and endorses Tregaskis' plea for disability studies to look at 'the other side of the coin'.

UNDERLYING ASSUMPTIONS ABOUT THE NATURE OF IMPAIRMENT AND DISABILITY

The underlying theories held by the professionals interviewed for my study reflected the thinking behind national policy documents. Their views about impairment and disability tended to reflect the thinking behind the social model of disability. They stressed that the young people in my study have the right to a certain standard of living and to be treated with respect:

> Pauline (social work): I don't think of it in terms of what services people need. It's what people's needs are and what can meet those needs. And I think, I really believe, that the quality of support should be at an individual level so that we can design what the individual person and their family needs. Em but I also recognise that that can result in providing services for more than one person. Em so I think that people need quality services. I also think that they need individualised services and I think they also need to be able to choose something that is completely different, that they don't have to fit into the services that are already there, if we can design something that suits the individual person.

This is in line with Dalley's client-focused model discussed earlier – people's rights are important and services should be tailored to meet needs. However, the professionals also recognised that the young people in my study are often overlooked and forgotten about when it comes to the planning, delivery and funding of services:

> Pauline (social work): Part of it is about resources which is both financial and human resources. Em I think part of it is about commitment, em in terms of agendas, you know, I think young people with "profound disabilities" are a small probably, you know, in the wider sphere of things, a small number of people but that shouldn't matter. My own view is that their families and those young people are probably, in my experience, some of the people who have the highest level of need in community care em so I think there is the thing about using resources efficiently and making sure they are focused where they need to be.

This suggests that there is a recognition that the managerial-planning model, with its concern to implement policies, often under conditions of resource scarcity, may play down underlying philosophies and principles when service provision for this group is considered. Thus their needs are often marginalised. The professionals saw person-centred planning as an essential tool to ensure needs-led services for people with "profound and multiple learning disabilities":

> Jillian (voluntary sector): ...the needs of all of us are very individual but with people with profound and multiple learning disabilities, who have very complex interacting needs, it [person-centred planning] is particularly important to ensure that services centre around the needs of the person.

The education liaison officer also stressed the young people's right to continuing education:

> Margo (education): ...ideally one would hope that young people would continue to have access to a range of experiences... similar to those that they had in education. Em the education system has moved on leaps and bounds over the years and young folks are able to access a curriculum that not only meets their needs, but affords them recognition for a lot of the achievements that they make... I think that it is very important that

> there is an opportunity to continue progress and that young people are stimulated and given a range of experiences beyond their school education and that, from what I hear, this doesn't always happen.

The family carers too, saw continuing education as one of their young people's rights:

> Catherine (Geri's mother): ...we had been told by social services that Geri could probably have the service which would mean two carers would come into the house, take her out every day in Geri's car and that would be Geri's day care provision.
>
> Anne (interviewer): And how did you feel about that?
>
> Catherine: Angry and I laughed and I said why would Geri want to have that as day care provision when we can do that any day of the week. That is not day care provision because Geri will need therapies. We actually, what we were looking for for Geri was for Geri to go on somewhere else and it would be like further education. We didn't want her to go to a day care centre where she would sit in her chair listening to her music all day because that is not what we want for Geri. We didn't want someone to take Geri out in the car to take her round the shops and sit in coffee malls all day.

Similarly, both the professionals and the family carers saw it as being the young people's right to have the opportunity to live independently from their family carers, either in their own tenancy with support, or in supported housing:

> Maureen (Simon's mother): Well they should have the choice, they should have the right to move on too, like every young person does and it should not be institutional.

Another feature of the social model is its emphasise on empowerment. People with disabilities are seen as being socially oppressed and the recipients of discriminatory practices. However, by involving people with disabilities in research and decision-making processes they can be empowered to bring about social change. The professionals interviewed in my study reiterated these ideas. They stressed the importance of consulting people with learning disabilities and their family carers:

> Pauline (social work): It's about... involving people, making sure that everything you design and develop has been consulted on and has involved people who experience [the services], families involved with young people, that they are fully involved in the development of policies and procedures as they can be.

However, according to Jillian, professionals also need to work in partnership with families:

> Jillian (social work): It's absolutely crucial, it's a very important principle to work in partnerships with families, they are the experts on their sons and daughters' likes and dislikes, their needs and they know them closely. They are the people who are really committed and love their sons and daughters dearly and are their best advocates. And it's not enough to just consult in inverted commas, you have to be guided by families and to work in partnership with them and not just listen and then feel you've done enough. It's also crucial to be very sensitive to the ways in which the person concerned may communicate and again I think you have to be guided by the family in this because you can't possibly pick up in the same way as they do how that person is going to express choices, preferences, happiness, unhappiness and that of course impacts on what services they might be wanting to use.

The above suggests that these professionals view people with profound physical and intellectual disabilities not just in terms of their impairments, but as people who have the right to make choices and indeed are capable of doing so. Similar views were expressed by the family carers. They saw beyond their young people's impairments and regarded them as people first, as "trapped inside a body":

> Helen (Faye's mother): ...in the middle of all of those, with all the medical problems she has still got a really good sense of humour, a wicked sense of humour that we would call it and a strong personality, her personality comes through and I think that, you don't want that to be lost, she is still a person. She is not a disability, she is a person first and foremost and the disabilities come second, that is the way that we have always looked at it and that is very much how the whole family sees Faye. I think her strong personality. Strangers very soon get to see that as well so that overcomes quite a bit.

The professionals at the young people's schools also seemed to have adopted the same way of thinking:

> Catherine (Geri's mother): ...the attitude of the school, the school's attitude was all of these children in this school have special needs but it is a school and that's how we will treat it.

The family carers seemed to be more concerned with what Thomas (2002) describes as "restrictions of being" or the "psycho-emotional dimensions of disability" than with "restrictions of doing"(p. 53). Helen was very upset about the comments a centre manager made about Faye at a FNA meeting (Chapter 6) and Maureen was very annoyed about the disparaging remarks made by some members of the public about Simon and his friends going out to a pub for their Christmas lunch (Chapter 7). They were deeply hurt by these remarks which suggested that their young people, in the words of Kylie's mother were "freaks", incapable of feelings, "things" who should be hidden away and segregated from "normal" society. Other people still view this group in terms of the personal tragedy theory:

> Richard (parent in the pilot study): We were in a lift and this woman came in. She looked at Jackie (young woman involved in the pilot study) and said, "Poor wee thing". Then put her hand on Jackie's head and began to pray for her.

However, this does not mean that the family carers ignored "restrictions of doing" – what people with disabilities are prevented from doing (Thomas, 2002). As Chapter 7 shows, they wanted their young people to be socially included and campaigned for their young people's right to access community services and resources.

Moreover, the family carers tended to define impairment and disability differently from professional categorisation. Catherine, when interviewed, referred to the children at Geri's school, which was a school for children with learning disabilities, as "able-bodied":

> They hadn't had a child in a wheelchair for quite a number of years and all the other children are able-bodied...

This suggests that Catherine tends to see impairment more in terms of physical impairments or multiple impairments. The profound and multiple impairments of their young people seemed to have changed the family carers perceptions of people with disabilities. People classified by professionals as having "mild" or "moderate" intellectual impairments were regarded as "normal" or "able-bodied" and people with mobility impairments were regarded as "like us but in wheelchairs". These different views of impairment and disability support Corker's (1999) arguments that disability is "ambiguous and unstable in meaning – as well as a mixture of "truth" and "fiction" that depends on who says what, to whom, when and where" (p. 3).

In line with the social model, the professionals tended to view disability in terms of societal barriers. The "problem" is not the person with disabilities, but the lack of appropriate goods and services:

> It [the social model] does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation.
> (Oliver, 1996, p. 32)

This is illustrated by their emphasis on social inclusion:

> Jillian (voluntary sector): ...community inclusion, ensuring that people can take part, just as you or I can, in all the opportunities and events that go on in the community. But nevertheless, because of their complex needs, they will still need extra support to this, so you have to provide that if inclusion is going to be a reality. And I think it's that recognition of people's very special needs, which really has to be in place, otherwise they just don't take part in things. And that particularly applies to health and personal intimate care needs.

This is reiterated by the professional from health. Although she describes her role in terms of assessing the healthcare needs of people with learning disabilities and the planning, giving and evaluation of care and treatment, she also sees herself as an "enabler", promoting:

> Tina (health): ...inclusion to mainstream services, [helping people with learning disabilities] to access mainstream services and primary healthcare services and we would see ourselves as enablers of that.

From the above, it is evident that both Tina and Jillian recognise that in order for young people with profound physical and intellectual disabilities to be included in society, not only must social barriers be dismantled, but also there needs to be a recognition that illness and impairment also cause "restrictions of activity". Therefore their thinking is more in line with Thomas' (1999) social relational definition of disability (see Chapter 2) than Oliver's definition quoted above. Thomas' definition of disability recognises that some restrictions of activity are caused by physical, sensory and intellectual impairments – "impairment effects" (Thomas & Corker, 2002). This is emphasised by Jillian in the quote above. She recognises that impairment effects need to be considered if people with profound physical and intellectual disabilities are to be included in society.

This is also the view held by the family carers in my study:

> Maureen (Simon's mother): And their health will always have to be at the forefront, I mean always, always.
>
> Helen (Faye's mother): It is health that dominates their whole life. I mean I know health is important to everybody but it actually dominates their quality of life.

However, this does not mean that the family carers favour an individualistic medical model. As Chapters 5-7 show, they do not see their young people as somehow "lacking" or unable to play a "full role" in society. Nevertheless, their emphasis on "impairment effects" suggests that the social model cannot account for all of their lived out experiences. As Humphrey (2000) states:

> ...the social model harbours a number of virtues in redefining disability in terms of a disabling environment, repositioning disabled people as citizens with rights, and reconfiguring the responsibilities for creating, sustaining and overcoming disablism.
> (Humphrey, 2000, p.63)

However as Dewsbury, Clarke, Randall, Rouncefield and Sommerville (2004) argue:

> ...in the matter of what we call "practical politics", that is the quite ordinary business of making-do, managing, coping... it is for the most part empty.
> (Dewsbury et al., 2004, p. 150)

From the above, it is evident that the professionals involved in my study adopted many of the assumptions associated with the social model of disability. As Dewsbury et al. (2004) argue this is hardly surprising as social constructivist arguments have resulted in assumptions related to one kind of expertise, namely that of the scientist, medical practitioner and therapist, being replaced with assumptions that privilege other forms of expertise, such as that of sociologists or people with disabilities. However, the above discussion suggests that there is a growing recognition of impairment effects and a shift in thinking which is more in line with Thomas' (2002) social relational definition of disability than Oliver's social model definition. Moreover, as my study shows, the family carers' concerns centred around both restrictions of doing and being. All of this suggests that thinking surrounding impairment and disability may be changing.

SUMMARY

This chapter attempted to apply the techniques of discourse analysis to key national and local documents concerning people with learning disabilities and the transition period from school to post-school provision. It used three levels of analysis – the "why" of policy (ideology), the "how" of policy (discourse) and the "what" of policy (text) (Kenway, 1990). It has shown that although the "what" of policy involves policy text, it also needs an understanding of textual meanings or discourses, as well as an understanding of the values, ideals and beliefs that they promote. Similarly, the "how" of policy involves an understanding of policy discourse, but this requires to be "read off" from texts and explained in terms of particular ideologies. The "why" of policy is mainly concerned with ideology but like the other questions it also requires reference to discourse and text to provide a full understanding (Gale, 1999). Thus these three levels are inter-related and influence one another (see chapter 3, Figure 11, p. 139).

The chapter also showed that these documents present "reality" in a particular way, in the words of Humes (2000):

> "Reality" becomes malleable, another commodity that can be packaged and marketed. What emerges is an Orwellian world in which words mean something other than that which they ostensibly denote. Thus "empowerment" involves taking on additional responsibilities without additional power; "ownership" requires unreflective acquiescence... and "consultation" is a process to be managed rather than a source of insight. (Humes, 2000, p. 46)

Furthermore, analysis of the documents showed that they disguised, or tried to hide, the imbalance in power relationships amongst policy-makers, professionals, people with learning disabilities and their families. However, it is still the voices of people who exercise authority and have access to privileged knowledge that remain dominant (Blackmore, 1996).

The chapter also looked at the underlying assumptions of professionals and family carers about the nature of impairment and disability. It found that the professionals involved with my study adopted many of the assumptions of the social model of disability, whereas the family carers tended to favour Thomas' (2002) social relational definition of disability which recognised impairment effects. This suggests that the social model may need to expand to incorporate impairment, or maybe a new model needs to be developed so that all people with disabilities are included.

To conclude, this chapter has shown that the lives of people with disabilities are dependent on social, political, ideological and economic factors. Therefore enhancing the quality of their lives requires changes in these powerful factors, if innovative services are to succeed.

Chapter 5 The reality? The young people's stories

This chapter focuses on the transition period from school to post-school provision from the perspectives of four young adults with profound physical and intellectual disabilities and their families. It tells the young people's stories – their experiences of schools, Future Needs Assessment (FNA) meetings, the transition process and their post-school placements. This is done through the eyes of their family carers as all of the young people have no speech and limited forms of communication. As I believe there are lessons to be gleaned by looking at the young people's school provision, the chapter concludes by looking briefly at the schools they attended. This chapter highlights the importance of people as social actors and their ability to resist the physical, material and social structures and processes which create impairment and disability.

THE YOUNG PEOPLE'S STORIES

Faye's story

Faye is twenty-six. She lives with her Mum and Dad in Devenport, a town in the west of Fogart. Her mother, Helen, is a full-time carer. Her Dad, Gordon, is an accountant and works for the local council. The couple have been married for twenty-six years. Faye's younger brother, Garry, is twenty-one and is studying politics and history at Edmington University. He now lives in Edmington but comes back home for visits.

Lack of oxygen at birth resulted in Faye being profoundly physically and intellectually disabled. She suffers from cerebral palsy and spastic quadriplegia. She is unable to sit up on her own or hold her head up. She wears a body brace and neck collar. Faye also has asthma and chronic chest problems. She requires nebulising at least twice a day to prevent asthma attacks as well as postural draining, percussion and frequent suctioning to help remove secretions from her chest and lungs:

> Helen (Faye's mother): ...the tube goes into her mouth and you are actually going down into her throat to activate the cough reflex and she coughs then, and the tube is part way down her throat and whenever the secretions, when she coughs them, you suction them away because it is quite an amount that builds up and she actually... She can be OK for most of the day but if she gets tireder towards the late afternoon and evening, we find we have to suction her more then because she is tired, she can't cough the same and the secretions build up more then.

When Faye was a baby she took myclonic jerks and medication was used to suppress this. However, with the onset of puberty, Faye started taking grand mal seizures and she was prescribed an anti-convulsant drug. Fortunately, now her fits seem under control. At nineteen Faye underwent an operation whereby a tube was inserted into her stomach and she is now gastrostomy fed:

> Helen: ...that has made a tremendous difference to her general wellbeing whereas before we struggled to get her to eat anything, drink anything... She aspirates less because she used to aspirate when she was eating and drinking but it still hasn't diminished the chest problems. They have actually increased but I think they would have been more if she hadn't had the tube.

Faye needs twenty-four hour a day personal care:

> Helen: I get Faye up about seven and she goes out at quarter past nine so it is from seven till quarter past nine. You are on the go the whole time, it's two and a half hours getting her ready to go out.

She is doubly incontinent, needs fed, dressed, washed, bathed, toileted and requires daily physiotherapy. During the night she requires turning to prevent pressure sores, suctioning and feeding. All of the family can carry out the personal care and medical interventions that Faye requires:

> Helen: The physiotherapist actually gave me the training for it, she put me through it all and I carried it out... that gave me the confidence then to come back, show my husband what to do, show the carer what to do and my son and it has worked well.

Faye has no speech but communicates using eye pointing, facial expressions and crying. She responds to yes/no questions, looking to her right for yes and to her left for no. Her mother describes her has having "a wicked sense of humour and a strong personality". She sees the funny side of awkward situations and tends to laugh at people's misfortunes. For example, she laughed when her mother fell on the ice when Faye was curling. Her facial expressions suggest that she enjoys listening to music, having her nails painted, her hair done, visiting the horse riding centre and going out.

School

Faye went to Westfield school, a special school out-with her region, run by a voluntary organisation. She travelled the twenty-nine miles there and back to the school on a daily basis. The school specialised in providing education for children with cerebral palsy:

> Helen: ...it was a multidisciplinary team with teachers, physiotherapists, speech therapists, occupational therapists, care assistants, social workers, the whole gamut, everybody was there and they worked together in the classroom in quite a holistic way with the children. Their programmes were all individually set out to bring out the best in that child, the potential that they had. Their targets weren't unrealistic targets, the targets were achievable targets for each child which gave encouragement both to the parents and the children when they were met and they very much encompassed the whole family in the care of the child as well. Their social, they had a social life as well where the parents, the family,

> were included and they took the kids away on holiday each year when they were in senior school and very much a relaxed but professional way that they worked and we were very pleased with everything there.

A comprehensive health care package was also provided "in house" at the school:

> Anne (interviewer): They coped with her medical care as well as her education?
>
> Helen: Yes, the nurses were there and they met with everything, in fact they had the paediatricians, the orthopaedic surgeons, dentists, ophthalmologists, all the associated clinics that you would go to hospital for. They all went into the school and the consultants all went into the school, they had their clinics there, the child would never have to be taken out and have to sit in a hospital for a length of time, for waiting times and the parents went across at the appointed time and any problems, they were all met with there and it was far better than breaking up a child's school day and taking them out.

The family were pleased with the provision provided by the school and felt it met all of Faye's needs – physical, emotional, educational, social and healthcare needs:

> Helen: ...you know what they say, you never miss the water till the well runs dry... I appreciated the school when she went to it but I think I appreciated it even more after she left and I realised just what was the things that they did, it was just, it was part and parcel of their day and they did it so well.

Future Needs Assessment process

At Faye's first FNA in 1988 her parents were told that Fogart had currently no provision for people with Faye's needs. They had centres for people with physical disabilities and centres for people with learning disabilities but no provision for people with multiple disabilities. Although Faye's parents felt anxious about this gap in provision, they were assured that by the time Faye was ready to leave school "something will turn up".

However, as school-leaving age loomed, no provision had been identified and Faye's parents went to visit the Everly Centre which was out-with the region. They found that this centre could meet Faye's needs. However, Helen and Gordon were uncertain as to whether Fogart would provide the funding for this placement. They went to see Fogart's director of social work but he would not guarantee funding for the Everly Centre. Nevertheless, he suggested that they apply for a place for Faye at the Everly Centre but also look at provision in Fogart. After a considerable time lapse Faye's application was turned down on geographical grounds.

Meanwhile Fogart began to identify places for Faye, and Helen and Gordon went to visit them. They became increasingly discouraged as they felt that none could met Faye's needs, especially her physical and healthcare needs. Eventually the Fraser Centre was identified as being able to meet Faye's physical needs. The family visited the centre, expressed their wish for a placement for Faye and were told a placement was available for her. However, official confirmation was received only a few days before Faye was due to leave school at the summer holidays. Thus an extension was granted to Faye so that she could remain at school until she was eighteen and a half in order to ensure that a smooth transition could take place.

After the summer holidays a meeting was held to discuss Faye's transition period. Prior to the meeting the assistant manager from the Fraser Centre came to the school to observe Faye at school and at the subsequent meeting she:

> Helen: ...launched into what I would describe as a tirade against Faye going to the Fraser Centre. She wasn't their normal client if you put it, she was appalled at the degree of learning disability that she had apart from the physical disabilities, this learning disability really put to her real problems. We even got the occupations of the people who attended the Fraser Centre, like we have bank managers, accountants, we have all

> these people who were suffering from MS, recovering from a stroke, from head injury, from something.
>
> Anne (interviewer): So she was insinuating that Faye wouldn't fit in?
>
> Helen: Yes, Faye would not fit in. She didn't even hint, she definitely stated that she was not the type of person for the Fraser Centre.

Everyone at the meeting was astounded at the turn of events. The meeting was abandoned as it appeared that the offer of a placement at the Fraser Centre had been withdrawn. Helen and Gordon and the social worker each lodged a formal complaint and the transition period was put on hold until it was confirmed that Faye still had a placement at the Fraser Centre. As Helen had expected this meeting to be an informal one to discuss Faye's transition to the Fraser Centre, Gordon had not gone with her for support. As it turned out this was an extremely upsetting meeting for Helen:

> Helen: I wouldn't cry in front of her but I did break down for the first time I broke down when I went out. We went into the headmistress', head teacher's room and I'm afraid I broke down then... My husband was furious when he got home to see how upset I was and we certainly didn't want it upsetting Faye because we had to think positively, we had her future to think on... There was no choice, that was the only centre, there was no luxury of a choice, she either went there or she stayed at home with me and I am afraid that wasn't an option, we had to get things sorted out... we put our differences behind us... they assured us that nothing like that would happen in the future and that it would be... everything would be done positively for Faye.

Things were sorted out and Faye started at the centre after a three month transition period.

Transition

Originally Faye was granted an extension to eighteen and a half to allow a six month transition period from her school to the Fraser Centre. However, because of a lack of communication between the agencies involved, the transition period only lasted three months, as it took three months to confirm Faye's placement at the Fraser Centre. Despite these initial problems, Helen describes Faye's transition period in favourable terms:

> Helen: ...and I have got to say it did go through eventually, the transition period did go through, they had to bend themselves backwards to make sure that it went through smoothly.

Faye was appointed a key worker from the centre and a physiotherapist, and they visited the school and worked with Faye and the school staff. During these visits the centre staff developed a relationship with Faye and gained knowledge about Faye from the school staff. Unfortunately, the school did not have sufficient staff to visit the centre but Helen went with Faye on her visits to the Fraser Centre and passed on her expertise and knowledge to the staff. After several of these visits, Faye began to attend the centre once a week and the school the remaining four days. Gradually attendance at the centre increased until Faye attended the centre five days a week.

Post-school placement

Faye has been attending the Fraser Centre for almost nine years now. It is run and funded by the social work department. The majority of the people who go there have physical disabilities resulting from strokes, head injuries or accidents. However, there are also two other young people with learning disabilities and needs similar to Faye's. The centre caters for seventy adults ranging from eighteen to sixty-five years. Most of the people who attend the Fraser Centre go there on a part-time basis.

Initially Helen and Gordon were assured that the centre could meet Faye's physical and medical needs but Faye's health has deteriorated over the years and she now requires nebulisation and suction, procedures which the centre are unable to carry out:

> Helen: ...if Faye became wheezy, if she was there and she needed nebulising, she [the physiotherapist] could carry it out because she was a health board employee and she was a physiotherapist and she could nebulise her but no-one else could. If she wasn't there it was agreed that I would be contacted and hence the reason I am always on call. I would be contacted and I would need to get up to the Fraser Centre. Now I am half an hours drive away and that was providing that I was at home, it would take me half an hour to get up there to nebulise her. In the meantime if they couldn't get me or they felt that with me going up there it was too long the only option is to take her to the hospital, is to get an ambulance, 999 and get an ambulance where she would be nebulised and they would give her oxygen as well and she would be taken to the hospital... I am on call all the time... if I am going any distance out-with you know the local shopping area or visiting or that, I have got to know that my husband is in the office that day because he can be contacted because he is the second person to contact.

At first, Faye was given a five day placement but this was reduced to a four day one. The staff felt Faye was "lethargic" and needed a break in the middle of the week to "recharge her batteries". However, Helen and Gordon felt that Faye's lack of interest in some of the activities offered, was due to them being inappropriate for Faye. Therefore, they asked for a psychological assessment:

> Helen: They did quite a lengthy one, they kept a diary at the centre, we kept a diary at home, they observed her at the centre and they had lengthy discussions with us. They met with Faye's carer at home and they just went over everything that we were doing and they went over everything that they were doing at the centre. It was quite a detailed report in the end and it highlighted everything that we had said, that she needed one to one, that the attention, her attention span was short and they felt that the activities, the group activities that they were including

> Faye in were too long, much much too long and that some of the activities were inappropriate for Faye, that they were beyond her comprehension, beyond her ability, so it gave the centre, it gave them a more concrete thing to work on, it was in black and white and her timetable was looked at and her activities changed and we settled back into a much better pattern after that but it took quite a bit of pushing, it took quite a lot of arguing you know along the way that they look at this and it is still, they can still slip back into... different things.

Helen and Gordon also feel that Faye needs more therapy input. Although there are no formal music therapy sessions at the centre, music plays an important part in the life of the centre in the form of music groups, the playing of instruments, and listening to and enjoying music. A speech therapist also works closely with centre staff on communication aids with Faye and she currently uses a "Big Mac". However, Helen and Gordon would like to see more physiotherapy provided for Faye at the centre. Originally Faye had three physiotherapy sessions a week but this has now been reduced to one with a care assistant. Moreover, her hydrotherapy sessions have ceased, as the physiotherapist claims Faye is not co-operative or motivated enough in the pool. However, Faye now receives massage sessions to help increase her circulation. Staff claim that Faye now only requires "maintenance physiotherapy". Helen and Gordon disagree:

> Helen: I have argued till I was blue in the face about the amount of physiotherapy that I felt Faye needed... I was getting absolutely nowhere so the way that we tackled it was to just take it on board at home and keep her level of physiotherapy at home...

They found that increasing Faye's physiotherapy, improved her tone and reduced stiffness. Despite these problems, Helen and Gordon feel they have good relationships with the staff. Moreover, Faye enjoys going to the centre and interacting with the other members, although there have been some members who have resented the high level of care that Faye needs. Helen describes Faye's placement there as:

> Helen: ...not ideal, I have got to make a compromise if you like that it is not what I would really want but until I can get what I really want we have just got to accept that this is the only thing that is there for her.

Simon's story

Simon is twenty-one. He lives with his Mum, Dad and elder brother, Colin. Colin is twenty-three and works for an engineering company. Maureen, his Mum, is a full-time carer and his Dad, Stuart, works as a Health and Safety Inspector for the same engineering company as Colin. The family stay in Glendinning, a town in central Fogart. Maureen used to work part-time when Simon was younger but she had to give her work up:

> Anne (interviewer): So do you work?
>
> Maureen (Simon's mother): No, I do not work unfortunately. I used to work part time when it fitted in with my youngest one Simon but times and basically tiredness.
>
> Anne: Looking after Simon you were too tired
>
> Maureen: Yep
>
> Anne: ... and trying to fit it round...
>
> Maureen: Trying to fit round day to day life it's impossible to work basically.
>
> Anne: So you really need to be...

> Maureen: A full time carer, yes.

Simon suffers from cerebral palsy due to a difficult birth. The umbilical cord was wrapped around Simon's neck and he suffered from lack of oxygen:

> Anne: Was it a difficult birth?
>
> Maureen: It was, it was a difficult birth yes. They had to get him out really really quick because the cord was really strapped tightly round his neck and when they got him out quick, they actually ripped me in the process and had to take him away for oxygen because there was no oxygen in the room whatsoever and he was away for about an hour with nobody telling us what had happened etc. etc. so we had to just wait and according to them he was OK and a couple of days later he had this big lump came up on his shoulder where they had cracked his collar bone with getting him out quick and trying to get the cord off his neck but they said that was just a normal process of birth.

Simon can sit but he cannot walk or crawl. However, he can weight bear and roll, although his rolling is unco-ordinated and non-functional. For example, if he sees a toy at one end of the room, he may roll to the other side of the room, believing that he has reached the toy. He can clap his hands and grasp toys but his grip is weak. He has no fine motor skills. Simon has no speech and communicates through facial expressions, vocalisations and gestures. For example, he screams when he is happy or unhappy but the sound is different and he can reach out for objects he wants.

Simon is profoundly physically and intellectually disabled and requires twenty-four hour care – washing, dressing, feeding, bathing, toileting and daily physiotherapy:

> Maureen: Every morning he has to be taken physically out of his bed and washed and fed and then he has, I mean he has his night clothes taken off

him, his day clothes put on and to be put in his wheelchair. Day to day in the house as in not in day care?

Anne: Yes.

Maureen: Then he has to be entertained, either by going out in the car or singing songs or putting some music on for him and it is a constant... to make sure that he is OK. Then it comes round to lunch time, then he has got to be fed again and it is the same process all the way through and then he has to have nappies changed constantly as well. Keep him entertained in the afternoon.

Anne: Do you have to give him any medication?

Maureen: He has medication for epilepsy. He has that first thing in the morning and last thing at night and he also has hay fever unfortunately. He has got to have this medication in the morning as well. Then at tea time we have to feed him again but all his feeding, all his food, he actually can't chew so he only can tongue lash, so with his food we have got to make sure that it is, not liquidised, but mashed up to a soft consistency. At night time he likes to relax on the floor and we put toys and different things round about him just to keep him happy and occupied, making sure that he is OK and then it comes to bath time or shower time and then we have got to put him in the bath and wash him and dry him, put his pyjamas back on and then it is feeding time again, supper because he likes his food, constantly and then he will maybe have a wee relax watching the television for a wee while before he goes to his bed but it doesn't stop at bed time because then through the night he could become agitated or he just wants company basically because he doesn't like being on his own at all and we have got to get up through the night and we have also got to change him, nappy change him and then every second night before he goes to his bed we have to give him

> suppositories for the toilet because his bowels just will not... the brain does not tell the bowels to work so this suppository is just like a wee reminder for the brain to make the brain work.

Simon becomes very excited when his coat is put on because he knows he is going outside, either in the car or for a walk. His increased vocalisations and bodily movements also suggest that he enjoys watching the family's pet dog running around, watching television and listening to music. His favourite television programmes seem to be "Countdown" and "Blockbusters", as he becomes very animated when he hears their theme tunes. Moreover, his facial expressions suggest he enjoys watching these programmes.

School

Simon went to a special school in Bamchester, nine miles from his home, run by the local authority. Maureen and Stuart chose the school Simon attended after visiting various schools in the area. Maureen describes Simon as having:

> Maureen: ...quite a good time at the school because everything was provided for him, education, physiotherapy, occupational therapy, music therapy, all the different therapies at the school and it was really good. And he had a good time apart from the long eight weeks holidays, it was a nightmare.

Although Simon's school provided segregated provision, attempts were made to include them in the local community:

> Maureen: Socially they were out and about as well, at different things. Plays, concerts and out in the local community. They did this quite a bit, go out to the local community and trying to integrate the kids so they were really good.

Future Needs Assessment process

Simon's first FNA meeting did not take place until Simon was fifteen, due to organizational difficulties in getting all the professionals involved with Simon together. Simon's family were made aware at this first FNA meeting in 1995 that there was no provision in Fogart that could meet Simon's needs and subsequent visits by Maureen to centres in Fogart confirmed this.

Maureen and other parents of children with similar disabilities then formed a group to persuade the local authority to provide provision. The group compiled a report showing the numbers of young people likely to be requiring post-school provision in the next five years and highlighted gaps in provision (see Chapter 4). They managed to persuade the social work and education departments and the local health board to form a working party to look into the matter. This working party, of which Maureen was a member, produced a report and as a result a development officer was appointed to compile an action plan. These events took place over a period of four to five years.

Meanwhile, at subsequent FNA meetings it was suggested that a package of care be provided for Simon:

> Maureen: ...but that all fell by the wayside as well and I thought well we don't need that, we are practically looking after them 24 hours a day, we don't need to be caring for them through the day as well and also we felt that if this did stop, the education that he was having and the input from the different therapies, physio, speech etc. that Simon being Simon, quite a lazy person, that he would just go into a shell. He wouldn't progress, he would actually take backward steps, he would... life really wouldn't be worth living for him, it really wouldn't.

When Simon was seventeen Maureen and Stuart were told at the FNA meeting that the local authority was considering setting up small units for people with profound physical and intellectual disabilities but they were unable to give a timescale. Meanwhile, Simon was approaching eighteen. Maureen and Stuart did not ask for an extension to nineteen as they felt Simon would not benefit from another year at school. Moreover, they felt that it was now the social work department's responsibility to provide provision. However, when Simon left school there was no provision for him and he had to be looked after at home by his family. It was a year and three months before provision was established for Simon:

> Maureen: I was absolutely shattered I have to admit, 24/7 [looking after Simon twenty-four hours, seven days a week] to look after Simon to try and be a wife and a mother to my other son as well and my husband and I was very tired, absolutely exhausted... I was just, I just felt I was hitting my head off a brick wall, I was tearing my hair out, I was absolutely screaming blue murder at them and they weren't listening so I had to go to the Press. So unfortunately it wasn't a very nice thing to do for to display my troubles to the whole of the Glendinning area but I felt it was the only thing that I could do to pressurise, to shame, is that the right word, to shame them into providing a place and to let everybody know that this is what was happening to me and my son. So he was front page news of our local newspaper with headlines 'Nowhere to go' which was quite appropriate because he had nowhere to go, he was stuck at home.

Three months after telling Simon's story to the Press, Maureen was informed by the social work department that a unit run by a voluntary agency was being set up to provide daycare provision for young adults with profound physical and intellectual disabilities. Maureen "was a bit dubious about [it] at first because they had only been involved with child care". However, she felt happy that Simon was at last being offered provision. Unfortunately, the starting date for the project kept being postponed and Simon was not able to start the transition period to Lemington Court until three months later.

Transition

At the end of the Future Needs Assessment process, Simon was left with no day provision and remained at home. His mother, Maureen, received no extra support from the social work department. However, both her husband, Stuart, and her elder son, Colin, gave her substantial support in her caring role, despite both being in full-time employment. During this period Maureen felt that Simon became frustrated, unhappy and was beginning to loose some of his skills:

> Maureen: The weight bearing was starting to tell, definitely the weight bearing was starting to tell and the communication skills, his communication, he was just sort of starting to withdraw slightly into himself.
>
> Anne: And did you have signs of him being unhappy then?
>
> Maureen: Definitely, screaming every single day, it was more frustration because he wanted to be out and about with different people other than myself. Even if I took him, if we managed to get him down in the town centre and things like that, he still wasn't happy because he wanted to be with his friends and he had no friends at all, he was left with nobody.

Despite constant telephone calls to the social work department, no provision was forthcoming. Maureen's husband became very angry and threatened to leave Simon at the social work department but to no avail. After fifteen months of having Simon at home, staff from Lemington Court came to visit Simon at home and he began to make visits to the unit; at first for one day a week, gradually building up to four and a half days. This was a very stressful time for the family. Maureen describes it as a "total nightmare".

Post-school placement

Simon has been attending Lemington Court for nearly three years now. He goes there four and a half days a week. Lemington Court provides short breaks for children with special needs at weekends and during the school holidays. It is run by a voluntary agency. However, it is opened during the week to provide day facilities for young adults with profound physical and intellectual disabilities. It is funded by the social work department and caters for four young adults between the ages of nineteen and twenty-one.

At first Maureen had concerns about the provision that would be provided for Simon but after having him at home for over a year she felt any provision was better than none:

> Maureen: Basically I was wanting an extension of the school but more young adult appropriate, for them to be with other young adults, more community based but I thought the learning and the education and the... the things that he had learned so far, I thought they would have maybe been wiped out. I really had a vision of it being like the different units that we went to see at first through that transition period and there was not much happening at these units when we went to see them and I had visions of Simon just being looked after, just looked after from Monday to Friday but by this point, to be quite honest, I wasn't fussy, I was needing him to be looked after Monday to Friday and I thought well if he gets in there then we can maybe fight to see if we could make things happen when he is there...

However, she is pleased with the provision there. She feels that Simon has a high level of therapeutic input — physiotherapy, hydrotherapy, music therapy, speech therapy — and that Simon enjoys a wide range of activities with his peer group such as swimming, baking, drama, tenpin bowling, going to the cinema and going on holiday with other members of the group. Maureen and Stuart feel they have good relationships with the staff and that they are welcome at the unit. The staff communicate with the family on a daily basis — formally through a diary and informally as the staff are also the escorts on the transport to and from the unit.

Yearly reviews, involving parents, staff and other professionals, are also held to discuss Simon's progress.

Lemington Court, however, was originally set up as a three year pilot scheme. It was suppose to provide provision for the young people until a new facility was set up. This new facility has not materialized and provision at Lemington has been extended for another three years. Maureen and Stuart are concerned about what will happen when the three years are up. By that time Simon will be nearly twenty-five and the voluntary agency's constitution, at present, does not permit them to provide services for people over twenty-five years old:

> Maureen: ...and the only thing that really bothers me now is what happens after this three years. Do we go back to square one? ...The future is in the balance at this moment...

Kylie's story

Kylie is twenty-one. She lives with her Mum, Joyce, and Dad, Bobby, in Kingliston, a town in central Fogart. Kylie's elder sister, Katrina, lives in England. She and her partner have recently had another daughter, making Kylie an aunt for the second time. The two families visit each other frequently. Joyce is a full-time carer and Bobby is a self-employed car mechanic.

Joyce suffered from eclampsia and toxaemia while she was pregnant; the placenta had stopped functioning and Kylie was starved of oxygen and food, as a result Kylie was born three weeks early by emergency caesarean.

Kylie suffers from cerebral palsy and epilepsy. She has scoliosis of the spine, dislocated hips and clubfeet but is able to move around by "bunny-hopping" (by transferring her weight back and forwards from her hands to her knees):

> Joyce (Kylie's mother): She is able to bunny hop around on the floor. She could manage up and down a couple of steps as we have got a dropped living room and then you know, it's a what is it you call it...
>
> Anne (interviewer): A sunken area.
>
> Joyce: Aye, aye so she comes up and down the two stairs and if she wants you, she can crawl to you and depending on which side, she can sit up and get up on the couch on her left hand side, that's her strong side and basically she is mobile, she has got mobility on her knees in the sense that it lets her go back and forth into any room that she wants to be in. Likes if the washing machine is on and she wants to go into the kitchen she can then proceed to do it on her own or into what we call Kylie's corner with certain toys that she has, plays with. So she has got the mobility that she can keep herself occupied and get from A to B if she needs to be.

Kylie is also able to crawl, weight-bear and sit up unsupported. However, her profound physical disabilities mean that she is totally dependent on others for her personal care. At the moment Kylie's epilepsy is kept under control by anti-convulsant drugs. Kylie also requires suppositories to aid bowel movements and is prone to chest infections.

Kylie communicates with people through gestures. She bunny-hops towards people and pulls their arm to gain their attention and express her desire for social interaction. She demonstrates her wish for affection by putting her arms around people and by putting her head forward to receive a kiss. Flinching, grimacing and scrunching up her eyes indicate displeasure. She indicates negative responses by lowering her head and putting her hand up. When in discomfort or pain she makes moaning noises and places her hand on the body part, which is causing her discomfort.

Kylie loves socialising, interacting with people and one-to-one contact, as can be seen by her smiles and increased animation when she is with people who chat to her. She especially enjoys playing turn-taking and action games with her Dad:

> Joyce: ...socialising with people and interacting. She loves the one to one contact that she has with people that they give her, she likes going out in the car or the day care bus if they are taking them out. She likes being out in her wheelchair. She likes television programmes such as Countdown, Blockbusters, Wheel of Fortune, Family Fortunes where you are getting all the noise activated responses, I have that on tape for her and when she is bored of a week-end when she is in the house with us I put it on and it keeps her happy and she jumps and gets all excited when she hears all the noises that she likes and playing with her dad, that is her main hobby, playing with Bobby. He does put a lot of input into her on the play side. I am the one that feeds her and gives her her enemas and brushes her teeth.

Kylie also enjoys playing with musical toys. She tends to choose a musical toy when presented with a variety of toys. She becomes animated when she hears popular soap opera theme tunes. Swimming is also one of her favourite activities as can be seen by her laughter and smiles.

School

Kylie attended the Ralph Harrison school, a special school run by the local authority in the grounds of a long-stay hospital for people with learning disabilities. She attended this school from the age of six until she was nineteen. Previously she had attended the special school in her local area but Joyce was dissatisfied with the provision and persuaded the education department to let Kylie attend the Ralph Harrison school:

> Joyce: I have nothing but praise for it, it was excellent. The input that they put into Kylie and it was top class, right from day one to the end of her time at Larchfield, eh Ralph Harrison, so I have no complaints about

> that whatsoever, always good, great input, great therapy, overall it was great and the teachers and parents, one to one, you could go in at any time. There was not any problems, so basically that was it.
>
> Anne: And they provided therapists to the school as well?
>
> Joyce: Yes they were all... worked in connection with the school, physios, OTs, speech therapists, they had everybody, the music, the art input aye, everybody.

Future Needs Assessment process

Kylie's first FNA meeting took place in 1995 when she was fourteen. At this meeting Joyce and Bobby were assured that provision would be available in Fogart for Kylie when she reached school leaving age. Moreover, the family would have a choice of placements which would be able to meet Kylie's needs.

At the fourth FNA meeting, when Kylie was seventeen, Joyce and Bobby felt it was time for a placement to be identified for Kylie. Although representatives from the social work department were invited to the meeting, no one came, much to everyone's disappointment. However, a representative from the St Catherine Centre (a centre for adults with learning difficulties) attended the meeting as the centre had been identified by the social work department as an appropriate placement for Kylie. She listened to Kylie's school report and said that the St Catherine Centre could provide provision for Kylie. However, her description of the activities offered by the centre made Joyce and Bobby realize that the representative from the St Catherine Centre did not understand or have knowledge of Kylie's disabilities or needs. Joyce and Bobby were very angry and asked for the meeting to be brought to a close. They felt that as there was no representative from the social work department present and the representative from the St Catherine Centre had obviously no knowledge of Kylie's needs, the meeting was a waste of everybody's time and should be drawn to a close. The others present agreed and Joyce suggested that the representative from the St Catherine Centre go to the classroom to meet Kylie. After meeting Kylie and observing her in the classroom, the representative from the centre admitted that it could not meet Kylie's needs. Following this meeting the head teacher made an official complaint and Joyce telephoned the social work department to voice their dissatisfaction. Up until this point Joyce and Bobby had been hopeful that provision would be provided for Kylie.

At the next meeting representatives from both the social work's children's team and adult team were present. However, the social worker from adult services had no experience of the transition period for young adults. Kylie was his first client. They told Joyce and Bobby that a care suite for young adults with "profound and multiple handicaps" was going to be set up in the St Catherine Centre. Joyce visited the proposed site and was shown the plans but, to date, this provision has not materialised. As no other provision was offered for Kylie, a school extension was applied for and granted.

Joyce and Bobby then went to the client relations officer to make a formal complaint against the social work department. The letter they received in reply was unsatisfactory and Joyce and Bobby took their case to a review committee. The panel found in favour of Joyce and Bobby. They acknowledged that the social work department had not made provision for Kylie, had had adequate time and had to find provision for Kylie. However, for the family things did not change:

> Joyce (Kylie's mother): They couldn't find anything, they didn't have the finances for it and because of the complications of them needing the medical backup as well and the input to a certain extent, I mean they had medicine then, they needed the medicine for the epilepsy, they had the epilepsy, so they needed the anticonvulsants, so they needed input from the health board as well but then social work, they all tried to blame the health board and the health board were saying it was the social work department and you were really feeling as though you were stuck in the Bermuda triangle a lot of the time...

As a result Kylie left school and had no adult provision to go to. She remained at home for eleven weeks and the family received no extra help. Then one day Joyce got a telephone call from the social work department informing her of an offer made by a voluntary agency to set up day provision for six young adults with "profound and multiple handicaps" in Gordon House (a residential provision for adults with physical disabilities). They expressed an interest in this project, providing that it could meet Kylie's needs:

> Joyce: ... so I says you get the meetings up and running and we will come and we will give it our once over and we will listen to see what they are going to put in and what their input would be because basically as I said, although I was desperate for a day provision, I wasn't that desperate that I would just put her anywhere, it had to come up to our standards because we had given Kylie a level of standard from the day she was born and it wasn't high expectations it was only what we would expect as parents, ken what I mean.

Meetings of interested parents, managers from the social work department and the voluntary agency were arranged. These meetings were stressful for the parents and heated discussions took place over issues surrounding the type of provision required for the young people and funding. However, eventually it was agreed that the unit would provide five day a week provision for six young adults with "profound and multiple disabilities" and be funded by the social work department. Kylie was given a placement there.

Transition

As no placement was identified for Kylie she too remained at home for eleven weeks until a placement was found. Like Maureen, Simon's mother, Joyce received no additional help but once again her husband was very supportive. Kylie missed the activities provided by the school, especially the swimming. Joyce describes Kylie and herself as leading restricted lives:

> Joyce: ...it did affect her though because she was in the house every day. I couldn't I mean you can't be mum, housekeeper, financier, psychologist, OT, speech therapist, physiotherapist, you can't be all that in a person so Kylie was, she was neglected in the sense by the social work department, she was the one that was penalised here as well I would say most of...
>
> Anne: Especially when she had to stay at home and she had no provision.
>
> Joyce: Especially when she was staying just at home and that in turn restricted my daily routine in the sense that if it was raining you couldn't go out with her. If it was too windy you couldn't go out with her. Then you had all the humphing and laying in the car in the wheel chair so basically it had a knock-on affect on me, so I suppose in turn yes it did have an affect on the family but being the type of person I am I condensed it, I didn't let it escalate into divorce situation or anything like that.

Ideally she would have liked a six month transition period for Kylie to ensure that knowledge of Kylie's needs, especially her feeding regime and her methods of communication, were passed on from the school to the unit staff. She would also have liked a gradual build up of provision at the unit. However, as it turned out there was no transition period for Kylie. She went straight to Gordon House. Joyce describes Kylie as "adaptable" so she settled in quickly and Joyce visited the unit to give the staff advice about Kylie's needs.

Post-school placement

Kylie attends Gordon House five days a week. Gordon House is run by a voluntary agency as a residential provision for adults with physical disabilities. However, it also provides day services for six young adults with profound physical and intellectual disabilities, five of whom attend five days a week, and two who attend on a two or three days a week placement. Placements are funded by the social work department. Joyce and Bobby are happy with the provision provided there for Kylie, describing it as giving "what Kylie needs in a day, she gets out of the day."

Kylie receives one-to-one based activities at Gordon House as well as physiotherapy and swimming. She also enjoys going out for bar lunches and shopping. Joyce and Bobby feel the unit can meet all of Kylie's needs and that they have a good relationship with the staff.

Geri's story

Geri is eighteen. She is an only child and lives with her Mum, Catherine, and Dad, Roger, in Corton, a town in the north-east of Fogart. Both parents are full-time carers for Geri. The family have only recently moved to Corton. Prior to that they lived in Ireland for two years and England for twenty-eight years, where Geri was born.

Geri has been diagnosed as having cerebral palsy and has had profound physical and intellectual disabilities since birth. She is registered as blind, is unable to walk or sit up unaided and has little functional use of her hands. She uses a wheelchair, which has been designed around her body structure to enable her to sit up. Geri has breathing problems as a result of inhaling mucoid into her lungs around the time of her birth and requires nebulisation, postural drainage and suction to remove phlegm from her chest. She also has reflux problems and a hiatus hernia. She is fed through a nasal tube and requires medication to aid digestion. Medication in the form of an anti-convulsant drug is also given to control epilepsy. Geri's disabilities mean that she requires twenty-four hour a day personal care.

Geri has no speech but communicates through body language and coughing. She will smile or frown to show happiness or displeasure and turns her head away if she does not want to be involved in an activity. Geri indicates her agreement or understanding by pushing her arms down, with her fists clenched and her mouth firmly closed. She also uses coughing to attract people's attention or to get people to perform a task for her:

> Catherine (Geri's mother): It [coughing] can be displeasure if for instance she is listening to her music and it is finished and she is really interested in listening to her music, she can cough, that is saying 'Could you put my music back on'. If somebody puts pop music on and she really hates it, it's to cough to say 'Please just get that music off, I hate it' and I can't remember, what else does she cough for.
>
> Roger (Geri's's father): Well she can cough just to attract our attention. Perhaps we are not in the room with her and she wants us to be in the room with her, so she might cough to attract us.
>
> Catherine: Say 'Come and get me'.

Geri's hearing is very acute and most of her enjoyment comes from listening to sounds – people talking, children playing, traffic and music. She loves listening to music – opera and classical, Disney music, television soap themes and silly songs, as evidenced by her broad smile. She also enjoys tactile and sensory stimulation. For example, she enjoys having a bath and her hair done, swimming, feeling the wind in her hair and bumpy rides. She also enjoys company and going out. She becomes very animated when people come to visit her.

School

Geri started Garefield school, a special state run school in England, when she was three, on a part-time basis. This placement was extended to a full five days after a month:

> Catherine: He [the teacher] actually came round to the house to talk to us about it because I personally was very reluctant for her to go to school because I just had her, I would have had her wrapped up in cotton wool

> and I would have seen school as a big thing, going out into the big world and I didn't think she would be able to cope. So what was going to be her school teacher came round to the house... [he] said he would be really looking forward to her going and felt there was so much opportunities for her, so we agreed to have a look round the school and I remember the day going to the school and looking round the school, I came out of that school and I cried all the way home because in the whole of Geri's life I had [never] met people who were so positive and optimistic and I had not experienced that since the day she was born and I was overwhelmed and I thought yes this is for her, this is for her and so Geri actually started to go to school and she was so stimulated that when she came in from school every day she was absolutely exhausted and that was the beginning, I suppose that was the beginning of her life really.

After attending Garefield for eight years, Geri made the transition to a special senior school – Mudford:

> Catherine: I was not happy with that whatsoever, I was very reluctant for her to move on. To me then she was going into another world where I felt she had been quite happy at the school and I was very unhappy about that and the same thing happened again, the teacher came round to the house for a chat and, you know... parents need to be given, put in the right direction... Well personally speaking I think sometimes I need a nudge and as Geri's schoolteacher said she had become complacent and too laid back and too comfortable in her environment and she needed a push... she needed to move on in a stage in her life and the changeover from... the transition from her junior school to her senior school was fantastic, absolutely, it couldn't have been better...

Mudford school offered a wider range of activities but had more pupils. However, Geri coped well with her new surroundings and integrated with other children with different kinds of disabilities. Both Catherine and Roger were pleased with the education services Geri received in England. The family also had a paediatric nurse who came to the house to offer the family support and who also liaised with the school about Geri's healthcare needs.

When Geri was fifteen, the family moved to Dunness in Ireland. The family went "shopping for schools" and moved into the catchment area of the school they had chosen for Geri. Depting House was a special school run by a voluntary agency. This agency provides a service for people with learning disabilities from birth through to adulthood. These services include schools, outreach services, employment opportunities and short break provision. Unfortunately, shortly after Geri started school there, she became seriously ill. However, the school provided an outreach service and Geri was educated at home and in the hospital until she was able to return to school:

> Catherine: ... it was just the whole system, the whole system seemed very geared up to giving a very very good service, not just to the young people and the children, but to the parents as well.

After two years the family moved to Fogart. They stayed in a town in the west of Fogart on a temporary basis and looked for a school for Geri:

> Catherine: I managed to phone an educational psychologist, somebody that we had spoken to in the past and he said that legally Geri was entitled to go to school even if it was on a temporary basis until we moved. And that did cause a lot of problems because we actually phoned the local school and we had a problem just getting an appointment. The head teacher at the school did not want Geri to be in the meeting with us. Asked if we could get a baby sitter and well we had just arrived in Fogart, anyway so we didn't know about, if they did have services, so we couldn't have got anybody to help. Roger's mum is very elderly so she couldn't have looked after her while we were in the meeting, so the three of us just went to the meeting. The attitude seemed to be it was an

> inconvenience and the "if" word kept being used quite a lot. If Geri was to go to that school, if we were to do this, if we were to do that and we felt a lot of obstacles were being put in our way like transport to and from the school, they have to put on a nurse on the transport to take Geri down to the school. This school was only about five, ten minutes from your mother's house? (Roger nods in agreement) and we even suggested that we could take, if it caused that much [of] a problem, we would take her to school and pick her up. There was talk of maybe her not even going to school full time, it would be part time and then it was suggested that the assistant head took us round to possibly one or two of the classrooms that Geri might go too but she wasn't to tell anybody who we were. And...
>
> Anne: And did she say why.
>
> Catherine: Oh no. And we then went... when we left that school meeting we both were feeling very, we felt the whole situation was very negative and we then came to the conclusion ourselves that we didn't want Geri to go to that school because if that was the head teacher's attitude towards the children, the staff and the parents, then we did feel that maybe Geri would not be given the proper treatment she should get if she went to the school, although it would be temporary.

The family looked around the area and decided they wanted to settle in Corton, a town in north-east Fogart. The family visited the local authority school there and decided that they wanted Geri to attend the school in Corton. However, transporting Geri to school in the north-east of Fogart, whilst staying temporarily in west Fogart, became a problem:

> Roger: We had a parental contract with Fogart Council to transport Geri to and from school, at so much a month, until we were settled in a property in Corton, which is what we did but that only lasted two, three weeks...

> Catherine: So we just felt that if we didn't take Geri to school, Geri would not go to school and that was our first experience, we have never really had problems with education in Geri's life in the past and that was the first time we have had these problems with education and I was very very disappointed. But once Geri got into the school then we were quite happy. We were happy, it was like we will have to cope with every stage that happens. The school is a very small school. It doesn't have the set up like the schools that she has been in prior to this school, but we felt that it was better than nothing. The staff were very nice, the staff had very good communication. Well actually that is not true, there was a lot of problems when she started with her direct school teacher because they had never had a child in a wheelchair. They hadn't had a child in a wheelchair for quite a number of years and all the other children are able-bodied [not in wheelchairs] and I think the teacher wanted Geri to fit in with her timetable, which to a certain extent is understandable, but that didn't always work out because of Geri's needs. Also going back to Geri starting the school, they never had a school nurse in the school and because of Geri's health needs they had to get a school nurse. Now the head teacher had been given this child out of the blue and she then had to quickly find a school nurse.

This situation was resolved but if the school nurse is ill or has time-off, Geri is unable to attend school as there is no replacement. The school did not have the wide range of activities and therapies provided by Geri's former schools but Catherine and Roger reluctantly accepted this:

> Catherine: But I think because we had such a problem with finding a school for Geri, with trying to get a social worker, with finding somewhere to live, it was like well, we liked the atmosphere in the school, we liked the head teacher, her attitude, the staff appeared to be very nice... we felt well we'll let her go there and see how we get on...

her first year was very different. She did, as Roger said, she did end up thoroughly enjoying going out, so in one way she gained that, but in another way she didn't have some of the skills that she would have had prior to that I think possibly got slightly lost...

Anne: And did you have, did Geri have physiotherapy and speech therapy? Did all the therapists visit the school?

Roger: Physiotherapy was included, she would get daily physiotherapy from the school nurse.

Catherine: That was something that we initiated.

Roger: So the physiotherapist from the local hospital trained up the school nurse to be able to do this physio on a daily basis and the physiotherapist then would come in once a week. But she also, at our request, visited Geri during school holidays, if she could, so Geri wasn't missing out her physio during school holidays.

Catherine: She didn't have a speech therapist.

Anne: No.

Catherine: No, there wasn't any other therapy.

Future Needs Assessment process

Geri's first FNA meeting took place when she was seventeen and a half. At this meeting Catherine and Roger were very concerned that a placement be found for Geri because they assumed she had to leave school at eighteen. However, it was suggested to them that Geri might be able to stay on at school for another year but this was not confirmed until Geri's eighteenth birthday. At the next meeting it was suggested that

Geri might go to the Diamond Centre in Corton. Catherine and Roger visited this provision and found it inappropriate for Geri:

> Catherine: ...the actual building itself has not got the facilities for Geri, changing facilities, that sort of thing. The group that actually attend Diamond are a lot older than Geri. There is quite a lot of them that are able bodied [have learning disabilities] and when I say older than Geri you can get people of 50 and 60 years of age going there, so that in itself is not acceptable for Geri and I was absolutely disgusted that they would even consider sending her there, so that was one of the options for them but not for us.

After notifying the social work department of their decision, they were offered a service which consisted of two carers coming every day to the house and taking Geri out in her car. They rejected this offer on the grounds that Geri needed an input from therapy services and a continuation of educational provision. It was then suggested that Geri be assessed for Gordon House (originally Catherine and Roger were told there were no places available there). Catherine and Roger visited Gordon House, Geri was assessed but then they were told that Gordon House could not meet Geri's medical needs. Meanwhile, through contacts with other parents of young people with profound physical and intellectual disabilities, Catherine and Roger found out about other post-school provisions and subsequently visited them. They contacted their social worker and told her they had identified two placements for Geri which could meet her needs – Lemington Court and Watson House, a sensory impairment assessment unit. Apparently the social worker and her manager had not been aware of the existence of these provisions. However, they investigated the possibilities of Geri attending these units. At the next FNA meeting the social work manager confirmed that there was one place available at Lemington Court and that Geri and another young adult were being considered for a placement there, either by giving one a full-time placement or both a two or three day placement. However, "there appeared to be some confusion with regard to Watson House, as to whether it would be offering long term provision or merely assessment. The situation to be clarified as soon as possible" (minutes of annual/leaver's meeting, 14 March 2001). The minutes also stated that Geri's parents would be informed as soon as possible about any decisions made about post-school provision for Geri. However, after three weeks the family had heard nothing from the social work department and as Geri was due to leave school in two months time they decided to contact the Fogart Carers Centre for advice. The manager of the Carers Centre sent a letter to the social work department requesting an update on provision for Geri and within ten days Catherine and Roger received a telephone call from their social worker confirming a placement for Geri at Lemington Court. However, there were problems surrounding transport to and from the unit (the unit is thirty miles from Corton) and it was suggested that the parents might provide the transport. They declined and transport was subsequently arranged. At the time of interviewing the parents, the family have still had no official offer of a placement for Geri at Lemington Court in writing, but a transition period has begun.

Transition

Geri's transition period took place during the last few weeks of the school summer term. A key worker from Lemington Court visited Geri's school on several occasions and Catherine and Roger took Geri to visit Lemington Court. However, the key worker from Lemington Court, having witnessed Geri being given suctioning at school, reported that Lemington Court had no trained staff to carry out this procedure. Catherine describes this as:

> Catherine: ...an anxious time because although we felt Geri was ready and we were ready and the unit was ready to receive Geri, she might not now go.

The staff did eventually receive suction training and at the time of writing it is hoped that Geri will attend Lemington Court four and a half days a week after the summer holidays.

Post-school placement

As Geri had not started at Lemington Court, her parents were unable to comment about provision there. However, they feel that the unit cannot meet all of Geri's medical needs. They have no one trained to change Geri's nasal gastric tube which will mean they will have to be on call:

> Roger: ...if it [the nasal gastric tube] came out accidentally while she was at the day service, there is no-one on the premises that could change that which will mean a call to us, so we would have to go down, if we were available, to change it or if we weren't available, taking Geri to a hospital who are willing to change it because not all hospitals might want to do that procedure or have anyone available on shift to do that procedure, so it may not be the nearest hospital that she would be taken to but a hospital that was prepared to do a replacement NG tube. So where we feel that the day service will be good for her emotional and educational needs, it certainly is still not going to be able to cope with her health needs 100%.

Catherine and Roger would also like Geri to spend some time at Watson House and they are currently looking into this.

In the next section I focus on the young people's school provision. I believe there are lessons to be gleaned by looking at the school provision provided for the young people in my study in terms of future provision and services, and in the case of Geri, the transition process.

SCHOOL PROVISION

All of the young people in the study attended special schools, either provided by the state or the voluntary sector. Faye, Simon and Kylie remained at the same school throughout their school life, although Faye did move to another building, "the senior school", between the ages of eleven and twelve. Geri was the only one who was transferred to new provision at the age of eleven. At first Geri's parents were reluctant for her to move on to another school but visits to the family home by Geri's junior school teacher, a smooth transition period and a favorable reaction to the senior school by Geri herself, helped to allay their fears:

> Catherine (Geri's mother): ...the transition from her junior school to her senior school was fantastic, absolutely, it couldn't have been better, the communication... What was going to be her teacher in the senior school would visit to the junior school and spend some time with the group of children that were going to move on so she didn't just go into the school and meet the children and the staff, she also arranged that when she was there sometimes that the parents could go in and meet her and then, that was done over a period of quite a few months and then there was the trip. We were to take Geri to her new school, what was going to be her new school one evening. They had a parents evening and we took Geri to that. I have to say it was a very old school, it was very busy, there were loads and loads of students. They didn't appear to have very much space for things. The corridors were busy, they were full of different things so I was... when I went into the school initially my first reaction was oh, I am not impressed. We waited to be seen, for Geri to be seen and taken round and then the staff came out to get Geri and us to go down to the classroom where Geri would be and then the whole thing changed completely, the atmosphere was fantastic, the staff were great. We were worried about Geri how she would react to moving on and we were basically being silly parents. In that situation we were being sad parents really because Geri's attitude was right well, show me what you have got. So of course she was taken into the class, she was taken into the sensory room and she was shown everything and it was a great evening. It was very successful and that of course, from then on I wasn't worried about her because I just could see...
>
> Roger (Geri's father): Geri was ready to go.

This successful transition from junior to senior school is compared to the transition period from school to post-school provision in Chapter 6.

The parents in my study were offered a range of school placements, both within and out-with their catchment areas and were instrumental in choosing the provision:

> Maureen (Simon's mother): Simon went to Hollywell School in Bamchester. At that time we had sort of looked round about for all the different schools and that was basically the closest and the most... the one that we felt suited our needs basically. Just due to getting on with the head teacher. We felt if we can get on with her we will get things done.

They all expressed satisfaction with their children's school provision and felt that their offspring were happy there. In addition, they saw the school as being able to meet their children's physical, educational, social and emotional needs by adopting a holistic approach and engaging in collaborative, multi-disciplinary teamwork. The children's medical needs were also attended to in the school by appropriately trained staff, the employment of a nurse full-time and the provision of medical, dental and health clinics in-house. In addition, Geri's school in Ireland provided an outreach service, short break provision and a hospice service as an alternative to hospital provision:

> Roger: ...after Geri had been at school for about 6 weeks she became quite ill and she was put on antibiotics by the GP and we kept her at home and tried to look after her at home. So her teacher came out to the house to help us, she gave us a break, she actually fed her for us.
>
> Catherine: Or if we wanted to go shopping.
>
> Roger: We could have gone out yes.

All the parents felt they had good relationships with the school staff, achieved through open door policies, good communication systems, involvement in their children's education and feelings of mutual respect and trust:

> Catherine: It was the atmosphere and the respect. What came over quite strong to me was the respect they had for their children and they had so much, they seemed to have so much respect for the parents. They saw the parents, I felt, this is my feeling, they saw the parents different to what I had experienced from the health profession, they saw the parents as doing a fantastic job and needing help and support and they, it was like they were there to be, they were there for you as well.

Although all the schools the young people attended were special ones, the youngsters were involved in events in their local communities, for example attending plays and concerts, and in turn the schools involved the community in their activities and events, such as Christmas services.

The findings indicate that both the young people and their families were positive about the provision provided by the schools. This is supported by other research. The Beattie Committee's focus group study (Scottish Executive, 1998 December) found that young people attending special schools expressed positive feelings about their schooling. Similarly, McConkey and Smyth (2000) and Redmond's (1996) studies found that both parents and their offspring were happy with school provision. They propose that this success is partly due to the family carers who look beyond the impairments of their children and to teachers in special schools who not only provide a learning environment for the children, but support for the families. I would also suggest that government legislation recognising these children's legal right to education, along with the changes to special educational provision recommended by the Warnock Report (DES, 1978) has resulted in parental choice and parents and children becoming more actively involved in school provision through Records of Needs and individualized educational programmes (IEPs). Moreover, the Warnock

Report also encouraged integration, collaborative working amongst professionals and working in partnership with parents. Unfortunately the young people's stories suggest that these principles have not yet been extended to post-school provision for young adults with profound physical and intellectual disabilities.

SUMMARY

The young people's stories suggest that the recommendations of the COSPEN Report (1988) regarding FNA meetings have not been implemented. Indeed, a comparison of Geri and Faye's stories seems to suggest that in Fogart the FNA process has changed little in the last thirteen years:

> Helen (Faye's mother): ...nothing has changed. When we were going through that period somebody actually said to me, it was a pediatrician said to me you are pioneering for all the young ones coming behind because Faye at that time, it was still quite... for someone with Faye's disabilities, it was still quite unusual if you like for her to be being cared for at home... she was leaving school, she had gone through school and she had got to adulthood and now there was the problem of what would happen now that she was into adulthood so yes I thought, I thought nowadays it would be a smooth transition, the place would be identified and that still doesn't seem to happen.

The chapter has also shown that the transition from school to post-school provision for young adults with profound physical and intellectual disabilities and their families has been problematic and emotionally upsetting. Moreover, at the end of the assessment process, access to continuing education was made more difficult because of the young people's continuing health and support needs. These findings concur with Morris' (1999b) study of young people with "complex health and support needs":

> There is evidence that many of these young people experience a failure of health and social services to meet their needs as they grow into

> adulthood. They are at risk of being socially excluded by services which segregate them from the rest of society and which pay inadequate attention to needs arising from poor health and/or mobility, sensory, cognitive and communication impairments.
> (Morris, 1999b, p. 135)

She argues that in order for services to make a difference to the lives of these young people, they need to start from the experiences of the young people themselves and focus on their needs rather than slotting them into existing services.

This chapter has attempted to do this by looking at the transition period from the perspectives of the young people and their families. The following chapter looks at how the difficulties and problems identified by the family carers might be overcome. It uses a collaborative multi-disciplinary approach as other researchers and reports (Lacey, 2000; Morris, 1999b; Social Services Inspectorate, 1997b) have emphasized the importance of joint planning and working across specialisms, as well as with the young people and their families in order to develop services that are "flexible enough to cater for individuals and families, rather than whole client groups" (Social Services Inspectorate, 1997b, p. 15).

Chapter 6 Realising the dream? – Overcoming the barriers

This chapter looks at the difficulties experienced by young people with profound physical and intellectual disabilities, their family carers and professionals involved with this group during the transition period from school to post-school provision. It also suggests some ways in which these difficulties might be overcome. The chapter considers the sharing of information, joint working and funding, Future Needs Assessment meetings and the role of transition co-ordinators.

For Faye, Simon and Kylie the Future Needs Assessment (FNA) process began shortly after their fourteenth or fifteenth birthdays in line with the requirements of the 1980 and 1981 Education (Scotland) Acts. For Geri, the first FNA meeting took place when she was seventeen and a half, as previously she had attended school out-with this country. One of the problems identified by both the family carers and the professionals involved in my study was the sharing of information – information for parents and the exchange of information both within and across agencies. This is discussed in the following section of this chapter.

SHARING INFORMATION

Family carers

The study found that the parents were given little or no information about the FNA process:

> Catherine (Geri's mother): ...we assumed Geri would have to leave school when she was 18 and it was hinted to us that no she probably could stay on for another year but nothing was being put in writing, so as far as we were concerned it was hinted to us by a social worker and it was hinted to us by the head teacher, but nothing was put in writing. So

> up until Geri was due to leave, up until Geri was going to be 18, we didn't know whether or not she was going to have to leave school.
>
> Anne (interviewer): You didn't know you can apply for an extension.
>
> Catherine: No I didn't know actually you could apply for an extension.

The parents also felt that both they and the professionals involved in the transition process had little knowledge of post-school placements available for their young people. This led to them having to "shop around" for provision.

Most of the information the parents did have about the FNA process came from other parents. This is supported by studies carried out in both Scotland (Scottish Executive, December, 1998) and England (Dee, 1997, 2000) and there is now a recognition in both countries that:

> ...having the right information at the right time is crucial, and making it readily accessible to family carers and young people is a major issue.
> (Shevill & McNair, 2001, p. 3)

The parents involved in the focus group discussion felt that an information booklet would have been helpful:

> Helen (Faye's mother): To have it in writing so that you can refer to it but also for somebody to be, you know, there, telling you or explaining...
>
> Maureen (Simon's mother): I agree with that...

They wanted the booklet to provide information about their legal rights, as well as the whole transition process. They suggested that the booklet be jointly funded and produced by education, social and health services. The transition project in

Southampton (Southampton City Council et al., undated) is planning to produce such a booklet for young people and their family carers to help them through the transition process funded by health, social services, education, housing and leisure services. Cohen et al.'s study (1999 March) also found that young people and their family carers did not just lack information about educational opportunities but also had little information about support from health services and social security benefits. They suggested that local authorities should develop a strategy to address this and that it should take into account the need for interpreting and translation. As Dumbleton (2002) states:

> Because teenagers with disabilities are dependent on a range of services that are funded and organized on an age related basis they have to negotiate the entry requirements of a range of "gatekeepers". Despite the recognition of the need for "key workers" most teenagers have to rely on their parents to gather, process and use information on topics as disparate as incapacity legislation, community care assessment processes, welfare benefit rights and access to health services.
>
> Families need information and advice both about the transitions between services that their sons and daughters must negotiate and about their own needs and feelings as they move from being the parents of children to carers for adults.
>
> (Dumbleton, 2002, p. 1)

The members of the focus group discussion also felt that it would be helpful if parents, who had already been through the transition process, could pass on information and share their experiences with other carers about to go through the transition period:

> Jillian (professional): ...if information is put together about the Future Needs Assessments whether a parent link, who had already been through that process, a parent who was happy to take on that responsibility, information could be put into that booklet so that at least families

> coming up through the process would have somebody who had been through that system to talk to...
>
> General agreement.

Routledge (2000), in his study, lists some practical ways of providing young people and their families with information about the transition period, as well as ways of increasing their participation and empowerment. They include:

> - means by which useful information can be accessed and used by families and young people to assist informed choice-making, such as videos, information booklets, transition fairs, courses for families and young people about adult services and link courses or taster opportunities
> - approaches which empower young people and their families in the transition process, including the use of advocacy in schools, independent advice and support, person-centred planning, adjustment to traditional planning and review, creative assistance to those who do not communicate with words and focused assistance for people from minority ethnic communities.
>
> (Routledge, 2000, p. 24)

However, the family carers felt that they were not the only group involved in the FNA process who lacked information. Sometimes the professionals involved seemed to have little knowledge or understanding of the whole transition process.

Professionals

The family carers felt that the professionals lacked information about their offspring's disabilities, needs and appropriate post-school placements. As seen in the young people's stories, this resulted in assessments which did not identify all the barriers to learning, and led to Faye, Geri and Kylie being offered placements, only to have them withdrawn when the identified provision discovered the extent of their full needs. The family carers felt that there needed to be more information sharing both within departments and across agencies. This was echoed by the professionals in Cohen et al.'s (1998 December) study. This study highlighted the difficulties of inter-agency working where health, social services and education have different priorities, responsibilities and ways of organising. Their study found that this causes social and health services difficulties when it comes to planning future services, as no information about numbers of people with disabilities is readily available to them. Moreover, agencies do not always have information about the young people being transferred to them. Morris' (1999b) study echoes these findings. She found that those responsible for commissioning services often had inadequate and incomplete information about what services are required. Moreover, the information that did exist tended to be based on diagnosis or service categories rather than generated by the actual needs of the young people concerned. According to Routledge (2000), all of this leads to young people and their families not having sufficient support during the transition period and lack of choice in service provision. It also makes it difficult for service planners to anticipate patterns of changing need.

The focus group in my study felt that a register might be one way of ensuring better information sharing both within and amongst agencies:

> Jillian (professional): ...I think if there was a register then at least the information would be there in one place and having it in one place rather than reliant on professionals to push out information at the system from different parts of Fogart in relation to individual families, there would be at least the material there and I think it is really important that that happens. Obviously, there are issues of confidentiality and agreement from families about who has access to that information and it is important that it is shared but that has got to be something that has been clearly agreed by the families, all the service users concerned.

As illustrated above the group were aware of such issues as data protection, confidentiality, the importance of involving people with learning disabilities and their families in the development of such registers and the establishment of protocols for sharing information amongst statutory agencies.

This idea has already been developed in Southampton. Their transition policy (Southampton City Council, Southampton & South West Hampshire Health Authority, & Southampton Community Health Services NHS Trust, undated) proposes that "information is shared jointly with relevant agencies, with the agreement of the young people and their parents" (p. 4). To facilitate this the Social Services Directorate, the Education Directorate and the Health Authority are working together to compile information on the needs of young people with disabilities. They will use this information to plan services and draw up a register for children with disabilities so that information can be shared with the appropriate agencies to ensure effective planning and targeting of resources. However, Southampton's policy goes further. As well as compiling a register and an information book for family carers, staff training is also planned so that staff are "aware of the full range of needs, services and entitlements of this age group" (p. 6).

Various researchers (Cohen et al., 1998 August, 1998 December; Dyson, 1998) have recommended the setting up of inter-agency databases to improve the flow of information both within and amongst agencies and to help achieve better planning, especially at the transition stage. Indeed, the SAY Report recommends that local authorities, health boards and health trusts set up and maintain local registers (Scottish Executive, 2000, recommendation 9, p. 34). They see databases as:

- Providing locally accurate information on numbers of people with learning disabilities. This information can be used for planning and commissioning
- Promoting an evidence-based and joined-up approach to local needs assessment for people with learning disabilities
- Enhancing knowledge of the population of people with learning disabilities across health, social care and education agencies.

  (Scottish Executive, Association of Directors of Social Work & Scottish Consortium for Learning Disability, 2002)

In fact Fogart does have a system whereby information from the education department about young people leaving school is passed on to the post-16 group, as is information obtained by social work assessments:

> Pauline (professional): Fogart does keep a register if you like but it is not a formalised process because I think there are legal implications about keeping a register of people and how you would set that up but because education and social work and resources get together at the post-16 group, all the information from education about young people leaving school is there at that meeting and we examine situations where there has never been a referral to social work for example and the education now go back and say to the parents would you like a referral to social work and that information is not shared unless the parents agree to that, so you know we are on the way with the post-16 group and certainly the profiles for individuals, we ask social workers to carry out their assessments now and send them to the post-16 group so that the post-16 group have an overview of all the needs of the young people who are leaving school this year...

However, despite this system, there are still inter-departmental problems with the sharing of information:

> Pauline (professional): ...there isn't always a hand over from the children and family disability team to the adults team. If a worker in the children and family team, this is an issue that I have at the moment, closes the case then the information then isn't passed to the adult team and that has been a major issue in the last year or two because they have kind of changed their system of working without referring to the community care teams and it was just by chance that I found out they were doing that, so there is a lack of communication there and I think that it had improved slightly before that but because of the pressure they

> are under they changed the system and so the information wasn't being passed on and in some cases it was but in some cases it wasn't.
>
> Maureen (Simon's mother): For some people... that [the case] had been sort of closed and then they move on and think at the Future Needs meetings, where is the... [worker] but there was nobody there for them because it had been closed.

Another problem with the post-16 group is that, at the moment, the group does not include health professionals. Furthermore, community health learning disability teams are only involved in the FNA meetings of young people who are currently on their caseload:

> Angela (professional): ...I would get invited to some of the Future Needs Assessments because the child was open on that caseload but for all the other children... we wouldn't get invited because we didn't get notification that there was a meeting... unless somebody is referred to us we don't actually work with them... and unless we get somebody referred to us we won't automatically be invited along to any of these meetings.

Yet the parents in the group felt strongly that their young people's continuing healthcare needs were an important issue to be considered at the transition stage:

> Maureen (Simon's mother): ...their health will always have to be at the forefront, I mean always, always.
>
> Helen (Faye's mother): It is health that dominates their whole life. I mean I know health is important to everybody but it actually dominates their quality of life.
>
> General agreement.

Routledge (2000) feels that at the moment there is not sufficient requirement for agencies to be effectively involved in FNA meetings and that this needs to be addressed. In some areas of England health services have introduced a healthcare transition plan to help co-ordinate the transfer of information and services from child to adult services. Currently, the post-16 group in Fogart is looking at ways of increasing the involvement of other agencies, parents and people with disabilities in the group.

The above suggests that there are problems surrounding both inter-departmental and inter-agency working. Indeed the professionals involved in my study recognised this:

> Angela (professional): that (inter-agency working) needs to be looked at, that we are more joined up with social work and I think that is going to come but the way that we work at the moment in health is different...

> Pauline (professional): We work in such big organisations, health, social work and education to get it together in terms of communication, it takes a tremendous amount of effort and work.

The focus group discussed whether it was appropriate to have a one-off divide between child and adult services both in terms of transitional planning and in meeting the needs of the young people:

> Angela (professional): You see that is where it is so confusing because the rest of the professionals in the health learning disability team, some of them only work with adults like the psychologist, speech and language only works with adults, physio only work with adults, whereas our psychiatrist will work with children as well and I think that is what makes the transition period really difficult because it is a whole bunch of new professionals suddenly you know arriving on your doorstep (nods of agreement)...

> Jillian (professional): Just wondering if there are professional reasons why if some disciplines continue to work with people right through life from childhood into adulthood with no transition as far as that discipline is concerned. You said, psychiatry, I think you said and to some degree community nursing but the other ones there is this change. Why is that? Why do speech and language therapists need to be different for children and for adults, why can't we have the same one? It seems to be an odd feature of the system which makes things more difficult at the transition time. If the staff, rather like the local area co-ordinators who would see people through a continuous process through their lives, then why can't other disciplines too? It would certainly help...

This view was also expressed by the professionals in Cohen et al.'s (1998 December) study. They too questioned whether a division between child and adult services was beneficial for meeting young people's needs.

The professionals in my focus group also felt that the regular re-organisation and re-structuring of social and health services made communication and the establishment of links and contacts difficult. Pauline stressed the need for good practices to be incorporated into new organizational structures that might occur following the SAY Report:

> Pauline (professional): ...things are changing with "Same as You?", with education and I think it is ensuring that the work that has begun to be done and the improvements that have been made... [are carried forward].

This view is also echoed by the professionals in Cohen et al.'s (1998 December) study. They reported that the field staff in the adult social services departments found difficulty in keeping up to date with how their own and other departments worked because of regular re-organisation and re-structuring:

> You just get to know what a service provides, then it gets reorganized. (Cohen et al., 1998 December, p. 17)

Cohen et al. and Dyson (1998) suggest that this problem might be overcome if each agency "produced regularly updated information about its systems, structures, case procedures and personnel" (Cohen et al., 1998 December, p. 26). This is endorsed by Routledge (2000). He sees such measures as improving knowledge across agencies and professionals, maintaining and building-up relationships and facilitating "effective and productive joint working" (p. 23).

Cohen et al. (1998 December) also found that differences in professional ethos and working practices across health, education and social services also caused problems with information sharing both within and amongst agencies. This problem was also highlighted by one of the members of the focus group in my study:

> Pauline (professional): I think there is a... in some schools, it is different from school to school, in some schools they build up a good relationship with social work and there is communication there with some local teams but in other teams they just don't gel. There's a kind of I suppose you could call it attitudes to each other and I know workers who have been along to meetings and have been treated really badly at meetings because everybody has had a go at them and things like that so you know there is sort of issues around professions sorting themselves out too and respecting each other's position.

The professionals involved in Cohen et al.'s (1998 December) study saw personal contacts with other staff in other agencies as important in breaking down such barriers as well as helping with the sharing of information about service provision and structures. They suggested that inter-agency training would improve mutual understanding of roles and facilitate the building up of personal links. Derrington's study (1996) concurs with this suggestion.

This section has looked at the difficulties experienced by family carers and professionals around the sharing of information. It has also suggested some ways of overcoming the barriers to information sharing. As highlighted by the discussion above, the sharing of information requires joint working across departments and agencies. Joint working and funding is the topic of the next section.

JOINT WORKING AND FUNDING

As already seen, joint working was considered an important issue for the members of the focus group involved in my study. It was also one of the themes identified from the analysis of the nominal group technique data (see Chapter 7):

> Pauline (professional): ...it is about the kind of joined up health, social work, education organisations. There is still too much... you know when somebody needs something, they can't decide whose responsibility it is to pay for it and I mean that is just in this day, unacceptable.

As shown by the young people's stories, the failure of agencies to work together led to fragmentation of responses to the young people's needs and delays or failures in accessing services. The group also felt that agency responses were crisis-led rather than needs-led:

> Helen (Faye's mother): ...it is really sort of acting to a crisis, there should be protocols set down.

> Pauline (professional): Yeh, clear roles and responsibilities but I mean I think you know we are moving along that way, there should be a pooled budget for this group. There should be a single management of that and planning for it.

This is supported by research (Jones & Bilton, 1994; Morris, 1999b) and reports (Audit Commission Report, 1994; Social Services Inspectorate, 1997b) which show that joint working, both within departments and across agencies, is essential if young people's individual needs are to be met.

Routledge (2000) describes how in some areas agencies have come together to develop joint transition policies and processes (see Southampton City Council et al., undated) and how in some areas local conferences on transition have led to working parties, secondments or use of joint-financed posts for service reviewer development. This happened in Fogart (see Chapter 4). Following an inter-agency meeting, organised by family carers to discuss their concerns surrounding the transition period and post-school placements, three working groups were set up to look at the difficulties faced by young people with "mild, moderate and profound learning disabilities". The working groups' reports (Cobain, 1997; MacArthur, 1997) resulted in the appointment of a development worker. Her report (Brown, 1997) led to an action plan being drawn up to improve services at transition:

> Pauline (professional): And out of that (Brown's report) there was a procedure put together but that has never been reviewed or renewed...

This concurs with the findings of Routledge's (2000) study. He found that initial enthusiasm did not always led to systematic action or the development of policy and practice. He suggests that because no one agency has responsibility for developing a comprehensive transition policy and practice, there are "difficulties in moving from the identification of the need for action through policy to service development and practice" (p. 22). Nevertheless, he outlines some of the key components for successful joint policy and practice (Table 33, p. 319). Although they refer to legislation in England, his recommendations are relevant to Scotland.

The focus group in my study also favoured the development of a transition policy drawn up by health, social work and education similar to the one developed in Southampton (Southampton City Council et al., undated). They saw the transition policy as a mechanism to assist with the provision of services:

> Pauline (professional): I think the transition policy is a good idea in terms of health, social work and education, getting together and developing that because that is a public statement and people have that to fall back on if they don't get the service that the organisations have promised.

Table 33. Possible content of joint agency transition policy

Joint agreement regarding the central aims and functions of transition activity
Clarity as to who is to benefit from the policy and process (target group)
Stages, phases and activities of transition (implementation plan)
Specification of roles for agencies, parts of agencies, and professionals (responsibilities)
Procedures and protocols in key areas, including:

- transfer of information for planning
- clarity of roles and activities associated with the 14+ review and implementation of plans
- agreed approaches to the empowerment of young people and their families in the processes of transition
- arrangements in respect of the key provisions of The Disabled Person's (Services Consultation and Representation) Act 1986
- post-14 arrangements and roles between children's and adult sections of social service departments and health services
- arrangements for co-ordinating assessments under relevant legislation and for service planning between the key agencies and professional groups in the final school years
- agreements in respect of key operational issues
- arrangements for transfers between specific services
- roles and responsibilities in respect of post-school transitions, including management co-ordination across agencies

Source: Routledge, 2000, p. 23

Morris (1999b) also argues that people with "complex needs" require commissioning and service provision which is "multi-disciplinary, integrated and user/needs-led" (p. 87). However, despite past (Court, 1976; DES, 1978) and current reports and legislation (Children (Scotland) Act, 1995; National Health Service and Community Care Act, 1990; Scottish Executive, 2000) urging agency collaboration (see also Appendix R, p. 778), there has been a failure to establish effective forms of co-operative working (Audit Commission Report, 1994; Jones & Bilton, 1994; Lacey, 2000; Wolfendale, 1994) at both local and national levels (Davie, 1993).

Dessent (1996), drawing on the work of a number of researchers (Davie, 1993; Local Government Management Board, 1994; Norwich, 1990; Wolfendale, 1994) identifies obstacles to effective inter-agency working (Table 34).

Table 34. Obstacles to inter-agency co-operation

Organisational/Structural
Different services administered by separate agencies;
Large, complex agencies with multiple sub-systems;
Lack of "coterminosity" in agency boundaries.

Professional
Separate training and conceptual background;
Different vocabulary relating to "need";
Different pay, conditions and status;
Inter-professional rivalry;
Loyalty to own agency/service.

Legislation
One agency has principle "ownership";
Legislation "overload";
Discrete statutory responsibilities;
Poor transferability and cross-referencing of legislation.

Resources
Funding channeled to separate Committees and agencies;
Limited "corporate" budgets;
Resource constraints;
Lack of clarity about budget responsibilities;
Conflicting policy priorities;
Partnership working is time-consuming and expensive.

Political/Attitudinal
Lack of political/managerial commitment to inter-agency co-operation;
Lack of officer faith in effectiveness of inter-agency co-operation.

Pressures
"Innovation overload";
Agencies dominated by internal priorities;
Restructurings.

Adapted from Dessent, 1996, p. 13

This table illustrates the complexity of achieving effective inter-agency working and has led Davie (1993) to remark that:

> ...the prevailing system is heavily loaded against multi-professional co-operation. If one were to attempt – with all the insights derived from research and common experience – to establish a process designed to

> keep the professionals apart, it would be difficult to conceive of any improvement on what we currently have.
> (Davie, 1993, cited in Dessent, 1996, p. 14)

Parker (1969) identifies the low level of "mutual interdependence" amongst agencies as the key to the difficulties experienced by agencies in working collaboratively together. He argues that the fact that health, social services and education can work with groups of people, such as people with disabilities and their families, in a largely independent way without co-operating with each other, leads to agencies working separately. He maintains that increasing the formal requirements for interdependence, along with looking at the issue from the "consumer" perspective, may lead to more co-operative working. This has led some writers (Dessent, 1996; Mallett, 1994) to suggest that parents have a major part to play in improving partnerships amongst agencies:

> Perhaps the greatest potential for positive change in resolving inter-professional boundary issues has come from the changing role of parents. They have the unique role (and opportunity) to facilitate, to inter-relate and ultimately to challenge where and how they receive services.
> (Russell, 1992, cited in Dessent, 1996, p. 15)

The members of the nominal group in my study also felt that families of people with profound physical and intellectual disabilities should be fully consulted about the development and planning of services (see Table 38, p. 364, item 19). Moreover, Simon's story (see Chapter 5, see also Chapter 4) demonstrates how parents were instrumental in persuading health, social services and education to work together to produce a joint report and action plan for the transition period from school to post-school provision in Fogart (Brown, 1997; Cobain, 1997; MacArthur, 1997). However, as Dessent (1996) comments:

> ...it must be regarded as a sad indictment if the better co-ordination of multi-million pound statutory and professional services must wait upon the voluntary efforts of busy parents already under stress because of their responsibilities in relationship to their own child. Nevertheless, the power of viewing the issue from the parent perspective is to expose the problems in terms which are acceptable and valid for all agencies and potentially to open the way to solutions.
> (Dessent, 1996, p. 16)

However, all is not "doom and gloom". Dessent (1996) gives examples of successful partnerships across the United Kingdom (pp. 16-17) and suggests characteristics of effective partnership work (Table 35).

Table 35. Characteristics of effective partnership work

The importance of combined, local political and managerial/officer commitment to partnership work across agencies.
A high level of inter-dependence between agencies in order for them to meet their own responsibilities.
A legislative framework which provides some degree of prescription about the outcomes or "products" of multi-agency work as well as the processes.
Service provision which is open to and responsive to the consumers' (parents') critique.
Partnership developments which meet some of the professional self-interests of the workers concerned.
The importance of mechanisms/structures and focal points for co-operative working (here the issue is one of ensuring a physical or organisational focal point for liaison, planning and decision-making).
The "key worker" concept offers a powerful response to parents of children with special educational needs *and adults with disabilities.*
The existence of some "pump-priming" funding or joint-resourcing for partnership work

(Words in italics are my additions)
Adapted from Dessent, 1996, p. 18

Although Dessent's work focuses on children with special educational needs, his characteristics of effective partnership work are also relevant to adults with disabilities. He also offers a number of options for increasing co-operative working (Table 36, p. 323). These options form a continuum from "the big bang" restructuring of the currently separate agencies into a unified "department" (see

Dessent, 1996, pp. 18-25) to the clarification of professional boundaries. Dessent concedes that his eight options are not an exhaustive list, neither are they separate entities:

> In reality, elements of each listed option (and others) will need to be utilized depending on current contexts and starting points. Co-operative working must also be seen as stretching across a continuum which begins at one end with a planning dialogue and can finish at the other with a fully integrated planning approach.
> (Dessent, 1996, p. 23)

Table 36. Options for increasing co-operative working

One integrated department consisting of health, social services and education
Corporate local authority approaches
Increased central government requirements for inter-agency partnership
Corporate funding arrangements
Agreed locations for multi-agency work
Structured levels of co-ordination and communication at policy and strategic planning level, area planning level and individual/family level
Agreed areas for collaboration, for example, the development of a shared data base, roles and boundaries in respect of the administration of drugs and medical procedures.
Clarification of boundaries between professional groups as well as their resourcing responsibilities

In an attempt to overcome some of the issues surrounding joint working and funding, the Scottish Executive has set out a framework to encourage joint management and joint resourcing within primary care and community care services (Joint futures, Scottish Executive, 2002). Joint management involves a co-ordinated approach to the planning, commissioning and management of services and joint funding refers to all aspects of resources – staff, equipment, property and money. The framework aims to:

- support people to remain in their own homes
- develop new and better ways of working
- provide a better quality of life for people with learning disabilities and others

- promote early assessment and intervention
- remove barriers within the care journey
- promote integrated services locally
- create a single point of access to community care services
- strengthen locality working
- develop "whole person" approaches to care
- break down professional barriers
- support the development of new skills.

Although the legislation focuses on services for older people, all areas of community care can be included. Furthermore, the legislation allows local agencies to pool their budgets. It remains to be seen whether local authorities will use these changes to improve the quality of life for people with profound physical and intellectual disabilities.

The members of the nominal group also recognised that funding is a major factor in the provision of services for people with profound physical and intellectual disabilities. They agreed with Routledge (2000) that progress is most likely when "resources are identified to facilitate needs-assessment and service-mapping and to generate proposals for service development" (p. 22). Like Dessent and the Scottish Executive, they favoured joint funding and the pooling of resources. However, they went further, advocating the ring-fencing of funds for people with "profound and multiple learning disabilities":

> Pauline (professional): ...there should be a pooled budget for this group. There should be a single management of that and planning for it.
>
> Jillian (professional): And really I think what it needs is a ring-fenced budget like Fogart's palliative care services are ring-fenced and I think that for people with PMLD [profound and multiple learning disabilities] that would be a very good idea as well because they are a very small group compared to the elderly or whoever (general agreement), they

> have very very massive intense needs and the only way that they are going to kind of compete for resources is if there is ring-fencing I think.
>
> General agreement.
>
> Pauline: That's discrimination again, just because they are a small group, doesn't mean to say they are any less important than anyone else.
>
> Maureen (Simon's mother): And they have not got the loudest voice...

This view that people with a learning disability have a low priority on the government agenda and that people with "profound and multiple learning disabilities" are "a minority within a minority group" is supported by research (Mencap, 2001 November, p. 7). In addition, people with profound physical and intellectual disabilities tend to be less valued in comparison to their non-disabled peers (Mencap, 2001 November). In the words of Ron Turnbull, whose wife was convicted of manslaughter of their two profoundly disabled sons because she feared they would be taken away from the family home and placed in residential care:

> At the end of the day people thought my sons were worthless, and we were too. I thought they were very special.
> (Mencap, 2001 November, p. 5)

Similar views about the worthlessness of people with profound physical and intellectual disabilities have been expressed by professionals. Hogg (1991) recounts an instance of a professional advocating that too great an effort must not be "put into maintaining the lives of such people who ".....in any way won't see their teens out."" (p. 166). Moreover, as Maureen says above, they do not have a loud voice. They use non-verbal methods of communication and most people do not understand this. As a result people with profound physical and intellectual disabilities rely mostly on the efforts of family carers to represent their views:

My voice is usually my Mum's
She can speak for two,
I've heard her shout for this and that
Even for a loo!

No matter what the obstacle
She will fight and try
But the powers that be, just pat my head
And then they walk on by.

However, parental views are not always seen as valid. Thus people with profound physical and intellectual disabilities often have no "voice" with which to demand better quality services (Mencap, 2001 November). Moreover, their family carers are so busy fighting to obtain services and equipment to meet their young person's basic needs (see poem above) that it is difficult for them to have the energy to fight for their sons and daughters' rights.. Therefore people with profound physical and intellectual disabilities tend to be overlooked or forgotten when it comes to policy-making and the planning, development and provision of services (Scottish Executive, 1999; Shared Care Scotland, 1997; Whorisky, 1999):

Forgotten by many in this world
Man has passed me by
Life has dealt me a cruel blow
But you won't hear me cry.

The barriers that we face in life
Are too numerous to mention,
We are the forgotten people
We don't warrant much attention.

As seen in Chapter 4, both the United Kingdom government's (DOH, 2001) and the Scottish Executive's (Scottish Executive, 1999, 2000) policies on disability seem to focus on increasing opportunities for paid employment but this group of young people are unlikely to be employed (Hubbard, 1999). Moreover, the SAY Report (Scottish Executive, 2000), although recognizing the needs of people with "profound and multiple disabilities" and making recommendations which could benefit this group, such as recommendation 29, (p. 93), does not ensure that families looking after young people with profound physical and intellectual disabilities will receive the practical help they need to care for their youngsters or receive services that are appropriate and of a high quality. As already mentioned (Chapter 1, p. 8) many parents are concerned about the implementation of some of the SAY Report's recommendations, fearing that this will mean people with profound physical and intellectual disabilities may get fewer services than they do now, especially specialist services.

This section has looked at joint working and funding. The later is further considered in the following section which focuses on Future Needs Assessment (FNA) meetings. This section begins by considering whether assessment and planning are needs-led or service-led.

FUTURE NEEDS ASSESSMENT MEETINGS

Needs-led or service-led?

The parents involved in my study went to the first FNA meetings with high expectations. They were confident that good quality provision would be available for their offspring. The FNA meetings usually began with a review of the young person's progress during the past school year and outlined future developmental and curriculum areas to be worked on in the coming year. Then the discussion centred mainly around post-school placements. However, as the young people began to reach school leaving age, discussions about post-school placements began to dominate FNA meetings. At the same time the parents became increasingly despondent about the usefulness of the meetings, the expertise of the professionals, the lack of communication amongst agencies and the lack of progress being made:

> Joyce (Kylie's mother): I really really really feel strongly about the fact that they just mucked us about and they made us go through all the stress and strain that I wouldn't want to inflict on anybody else in our position.

These findings are supported by the COSPEN Report (1988) and by Hubbard (1992) and Wood and Trickey's (1996) studies. Hubbard (1999) argues that because the FNA meetings involve a changing group of multi-disciplined professionals, with no-one acting solely on behalf of the young person and their family, assessment and planning becomes service-led rather than needs-led. In contrast, the parents participating in my study wanted good quality post-school provision for their offspring which met all of their needs — physical, educational, social, emotional and medical. They rejected the idea of "packages of care" as they wanted a continuation of their young people's education. They stressed the importance of education continuing into adulthood, seeing it as a right for everyone. They saw education in broad terms, regarding the provision of therapies, such as physiotherapy and speech therapy, as an essential part of their young people's education:

> Helen (Faye's mother): ...I mean that [lifelong learning] is everybody's right isn't it, I mean that is our right as well. I mean we can go and access anything that...
>
> Pauline (professional): That is clearly laid out in the Beattie Report and the Education Act but certainly education, there is one person in education who comes to the post-16 group and she really has a fight on her hands in terms of putting the case across for profound learning disability. It is just, our education service just don't listen to that post 18. The colleges and everything are great for that sort of thing you know, for younger people with perhaps a less level of need and they have a really good relationship... but it is almost again like there is nothing really for profound...
>
> Helen: Yes, that's why I'm saying...

> Jillian (professional): It's particularly important because people with profound and multiple learning disabilities aren't realistically going to be able to think about employment (agreement from family carers), so education is their key thing.
>
> Maureen (Simon's mother): They need a constant stimulus to keep them...
>
> Helen: And that is why I was saying even that physiotherapy was part of their education (general agreement) so you have got to carry that forward, that is part of their lifestyle, that is part of their learning.
>
> Pauline: The Beattie Report says that in all sort of community resources where people with profound disability are placed that there should be education input into those and there isn't at the moment. Some people working in them have backgrounds in education and community services and users skills but that is just pot luck...
>
> Jillian: And that is a driving issue for staff isn't it because a lot of colleges are not going to have the skills necessary to work with people with PMLD so there is a very major skills issue which hopefully the Scottish Consortium will start addressing and developing training modules across the learning disability section and [they] are very keen to get into that so hopefully in a years time they will have a shelf full of things people can use.

For the young people who are the focus of this study, education department involvement stops when they leave school. In Scotland there are no further education colleges which cater for the educational needs of the young people in my study. However, the "Enhancing Quality of Life" project (Dee, 2001) is currently working with practitioners in England to develop a curriculum framework and materials for people with "profound and complex learning difficulties". In addition, the Orchard

Hill College in Surrey provides an educational programme for adults with "complex learning difficulties" (Allen, 2002). Perhaps following the Beattie Report (Scottish Executive, 1999) and the SAY Rreport (Scottish Executive, 2000) such initiatives will be developed in Scotland, although at the moment the priorities for the latter report are employment, local area co-ordination and hospital closures.

The parents in my study quickly found out that the FNA meetings focused on existing services, rather than needs-led person-centred planning (see Chapter 2, Table 8, p. 71):

> Joyce (Kylie's mother): I always say that you could have 50 young adults with profound and multiple handicaps in a room at a school all leaving at the same time and I think that they thought that every one of them was going to need the same provision. Trying to get them to understand that you had to address each individually, each of them individually and it was like talking to a brick wall.

They gradually became disillusioned with the whole FNA process and began to feel that the authorities were "just not interested in providing, it always comes down to money."

Lack of funding for provision for this group was acknowledged as being a problem by the professionals in the focus group discussion:

> Pauline (professional): ...once the young person becomes 18 they come under the Community Care Act and under that Act the local authority is obliged to assess for need and to provide for those needs within the resources that it has.
>
> Helen (Faye's mother): But then it is always within the resources...

> Pauline: So it is actually in the Community Care Act that stipulates you know in terms of that, you know once a person is 18.
>
> Maureen (Simon's mother): Because in black and white it's they are obliged to, it doesn't say they have to.
>
> Helen: Uhuh.
>
> Pauline: They have to assess.
>
> General yes.
>
> Pauline: And they have to meet the needs within the resources that they have as best they can so there is no... (nods of agreement from family carers) legal requirement for the authority to provide for those needs if they don't have the resources... resources aren't unlimited and you know there is some sort of fairly heavy decisions that have to be made at times and then we have to try and get finance from elsewhere if our budget goes over...

The professionals in the group recognized that there needed to be a financial commitment at both local and national level to meeting the needs of people with profound physical and intellectual disabilities and their family carers:

> Angela (professional): ...there has to be a commitment from the planners, from the budget holders, towards planning to meet these needs and I think that's at the moment that's the bit I feel is kind of like a brick wall...
>
> Jillian (professional): I think the difficulty with people with profound and multiple learning disabilities is that they do have a great tangle of inter-related needs and they are a small group but their needs are very expensive to meet and because they are a small group they find it very

> hard politically to compete with larger groups who have less perhaps intense needs and this is sort of a built-in problem...

Certainly recent research (Cohen et al., 1998 December; Morris, 1999b; Pearson, Flynn, Maughn, & Russell, 1999) suggests that people with "complex needs" are less likely to receive effective support in transition than other groups of young people with disabilities. Moreover, organizations such as the North West Training and Development Team (NWTDT), have been reporting concerns amongst service providers about an anticipated increase in the number of people with "complex needs" coming through from childhood to adulthood. They are concerned that existing service structures and inter-agency working arrangements are likely to make it difficult for them to provide successfully for some of these young people. This may lead to:

> ...unsatisfactory and insufficiently supported placements within existing services, export on a temporary or permanent basis to external "specialist" providers, or strong reliance on informal care arrangements with consequent effects upon the families themselves"
> (Routledge, 2000, p. 20)

Agencies and research also highlight:

- lack of competence within existing service settings to meet certain needs, especially when people have complex health care needs (Pearson et al., 1999)
- lack of effective role arrangements within specialist services – crucially on health and social care roles
- inadequate agreements, systems and protocols between specialist and non-specialist primary care providers.

  (Routledge, 2000, p. 20)

The young people's stories in Chapter five suggest that these things are already happening.

Lack of funding, as shown by this study and others (Collier, 1997; Morris, 1999b; FEFC, 1997), means that often there is little or no provision for this group of young people who are the focus of my study. To quote Faye's mother:

> Helen: ...there was nowhere it seemed that could cater for children like Faye when they left school. She didn't conform if you like, she didn't fit into the neat category of just having a physical disability or just having a learning disability...

The parents felt that if there was no provision available, professionals should be honest with the families:

> Maureen (Simon's mother): I was being told the different day care services that were available. Although they knew Simon's needs, none of these at all were totally suitable and I felt they were just pushing me from pillar to post to different day care services everywhere and none of them would be able to take Simon and like you (looks at Helen) I just got angrier and angrier and angrier and I mean they knew, to me they knew fine well that Simon wouldn't be <u>able</u> to go to any day care centre that was available for his next step but they just kept telling me about the different places and I think why, I mean why could they have not come up and said well quite honestly at this moment there is nothing.
>
> Helen (Faye's mother): We just kept being told don't worry about it.
>
> Jillian (professional): Something will happen.
>
> Helen: I didn't at the time, you know oh don't worry something will be there and I thought something would be there.
>
> Maureen: We were told that at the beginning as well but then I thought, no, there is nothing there and then I was really really getting worried and

> it proved to be. I was really worried then because Simon was left at home with nowhere to go.

Lack of appropriate provision for this group seems to fit in with MacKay's (2001 June) second rationale about the disappearance of disability:

> This rationale is heard when people see disability as uncomfortable politically or intellectually, and so deny its existence. Existence is allowed recognition when something can be done within existing resources, or when it fits prevailing dogma... the practical consequence of denying the existence of a disability is that specific needs may not be addressed properly, and clients and their families may have to take their luck with generic services.
> (Mackay, 2001 June, pp. 4-5)

This seems to be what happened to Faye after she left school. She was slotted into an existing service for people with physical disabilities. However, this was the situation in 1988 and since then provision for young adults with profound physical and intellectual disabilities has been set up in Fogart. Unfortunately, these placements seem unable to meet all of the young people's medical needs. This may be the result of too heavy an emphasis on the social model of disability (see Chapter 2) to inform the delivery of services. This model sees barriers to learning and social inclusion as being socially constructed. However, in the case of the young people who are the focus of my study, their impairments cannot be overcome by social solutions or environmental changes alone (Crow, 1992; French, 1996; Thomas, 1999). Their impairments require therapeutic and medical interventions so that the young people can have a quality of life that is relatively free from pain and prolonged illness. Perhaps if the delivery of services was based more on a transactional model of disability which sees impairment and disability both as discrete entities, as well as interacting, all of the young people's needs would be met in their post-school provision.

Although there is now post-school provision for young adults in Fogart, the young people's stories suggest that planning for this group tends to be "crisis-led". It seems that parental pressure was instrumental in the setting up of provision for this group (see Chapter 5). Moreover, the parents are uncertain whether the provision for their offspring will continue, either in its present form, or in a reduced way, as demand for provision increases as forecast by research studies such as Alberman et al., (1992), Blum, (1991) and Stevenson et al., (1997). As already discussed, although by law young people with disabilities have a right to an assessment of their needs, they have no right to services.

Whilst the Scottish Office (1998a) and the Scottish Executive (2000) advocate life-long learning for all, provision for young adults with profound physical and intellectual disabilities is under-resourced. As already suggested in the previous section, one way of overcoming this problem might be the pooling of budgets by the health board, social work department and education services, as well as joint working which encompasses strategic planning, service commissioning and service provision (see Southampton City Council et al., undated). Indeed, as described earlier, Fogart has set up a multi-disciplinary post-16 group which looks at the transition period from school to post-school provision. This group is able to negotiate with other organisations for services as it has a small budget. However, the group experiences financial difficulties when the young person has high care needs such as the young people who are the focus of this study:

> Pauline (professional): ...we can commit to a young person's care, I mean somebody with very high needs and it is £80,000 a year which you are at least talking about, a quarter of the budget straight away...

This idea of a transition team is supported by Routledge (1998). He argues:

> Perhaps the most important requirement is to allocate workers with appropriate skills to offer consistent involvement, at a reasonably intensive level over a substantial period. Workers involved in transition

> assessment and planning need to get to know the young person and their carers well, over a reasonable period of time so that their real needs and aspirations can be properly identified.
> (Routledge, 1998, p. 15)

However, although admitting that there are considerable advantages to having a transition team, Cohen et al. (1998 December) highlight several drawbacks:

> Would it facilitate smooth transition and the provision of services appropriate for young people, or result in more bureaucracy, by replacing one transition by two? If, as some professionals argued, adequacy of adult services is as much of an issue as effectiveness of planning systems, could the establishment of a transition team on its own, without accompanying service developments, just paper over the cracks?
> (Cohen et al., 1998 December, p. 19)

The young people's stories (see Chapter 5) show that the adequacy of adult services is as much an issue in the transition stage as the effectiveness of planning systems. All the young people and their families experienced considerable difficulty in finding good quality post-school provision. This problem is not particular to Fogart but is reflected throughout the country (Bradley et al. 1994; Dee, 2000; Hogg, 1991; Morris, 1999a, 1999b). Hogg (1999) suggests that this is partly because it is only recently that further education for adults with profound physical and intellectual disabilities has begun to be developed but also because services for this adult group are more costly than for other groups of people with learning disabilities (see Chapter 1). This was acknowledged by the focus group members:

> Jillian (professional): ...groups like people with PMLD (profound and multiple learning disabilities) tend to fall foul of the system until they get into a crises situation and because they need long term planning and lots of resources they tend to always be behind in the queue.

Therefore the parents felt that there should be a legal obligation on authorities to implement the recommendations of the FNA process:

> Helen (Faye's mother): ...I think it should be the same as the Record of Needs (nods of agreement from family carers), the Future Needs Assessment, you kind of wonder why you have them if there is no obligation to carry it through.
>
> Maureen (Simon's mother): That's right.

This view was echoed by the professionals in Ward et al.'s (1994) study. The professionals involved in this study found the idea of recording young people's special needs, whilst being unable to meet these needs because of financial constraints, deplorable.

The professionals in my study also described how at the moment the way funding was allocated prevented effective planning and delivery of services:

> Pauline (professional): ...finance is only available on a year to year basis in local government.
>
> Jillian (professional): That's right.
>
> Pauline: You only get a yearly budget and I think it will make a difference when the budget is changed to three yearly and there will be a better opportunity to plan.

Similarly, commissioning of services means that it can take up to at least a year for new services to be set up:

> Pauline (professional): ...we used to have all our own services, all our own resources in the local authority. Things changed and we got into a

> position where we have some but we purchase new resources or more specialised resources and that process takes time, there is no doubt about that. We have to put together a schedule for what the service requires, they have to be put out to tender because there is legislation that we have to put them out to tender to give, you know to be fair and then there is a contracting period as well... it takes at least, I would say, at least a year to set up a new resource, to negotiate it.

However, the professionals in my study are hopeful that joint funding, joint commissioning arrangements, pooled budgets, the Independent Living Fund (ILF) and the Direct Payments scheme will improve services for people with profound physical and intellectual disabilities (see Routledge, 2000; Turner, 2000). Unfortunately, some families and young people with profound physical and intellectual disabilities do not qualify for ILF as the cost of their care packages from the social work department are above the ceiling for ILF payments. This is because the high level of care they require is costly. Moreover, the Direct Payments scheme was only extended to include all people with a learning disability in 2003 and it remains to be seen whether it will enable this group to purchase the services that they need. However, the SAY Report does recommend that local authorities, health boards and the voluntary sector look at the extra needs of those with "profound and multiple disabilities" and their carers. Moreover, it suggests that the Centre for Learning Disability should set up "a national network of support to local providers offering advice and training on the extra needs of people with profound and multiple disabilities" (Scottish Executive, 2000, recommendation 29, p. 93). However, the report fails to set a framework for the delivery of services to this group of people. Mencap (2001 November) argues that people with "profound and multiple learning disabilities" and their families need "practical hands-on services" (p. 41). This is echoed by the parents in my study of the transition period. They want the outcomes of the FNA meetings to be legally recognized so that authorities must provide day and educational opportunities for their youngsters, as well as a "pot" of money to follow their offspring throughout their lives to ensure that services are appropriate and of a high quality.

Mencap makes several recommendations in its report (Table 37) which aim to ensure that practical help is given to people with "profound and multiple learning disabilities" and their families. These recommendations are also designed to improve the standard of services so that "people with profound and multiple learning disabilities have real choices in how they live their lives" (p. 41). They are similar to some of the proposals put forward by the focus and nominal groups in my study to overcome some of the difficulties experienced by the young people and their family carers.

Table 37. Some of Mencap's (2001 November) recommendations for the delivery of better services to people with "profound and multiple disabilities"

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1. The Government should set clear objectives for services for people with profound and multiple learning disabilities, clearly outlining the outcomes that Social Services, health and other agencies are required to deliver. The Department of Health should publish performance indicators setting out key targets for health and Social Services to achieve over a five year period.

2. The Government should ensure that guidance on the implementation of Valuing People, the White Paper on learning disability services (England and Wales' report on learning disability), places an obligation on local agencies to target services at children and adults with profound and multiple learning disabilities.

3. The Department of Health should evaluate the Joint Investment Plans for their success in developing strategies that deliver more consistent services for people with profound and multiple learning disabilities and their families and carers.

4. The Department of Health's new guidance on eligibility criteria, Fair Access to Services, should ensure that people with profound and multiple learning disabilities living in the family home are defined as a "critical priority" when defining priority for services.

6. The Government should instruct the Social Services Inspectorate to inspect a sample of local councils to determine the quality of services for people with profound and multiple learning disabilities. This should include a thematic inspection of assessment and care packages for children and adults with profound and multiple learning disabilities. Government should promote good practice from these inspections in regional seminars.

7. The Government should instruct agencies such as the Commission for Health Improvements, the Social Care Institute for Excellence and the Care Standards Commission to develop standards for services for people with profound and multiple learning disabilities. This will assist in raising of standards and improving the quality of services.

8. Local Learning Disability Partnership Boards should identify the number of people with profound and multiple learning disabilities in their area, review services currently provided, and draw up an action plan for the improvement of services within a prescribed period.

9. Local Learning Disability Partnership Boards should be expected to identify a champion for promoting services for people with profound and multiple learning disabilities and their families and carers.

11. Social Services, health and other agencies should ensure that carers are actively involved in the design and delivery of services and in tailoring individual packages of care. Carers' views should be recorded and used in the planning and commissioning of services.

12. Social Services, health and other agencies should have a dedicated team sufficiently trained to understand the needs of people with profound and multiple learning disabilities. That team should have the understanding, skills and experience to carry out the initial assessment, provide and review service provision, and ensure that services are co-ordinated between different agencies.

13. Service providers should ensure that once children with profound and multiple learning disabilities have been identified as being in need under the Children Act, they are regarded as a priority for adult services under the NHS and Community Care Act.

14. Direct Payments and brokerage arrangements should be promoted to parents of children and adults with profound and multiple learning disabilities, and support services should be set up to enable parents to use these easily and effectively.

15. Social Services, health and other agencies should develop a person-centred approach, putting people with profound and multiple learning disabilities and their families and carers at the centre of the process for planning services. This must include day services and respite care. Government guidance on developing a person-centred approach should reflect the needs of people with profound and multiple learning disabilities.

16. Parents should be informed about the Independent Living Fund and the ways it can be used to support adults living within the family home.

17. Social services should ensure all families of children or adults with profound and multiple learning disabilities have a multi-agency key-worker to provide a single point of access to information, and better co-ordination of services.

Adapted from Mencap, 2001 November, pp. 41- 43

According to Thomson (1998), this endorsement of a needs-led approach within resource constraints causes parents considerable stress and can result in health problems. The findings of my study support this suggesting that the transition period affects the whole family as illustrated by the quotes below:

> Maureen (Simon's mother): ...Colin (Simon's brother), I mean he was more a carer than anything else because he used to say "Right mum, away you go out, I'll watch him for such and such a while."

> Joyce (Kylie's mother): Stressful for me in the sense that I have to say that I had to go on anti-depressants just the way I was feeling...

> Roger (Geri's father): I'm very stressed, unable to work at the moment because everything that we need for Geri for her to be able to continue in the happy frame of mind and a level of health that she is now enjoying, it takes up so much time that we or I don't seem to have been able to... I can't think of anything else, especially work at this particular moment.

> Helen (Faye's mother): ...it was very stressful. I couldn't see a future for Faye and I couldn't see a future for me while this was going on and that puts quite a lot of strain, there was my son in the family, there was my husband, it puts a lot of strain between a husband and wife.

However, until society takes on the responsibility of providing services and making provision for people with profound physical and intellectual disabilities, the parents in my study feel they need to keep campaigning for services:

> Helen (Faye's mother): ...I think keeping the high profile of PMLD and I know it seems to be down to parents a lot of the time but I think professionals are taking it on board more now as well. But I think just keeping a high profile of PMLD at the front because very often if a place is found, that is fine, we will just forget about it you know, it is swept under the carpet... So I think just keeping the profile high on the agenda.

> Jillian (professional): I think that is extremely important, I think it is a very tall order for parents and I am always extremely impressed by parents like yourselves who put a huge amount of energy into keeping that profile high and making sure that the needs of your sons and daughters are listened to at points where people make decisions.

There is acknowledgement by the parents that the needs of their young people are beginning to be more recognized by professionals working at the ground level and that they need to target senior management level:

> Helen (Faye's mother): ...the social workers, their hands are tied so very often and it is higher up the decision-making ladder that has to know exactly, you know the profile has got to reach them in some way.
>
> Maureen (Simon's mother): That's right. My social worker felt that she was on her own constantly.
>
> Helen: Yes, yes.
>
> Maureen: She was just as frustrated as us because there was nothing available for Simon to move on to.

The above discussion suggests that although professing to be a needs-led approach, FNAs for young people with profound physical and intellectual disabilities are heavily constrained by resources and funding. Some writers suggest (Hubbard (2002) that increasing young people's and their family carers' involvement in FNA meetings, together with the appointment of transition co-ordinators, will help to ensure that FNA meetings are more needs-led. This is discussed below.

Increasing participation

Professionals

My study also found that FNA meetings were usually attended by the staff involved with the children at school, the educational psychologist and a doctor. However, sometimes there was no representative from the social work department.

This concurs with Hubbard's (1992) study and the SAY Report. The former found that social work contribution to the FNA is usually from children's services and usually they only have limited knowledge of post-school placements. The parents involved in my study felt strongly that it was essential for representatives from the social work department to attend FNA meetings as they were the providers of adult provision. They also felt that such meetings without social work input were a waste of time:

> Joyce (Kylie's mother): I felt that the future needs meetings at the school were a total and utter waste of everybody's time and the school especially, they put so much work into it, so much preparation for the meetings, took time out of their days, Bobby [Kylie's father] took time off his work, I took time out of my day and the social work's involvement was absolutely and utterly ludicrous, it was a joke, it was a joke because the children's team said that it was going to be the adult social work department's job to find them placements and that was the first of the adult team [Kylie's FNA meeting when Kylie was seventeen], adult side of it, knowing about it.

This problem is also highlighted in Thomson's (1998) study which found that all the agencies who could contribute to the transition process were not always involved. Moreover, as Simon's story showed (see Chapters 5 & 6) there are also organisational difficulties in getting all the professionals involved together for meetings. As stated by the professionals involved in the focus group, often workload pressures affected their participation and attendance at FNA meetings:

> Pauline (professional): ...and teams are under an incredible amount of pressure (general agreement), I can only speak for social work teams which I manage but... and I know how difficult it is for them to sometimes even get along to meetings because they are under so much pressure. You know it is things like if social workers are off ill or away on training their posts aren't, nobody temporary is brought in to cover...

Sometimes this resulted in them prioritising work and often attendance at FNA meetings was not seen as a priority:

> Jillian (professional): ...there are always conflicting demands and people may not turn up just simply because they haven't prioritised and particularly if they think they have got a couple of years grace

> before the young person leaves school, they think oh well that can wait till next week when actually the time is really very short.

Cohen et al.'s (1998 December) study also highlighted this problem and argued that specific resourcing of transition work is urgently needed. They suggest that workers be given protected time within their job description for transition work and that consideration be given to other resources which might help them to do their work more effectively. Perhaps transition co-ordinators have a role to play here.

Unlike the parents in Hubbard's (1992) study, the parents in my study did not feel intimidated by the large number of professionals attending the FNA meetings. Both parents usually attended the meetings with the mothers playing a major role in the discussions and the fathers a supportive role. They had good relationships with the school staff, felt part of the school team and as a result felt able to express their opinions freely. However, Faye's story (see Chapter 5) suggests a need for staff training in relation to the management of FNA meetings and interpersonal skills. Moreover, Faye's mother acknowledges that for some parents the FNA meetings could be intimidating. Certainly the parents in Hubbard's (1992) study felt that the meetings were too large and saw themselves as only playing a minor role. In contrast, the parents in my study welcomed the large number of professionals who attended:

> Catherine (Geri's mother): Well I actually felt because there was so many people at the meeting that everything would be, Geri's future would be discussed and people would, they would all have their input to help find provision for Geri when she left school. I didn't think that we would be in a situation where the first... I didn't expect after the first meeting we had that people would actually go away and appear to do absolutely nothing about it.

The above quote suggests that there may be a lack of monitoring of the process. This is discussed later in the section about the role of transition co-ordinators.

The young people and their family carers

None of the young people involved in my study played a part in the decision-making process at the FNA meetings or attended them. Faye's mother was thankful that Faye was not present at the meetings because of the sometimes negative and hostile views expressed by some professionals. The parents said that their offspring were unaware of what was happening at this time and they made every effort not to upset their youngsters, even although they themselves were under considerable stress:

> Anne: (interviewer) Did she ever attend any of your Future Needs Assessment meetings?
>
> Helen (Faye's mother): No. I don't think I can ever remember her being at the Future Needs meeting and she certainly thankfully wasn't at that meeting [see pp. 271-272] ...she was unaware of what had gone on and we certainly didn't discuss it in front of her. We were upset enough that night. My husband was furious when he got home to see how upset I was and we certainly didn't want it upsetting Faye.

In her study of post-school planning for young people with disabilities in Scotland and Ontario, Tisdall (1996) recommends that young people become more involved in the post-school planning process. She criticizes FNA meetings for disempowering young people and not actively involving them in planning and co-ordinating their post-school lives. She urges that alternative structures be considered to address the problems of transition from school to post-school provision for young people with disabilities and argues that "professional-intensive, inter-agency assessments" (p. 30) may not always be the best or only method.

As well as stressing the importance of encouraging young people to actively take part and be involved in FNA meetings, Dee (1997) and Hubbard (2002) also stress the importance of active carer involvement. Cohen et al.'s report (1998 December) echoes this, recommending that:

> Future work on developing transition services needs to build in elements which facilitate the active participation of service users. This participation should be seen as a central criterion for the effectiveness of transition planning, and may affect decisions about systems and procedures...
>
> (Cohen et al., 1998 December, p. 25)

However, they found that although professionals in their study felt that participation and empowerment was important for young people and their carers, in practice other considerations were given precedence. They suggest that most professionals are too caught up with the constant pressures of their everyday work and as a result are not able to give much attention to including young people and their carers in procedures and practices. They also found that young people with no verbal communication were rarely actively involved in the decision-making process (see also Chapter 2). Often their view was missing and there was an assumption that family carers and professionals represented their interests and viewpoints. However, Cohen and her colleagues suggest that carers may have their own needs, concerns and rights and that professionals may be constrained by agency structures. Therefore they suggest that if people with communication difficulties are to have the same rights as everyone else, then their viewpoints need to be taken into account. Thus they recommend that an independent advocacy system be set up for these young people during the transition stage. A report to Southampton Transition Partnership (Royall, undated) endorses this and urges professionals to "get together to share creative ideas and positive experiences of how to involve all young people in an individually meaningful way" (p. 23). It has been suggested that one way of doing this is through person-centred planning.

Person-centred planning

Hubbard (1999) proposes using personal profiles to involve young people and their families in the decision-making process to ensure that they have the opportunity to express their thoughts and views. She describes the profile as:

> ...a body of information that the young person and the family have agreed they want recorded for the purpose of facilitating a greater understanding of themselves by other people and to help decide what will happen after leaving school.
> (Hubbard, 1999, p. 4)

This sounds similar to the person-centred planning approaches discussed in Chapter 4. Hubbard (2002) sees person-centred planning (PCP) as providing a holistic, needs-led, co-ordinated approach which is centred on the individual and involves joint decision-making. In this approach:

- The focus is on the person and their life – the planning meeting is not to discuss the difficulties the service or the professionals may be experiencing or the constraints they are working within
- The person and people who love and care for the person are the primary authority
- The professionals are to be on tap and not on top – they are there to provide advice, knowledge, support and service – it is not their meeting
- The control is with the focus person and their advocates
- Universal needs are as important as medical needs
- The focus is on individual gifts and aspirations, not individual needs and deficiencies
- There is a future orientation
- There is a commitment to address conflict openly and honestly
- There is a commitment to reach a consensus for action
- There is a willingness to come up with non-traditional solutions
  (Charles & Johnstone, 2002, p. 5)

Both the parents and professionals involved in the focus group discussion in my study felt that the FNA meetings were lacking in structure and professional commitment to take things forward:

> Helen (Faye's mother): I think we need more of a structure at the actual assessment and people know what they should be going away and doing because I think that is very often... you know instead of just saying och well don't worry something will turn up.

> Angela (professional): It is almost like they have got to have a meeting for the sake of having a meeting and again that puts people whose time is limited anyway off, you know put off going along because they think well what's the point, nothing is going to be decided, you know I have got other things I can be doing, I'll be away doing that kind of thing.

> Maureen (Simon's mother): Because we felt that before, people have turned up and been there just for the sake of being there and half an hour later would scoot because they know find damn well there is nothing to go on to, so I mean it was just I turned up, clock me down, I have been and I am away.

They felt that transition co-ordinators could play an important part in ensuring that progress was made between FNA meetings by using person-centred planning tools:

> Angela (professional): (an action plan) ...laid out at the end... this is what we are going to do in the next six months or whatever time plan.

> Jillian (professional): And this is the person that is going to do it.

> Angela: Yes that they are actually responsible for doing something and accountable for doing it, and again as you say, having the transitional co-ordinator, whoever that person is, being responsible for checking up on people if you like to make sure that that is happening.

> Angela: (it is) ...person centred, it is looking at this individual and what do they need and it does get people to sign up to doing, you know,

> whatever the action plan is that is decided at the end of it, so maybe that is something that somebody could look at you know for using with children in the Future Needs process.

However, there was also a recognition that person-centred planning faced the same problems as the FNA meetings in terms of commitment to take things forward:

> Angela (professional): ...at the end of the day it is down to the individuals who said that they are going to do something to actually get off their backsides and do it.

Nevertheless, Charles and Johnstone (2002) argue that:

> When person centred planning works it builds a desirable future for the person and engages the energy, commitment and ingenuity of others to make that future happen.
> The process also seeks to build commitment to change and the development of creative solutions to long-term problems, not just analysis.
> (Charles & Johnstone, 2002, p. 6)

Duffy (2002) also argues that:

> Planning is not enough: to make a plan is to make a commitment to act on that plan and if we do not act we are breaking our word.
> (Duffy, 2002, p. 1)

Dumbleton (2002) cites instances of parents and professionals using person-centred planning successfully at the transition stage. Indeed, one of the professionals who took part in the focus group discussion in my study also found person-centred planning a useful tool:

> Pauline: I was involved with somebody who used that when she was leaving school and her mum was you know quite heavily into that and it, I mean it completely changed the dynamic of the Future Needs meeting so it was very much focused on the report that the young person had done themselves with their mum and that was really really good...

Charles and Johnstone (2002) view Essential Lifestyle Planning as being a useful tool to help "people with complex physical and medical support needs (who) do not use words to communicate" (p. 16). As described in Chapter 4, this tool was developed by Susan Burke-Harrison and Michael Smull. It was originally developed to supply service providers with information about people who were leaving long-term institutionalized care. It has also been used in residential care settings as a way of ensuring that staff provide services in ways which suit the person. However, it has also been used to help people make changes in their life, plan their future and organise the support and services they need (see Smull, 2000 November 12). As suggested by the focus group, Essential Lifestyle Planning might be a useful tool for planning the transition stage for this group and also for increasing the young people's and their family carers' involvement in the decision-making processes.

The above discussion has made several references to the role of transition co-ordinators in increasing young people's and their family carers' involvement in FNA meetings. It has also suggested that the transition co-ordinator may have a role to play in ensuring that progress is made between FNA meetings. The role of the transition co-ordinator is discussed more fully in the next section, with particular focus on the monitoring of the FNA process and the transition period.

TRANSITION CO-ORDINATORS

Both the family carers and the professionals involved in the focus group discussion in my study stressed the need for someone to assist family carers and their young people with profound physical and intellectual disabilities through the transition process. Several studies (Cohen et al., 1998 December; Dessent, 1996; Hubbard, 1999; Routledge, 2000) and reports (Beattie Report, Scottish Executive, 1999; the

SAY Report, Scottish Executive, 2000; Southampton City Council et al., 1999 December) support this idea. Indeed, Capability Scotland has recently participated in a project aimed at developing a new model of practice which proposes the development of a transition co-ordinator. They see the transition co-ordinator as providing a link between each individual young person, their family, school staff and all those involved in planning and delivering post-school services. Hubbard (2002) envisages the transition co-ordinator's role as:

- developing a working relationship with the young person and their carers
- preparing the young person and carers for leaving school
- offering support at Future Needs meetings
- following up on actions made at meetings
- developing contacts with agencies involved in the transition process
- developing person centred profiles
- developing person-centred action plans
- supporting young people after leaving school.

This idea of transition co-ordinators was also welcomed by the focus group members. In fact one of the professionals described how she had appointed a worker in her team to work with young people and their families during the transition period:

> Pauline (professional): In one of the teams that I manage... I appointed a worker to work solely with young people in transition and that was her caseload that she carried, that singly, and she was known locally with health and with education, that was her sole role but that was only in one team in Fogart and that worked particularly well. But for other reasons, other teams couldn't take that on... I know that that worked well, so I think it is important to have somebody who specialises in that area whatever their background, (general agreement) that they know about issues for parents...

> Pauline: ... it doesn't matter... you know it doesn't really matter who it is or what background they are from (general agreement) but as long as they have got a clear role then that's their responsibility and families know who to go to.

> Jillian (professional): I do feel that a transition co-ordinator would be a very useful person in gathering information together too, I think that would be extremely helpful.

There was also optimism that the newly appointed Local Area Co-ordinators (LACs) recommended by the SAY Report (Scottish Executive, 2000, recommendation 2, p. 20) would help facilitate the transition process:

> Angela (professional): I think the local area co-ordinator when they come about... will be aware of all the people that are living in their area who have a son or daughter and I think them having that knowledge might help as well, because obviously they will be part of feeding into the planning process as well, I would imagine, certainly from my understanding of what their role is going to be and certainly putting people in touch with specialist teams, because they will have, well they should have, local knowledge of what is available in their area. So I think that might go some way to help as well.

However, it was also recognized that Local Area Co-ordinators (LACs) might not have the knowledge and skills required to co-ordinate transition services for people with profound physical and intellectual disabilities:

> Pauline (professional): ...if you have workers who have a wide range of responsibility they are not always going to be skilled or in tune to young people with profound needs and they are not going to find it easy and it is about identifying people who are good at that and making sure it is them that go to meetings because there is no point in sending anybody.

General agreement.

Helen (Faye's mother): I think that is a very important point.

Pauline: You need somebody who is going to function and take things away too.

Helen: Because we have had, I think we have all had the situation that we have had a worker there who has had no experience at all of young people even, you know they have been moved over from the elderly and the needs (we are discussing) are for a profoundly disabled young person.

Monitoring

As highlighted previously, the parents felt that there was a lack of effective monitoring of the FNA process. Often decisions made at FNA meetings were never implemented. The Social Work Services Inspectorate Report (1998) concurs with this. It found that follow-up arrangements frequently broke down. According to the SAY Report (Scottish Executive, 2000), this is for a number of reasons. Firstly, it is because education authorities have no responsibility for putting FNA into practice after the child leaves school. Secondly, there is no legal duty on agencies to implement the recommendations of the FNA process. Thirdly, because putting the FNA into practice often requires resources provided by other agencies and fourthly, social work departments rarely commit funding to resources two to five years ahead. To ensure that progress is reviewed and monitored, the Beattie Committee (Scottish Executive, 1999) suggested drawing up an action plan to ensure progress (Table 7, p. 66). Thomson (1998) also suggests that follow-up arrangements often break down due to variations in practice between agencies, as well as a lack of formal mechanisms for exchange of information both within and amongst agencies. The latter is demonstrated in Simon and Kylie's stories. Both had FNA meetings in 1995. Simon's parents were told there was no provision for Simon in Fogart to meet his needs, whereas Kylie's parents were assured that a choice of placements would be available for Kylie when she reached school leaving age. This lack of monitoring and follow-up arrangements means that the parents in my study had to enlist other people's help. Simon's parents became members of a parent pressure group, Geri's parents sought help from other parents and enlisted the services of the local Carers Centre, Kylie's parents went to a review committee and Faye's parents had meetings with the director of the social work department.

The focus group also felt that mechanisms should be in place to pick up any problems with placements and facilitate future transitions. They stressed the importance of transition planning being seen as an ongoing process:

> Helen (Faye's mother): ...nobody stays the same...
>
> Maureen (Simon's mother): No never.
>
> Helen: Never. You hope it is an improvement but sometimes it can actually be a deterioration because of their health needs.
>
> Maureen: Yeh, that's right.
>
> Helen: It is not to say that what will suit them at 16, 18 is actually going to be the same in 20 or 30 years time.
>
> General agreement.

This has been highlighted by other researchers (Routledge, 1998; Wood & Trickey, 1996; Cohen et al., 1999 March) and by Scottish Executive reports (Beattie Report; SAY Report). Cohen et al. suggest that:

> Inter-agency transition planning needs to have a broader remit than at present, and to focus on longer term plans including plans for the next stage after college, and general plans for living and care arrangements.

> A mechanism is needed for follow-up after school leaving, to see if plans have worked out.
> (Cohen et al., 1999 March, p. 48)

Hubbard (1999) suggests that some of these problems may be overcome by the appointment of transition co-ordinators and the use of person-centred planning tools.

Transition

The stories indicate that because placements are not identified soon enough for this group of young people, transition is at best short and at worst non-existent. For the parents left with no provision after the FNA process life for both them and their young person was very stressful. Both Kylie and Simon missed the stimulation of school life and the social interaction with their peers. In addition, they lost some of the skills they had developed at school.

The parents involved in this study would ideally like to see a six month transition period so that staff from the school and the identified post-school placement can liaise and communicate with each other. However, the focus group members recognised that the timescale might vary depending on the individual:

> Helen (Faye's mother): Faye is very much a one to one person and got very very uptight at change so it had all to be... because at that time she was still being fed orally and for a stranger to go in and feed or give Faye a drink it was virtually impossible, it had to be very very gradual...

Catherine's account of Geri's transition from junior to senior school (see Chapter 5) shows that staff visits to the parents, family visits to the new placement, good communication between all parties involved — family, school staff and new placement staff, as well as exchange visits by staff to work with the young person in their old and new settings, lead to a smooth transition.

Like Hubbard (1999), the parents saw the transition co-ordinator as helping to ensure a smooth transition – helping parents to identify post-school placements, arranging visits and accompanying the young person and their family on such visits:

> Helen (Faye's mother): ...somebody to take the onus away from the parent, yeh because the parent has to end up doing the leg work...
>
> Helen: I think the personal touch has to be there in that the co-ordinator or (someone) who would know the young person, know exactly what their needs were and would they fit in with you know, (a), (b) or (c) (post-school placements).

This study has shown that both family carers and professionals would welcome the support of a transition co-ordinator during the FNA and transition processes. From the young person's and their families' viewpoints, the transition co-ordinator would help by:

- taking time to get to know the young person and his/her family
- assisting them to develop person-centred profiles
- acting as an advocate for the young person
- enabling them to become actively involved in the FNA process
- offering help and support when dealing with statutory and voluntary organizations
- overseeing and co-ordinating FNA meetings
- following-up on decisions made at FNA meetings, identifying appropriate post-school placements
- ensuring a smooth transition from school to post-school placement
- being involved in any further transitions

From the professionals' viewpoint, the transition co-ordinator would help to:

- organize FNA meetings
- ensure the relevant agencies received information about the young person prior to the meeting and attended the meetings
- follow-up on and implement decisions made at the meetings
- support the young person and his/her family through the transition period
- negotiate the most appropriate package of care for the young person
- provide initial support for the young person in their new placement
- co-ordinate future transitions

However, although the group felt that the appointment of a transition co-ordinator would alleviate some of the problems identified by the family carers, like Routledge (2000), they felt that organizational, administrative and resource difficulties also needed to be addressed:

> It still appears to be the case, in the main, that the separate agencies, sub-parts of agencies and professional groups are focused on their own interests and coherence is too often the exception rather than the rule. It appears that local factors such as resources, policy, organization and agency culture, and individual professional interests or availability, are strong determinants of de facto transition support arrangements.
> (Routledge, 2000, p. 19)

> The difficulties faced by young people and their families are compounded by policy and organisational fragmentation, which makes it difficult for service agencies and professionals to provide the coherent and co-ordinated assistance most likely to promote a positive and successful transition experience.
> (Ibid., p. 18)

SUMMARY

The focus and nominal groups identified various organizational, administrative and funding issues which needed to be addressed in order to improve the transition process for young people with profound physical and intellectual disabilities and their family carers. They suggested the setting up of an inter-agency database or register to improve the flow of information both within and amongst agencies and to inform planning processes and the commissioning of services. They also questioned the appropriateness of the division between child and adult services for meeting the needs of people with profound physical and intellectual disabilities. They expressed optimism that joint policies and training, collaborative inter-agency working, aided by the appointment of transition co-ordinators to oversee and implement the whole transition process, would help to alleviate some of the problems experienced by the young people and their families. They also stressed the importance of transition co-ordinators having appropriate knowledge, skills and understanding of people with profound physical and intellectual disabilities and their needs. They also felt that person-centred planning might be a more effective way than FNA meetings in providing for the needs of this group and for ensuring that post-school plans are implemented. Moreover, they also felt that it would be valuable to have an information booklet for family carers about the whole transition process, which also contained lists of appropriate post-school placements and contact families, who had been through the transition process.

The group also considered funding constraints. They recognised that the needs of people with profound physical and intellectual disabilities needed to be given a higher priority at both government and local level. Emphasis was placed on the need for the young people to have continuing education as a right and for appropriate, good quality provision and services to be in place for the young people in adulthood. They supported the development of a transition policy at local level and stressed the need for commitment by both local officers and government to the provision of services for this group.

The problems experienced by the young people and their families in my study during the transition stage (see Chapter 5) are perhaps similar to those of other young people with disabilities and their families and thus the solutions the groups have proposed may be relevant to other groups of young people with disabilities. However, the group of young people who are the focus of my study are the "forgotten group" when it comes to the provision of services, especially in adulthood:

> Many services were not available to families of people with profound and multiple disabilities. Many people were not receiving care that met their son or daughter's specific needs, or the support they needed themselves.
>
> Where services were available, they were not always delivered in a prompt and effective manner. Often, they were not of a sufficiently high standard. Families and carers did not feel assured that the staff were sufficiently trained or skilled for the work they were doing. In most cases, carers did not have a say in what services they got or how they were delivered.
>
> (Mencap, 2001 November, p. 40)

By using the nominal group technique, I hoped to give the parents "a voice" in expressing their views about appropriate, good quality post-school provision and services for their young adults. This is the topic of the next chapter, Chapter seven.

Chapter 7 Life after school?

This chapter is divided into three parts. The first part looks at the young people's current post-school provision. The second part focuses on the kinds of provision and services the family carers and professionals would like to see provided for young people with profound physical and intellectual disabilities. This part consists of two sections. In the first section I present the results of the nominal group technique. The second section discusses the themes that emerged following analysis of the data. The final part of the chapter looks at the family carers' hopes and aspirations for their young people's futures.

POST-SCHOOL PROVISION

All the young people in the study seem happy with their post-school provision, although Faye finds some of the activities provided are boring and thus tends to loose interest. This reflects the findings of other studies (Beyer & Kilsby, 1995; Scottish Executive, 2000) which report that young adults with learning difficulties find day centres boring. Most of the parents are also happy with the provision. However, Faye's mother believes her daughter is not ideally placed. Her views echo the criticisms of other family carers who describe day centres as lacking direction and failing to provide learning and developmental experiences for the young people (Beyer & Kilsby, 1995). MacKay (2001 June) would argue that this reflects the "nothing can be done" rationale which sees people with disabilities as the victims of tragedy (Milner 1976, 1978; Oliver, 1996) and society's role as one of providing care and treatment. Whilst acknowledging that care and treatment have their place, he maintains that for people with "the most severe degrees of intellectual disability" care and treatment "often seem close to acceptance of defeat and low aspiration" (p. 4).

Looking at Seed's (1996) models of practice (Chapter 2, Table 9, p. 77), it seems that Faye is based in a centre closest to the shared living model. However, Helen and

Gordon's attempts to encourage the centre to provide more stimulating and appropriate activities for Faye, suggests that they believe a centre based on the further education model would be more appropriate for Faye. Moreover, Faye's story supports MacArthur (1997) and Brown's (1997) reports which found that resource centres had no nursing support and limited therapy provision. In Faye's case both are provided by the family. Helen and Gordon are on call if Faye requires nebulisation and extra physiotherapy is provided at home by the family and Faye's paid carer. Geri's parents are in a similar position. Although Geri has not started Lemington Court, the staff there cannot replace Geri's nasal gastric tube should it come out and they too will be on call. As Geri's mother points out:

> Catherine: ...as parents we are expected to do this and as parents we do it and we are not trained nurses and we are just parents who have been given this role. But I think red tape is saying that the people who carry out these procedures either have to have nursing training whereas we, as parents, don't have nursing training and we carry out the procedures.

Thus although Catherine and Roger feel that Lemington Court can meet Geri's physical, social, educational and emotional needs, it cannot meet all her medical needs. According to Faye's mother (who is a member of a working group set up to look at day services for adults with learning disabilities in the local area) no centres in Fogart have staff trained to cope with all Faye's medical needs. She would like either a nurse to be at the centre or for staff to be given training and that training recognized by an increase in salary. However, there appears to be difficulties with these solutions:

> Helen: ...it is all to do with unions and training of non-medical staff to do medical procedures, they seemingly, they can't take on board this training. They are not allowed to take on board that training... I have asked if a nurse could be, could work in there... they have said no, that it is a social work establishment. They won't put a health worker in, a nurse in...

In contrast, Simon and Kylie's parents are happy with the provision provided. From their descriptions it seems that Lemington Court and Gordon House are centres closest to Seed's (1996) further education model (Chapter 2, Table 9, p. 77). They aim to provide continuing education and develop physical, sensory, intellectual and social skills. This is what the parents involved in my study wanted:

> Joyce (Kylie's mother): ...basically I wish that she could have stayed at Ralph Harrison [Kylie's school] but I wanted something that gave her a continuation of the continuity that she had had from day one there, from each, you know, every input from every aspect and every department and that I would still want...

This is akin to Seed's (1996) further education model and Hubbard's (1999) "moving on" model of service provision and delivery:

> [This model] embodies the idea of progression for the individual, from one set of circumstances towards new and changing ones. Implicit in the model is the principle of lifelong learning and the achievement of goals so that the acquisition of life experiences and the development and maintenance of skills and abilities provide the individual with the opportunities to change their lives in the ways they choose as adults.
> (Hubbard, 1999, p. 8)

Hubbard identifies three underlying philosophies of the model – lifelong learning, "based on the holistic development of the individual" (Ibid., p. 9), service delivery, which is needs-led, and inclusion:

> The model puts an emphasis on everyone, including the users of the model, having a socially integrated role and the right to an "ordinary" lifestyle.
> (Hubbard, 1999, p. 9)

This model reflects the principles of normalisation and the "ordinary" lifestyle approach discussed in Chapter 4. Although all the young people have provision at present, the future for them is uncertain. Geri and Simon's parents are unsure about future provision and services for them after they reach twenty-five. At the moment no provision has been identified. Similarly, Kylie's parents, although at present receiving a five day placement at Gordon House for Kylie, fear it may be reduced to a two/three day a week placement as demand increases. As for Faye's parents, they fear that policies of "social inclusion" may result in the Fraser Centre being closed down and services provided in the community (Scottish Executive, 2000).

As discussed in the literature review, continuing education for young people with profound physical and intellectual disabilities has only recently begun to be developed (Allen, 2002; Byers, Dee, Hayhoe, & Maudslay, 2002; Hogg, 1991; Jones, 1989). Therefore one of the study's aims was to suggest criteria for appropriate, good quality provision for this group of young people by using the nominal group technique to investigate parents and professionals' thoughts and opinions. This is discussed below.

RESULTS OF THE NOMINAL GROUP TECHNIQUE

Table 38 shows the "top ten" items generated by the group.

Table 38. "Top ten" items generated by the group

Number of item	Ideas generated	Number of votes
7	Healthcare – access to health screening, health promotion, healthy living, supporting families in healthcare needs related to disability, support during illness and crisis support. Multi-disciplinary team at all levels of care. Practical help. Training and ongoing support for carers in healthcare procedures, use of equipment, moving and handling.	4
10	Day services open seven days so people have a choice and respite (in terms of a break for carers, but must be enjoyable for person) linked to the centre with appropriate client mix for reasons of health and safety.	4

13	Staffing levels must at least be one to one, sometimes need to be two to one e.g. for hoisting. Also need to have good back-up when staff is off ill or if staff meet problem not equipped to deal with.	4
3	Staff trained in aspects of personal development, education, healthcare procedures, social care so that they are independent from parents' help and outside professionals.	3
6	Provision has an individual lifestyle plan which is on-going and developed by person-centred planning based on needs and interests.	3
8	Recognition that every family situation is different so need to design a choice or selection of flexible services to meet needs e.g. respite care and to be able to buy and organize them for themselves e.g. Direct Payments, Independent Living Fund.	2
15	People planning services need to accept that good quality care for people with profound and multiple learning disabilities is expensive and that there are more living in the community because of closure of long-stay hospitals and because of improved medical care, so need is increasing. Public services need clear roles and responsibilities, joint funding, joint responsibility. Funds ring-fenced.	2
11	Day services centre-based with good programmes. Need to access community resources but they need to be equipped. Outings need a purpose and to be meaningful. Attitudes need to be welcoming. Public need to be educated.	1
17	Need special dedicated services. Healthcare and special needs have to be met first for social inclusion to take place.	1
19	Parents fully consulted in planning services and choosing staff.	1

Table 39 (p. 366) shows the five themes which emerged from content analysis of the data (see Chapter 3) and examples of the items they contain (see Appendix N, Table 43, p. 734).

Table 39. Themes and the items they contain

Theme	Item
Inclusion and specialist services	1, 2, 5, 10, 11, 16, 17
Joint working and funding	15, 19
Choice	4, 6, 8, 9, 10, 18
Staff	1, 3, 12, 13, 14, 19
Healthcare needs	7, 5, 9, 14

Themes

As the discussion on the following pages of the five themes shows, the ideas generated by the group bear similarities to the seven principles described in the SAY Report (Table 40).

Table 40. The seven principles of "The same as you?" report

1. People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others.
2. People with learning disabilities are individual people.
3. People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.
4. People with learning disabilities should be helped and supported to do everything they are able to.
5. People with learning disabilities should be able to use the same local services as everyone else, wherever possible.
6. People with learning disabilities should benefit from specialist social, health and educational services.
7. People with learning disabilities should have services which take account of their age, abilities and other needs.

Source: Scottish Executive, 2000, p. 42

However, whilst some of its recommendations will have potential benefit for the young people in my study and their families, the needs of this group, although recognized, are not a priority for the Scottish Executive. Its priorities are local area co-ordination, hospital closure and employment. In fact some parents of people with profound physical and intellectual disabilities are concerned about some of the report's recommendations, such as the move away from traditional day services and specialist health services, fearing that their offspring will receive fewer services than they do now. They feel that there is still a lack of understanding about the degree of disability of their youngsters, as well as their needs. In addition, they still feel they are "the forgotten people":

When will the world waken up
And take a look at me?
I'm the Forgotten People
And I'm longing to be free.

The remainder of this section discusses four of the five themes – inclusion and specialist services, staff, healthcare needs and choice which emerged from analysis of the data. Joint working and funding was considered in the previous chapter.

Inclusion and specialist services

In the past decade governments have expressed their commitment to "social inclusion" – "helping people to feel and be part of the society in which they live" (Scottish Executive, 2000, p. 131). As already seen in Chapter 4, this is reflected in a number of key documents such as "Social inclusion: Opening the door to a better Scotland" (Scottish Executive, 2000) with respect to both educational provision, health services and community care provision (see Appendix R, p. 778). However, there is also a recognition that people with "multiple and profound disabilities" will continue to need specialist services (Scottish Executive, 1999, 2000). Establishing a balance between the two was an important issue for those involved in the nominal group discussion in my study. Although the group endorsed the principle of social inclusion, they too felt that there needed to be a balance between the provision of specialized services and inclusion into the community. This view was shared by both the parents and professionals:

> Jillian (professional): ...I think it is this debate about special dedicated services and inclusion, I think it is really important, particularly for things like healthcare, to say that people aren't going to be included into the community until their special needs are met first because I think there is a lot of talk about community inclusion which tends to make people who are asking for special services feel guilty and inclusion is not going to be real for people who have got substantial disabilities unless those special needs are met first.

They saw it as essential for young people with profound physical and intellectual disabilities to have a base (Table 38, p. 364, item 11). Ideally this base would be near the young person's home and be "small, comfortable and homely-like, not institutionalized". The building would have to be wheelchair accessible and have what the parents describe as "a special care suite" (Appendix N, p. 734, item 1). This care suite would have all the equipment and facilities necessary to meet all the care and healthcare needs of the young people. The centre would be opened seven days a week so that the young people and their families could have flexibility and choice in terms of accessing the services and activities provided at the centre.

A comparison of day services provided to people with "profound and multiple disabilities" in two different day centres, conducted by Rose, Davis and Gotch (1993), supports the group's arguments for specialized provision. Rose et al. found that specialized day provision, within a learning disability service, produced more favourable outcomes than integration within the service. However, they maintain that their findings do not indicate that a more integrated provision cannot produce a high quality service. To achieve this however, requires close attention to the quality and quantity of staff-person interactions, attention to the planning of activities, careful management of staffing resources and activities, staff training and the development of good relationships with agencies and parents (Emerson et al., 1999a, Emerson, Robertson, Gregory, Kessissoglou, Hatton, Hallam, Knapp, Jarbrink, & Netten, 1999b; Hogg, 1999). These criteria were also identified by the family carers and professionals in the nominal group technique discussion (see Appendix N, p. 734, items 1, 3, 9, 11, 12, 13, 19) and are discussed more fully below.

The parents also stressed the importance of having the correct mix of disabilities in the centre. For example, they felt that their youngsters were very vulnerable because of their profound physical disabilities and therefore should not share facilities with people with challenging behaviour:

> Helen (Faye's mother): [an] appropriate how do I say client mix (nods of agreement from Maureen and Jillian) so that there is no... they are very vulnerable, so that there is no threat if you like. Somebody maybe with a different condition, not different condition but...
>
> Pauline (professional): It's a safety issue isn't it?
>
> Maureen (Simon's mother): Yes, health and safety.
>
> Jillian (professional): [it's] not mixing... people who are physically very dependent and people with challenging behaviour. Or people who are ambulant and have challenging behaviour.

Yet reports and studies often classify people with profound physical and intellectual disabilities under the broad term "people with complex needs":

> Complex needs [arise] from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behavioural difficulties.
> (Scottish Executive, 2000, p. 3)

Similarly, autism, mental illness and challenging or self injurous behaviour is often included in the term "profound and multiple learning difficulties" (Lacey, 2000) (see Chapter 2), a term frequently used to describe the young people who are the focus of this study. However, the young people catergorised in this way have very different needs and the services they require have little in common except that in the words of Hogg (1991) they seem to challenge and bewilder service providers (see Chapter 2). Dessent (1996) concurs with this, maintaining that the compartmentalization of people with disabilities is often "an administrative convenience rather than a proper developmental distinction" (p. 8).

Although the group thought that the young people needed a base they also wanted them to use community facilities (Table 38, p. 364, item 11):

> Jillian (professional): It was really just that educational opportunities shouldn't necessarily all be based in the centre, they could take place in colleges or community facilities.
>
> Maureen (Simon's mother): Outreach facilities. Yeh.
>
> Jillian: Yes so it is exploiting whatever is available out there and ensuring people have access to it.

This concept of establishing a balance between the need for specialist services and the goal of social inclusion for everyone is also reflected in the Beattie Report (Scottish Executive, 1999) and the SAY Report (see Table 40, p. 366, numbers 5 & 6). The latter also acknowledges that people with "multiple and profound disabilities" will need "structured day opportunities" but they can also be involved in "everyday activities in the community (with support)" (p. 55). However, the group involved in my study also stressed the importance of inclusion being meaningful:

> Helen (Faye's mother): I am afraid that everything is going to be too much... accessing outside if you like, going out for the sake of going out. Yes if it is a good choice, a good thing that they are going out to do but not just going out for the sake of going out because if it is pouring rain,

> oh we have got to go out. I still feel there is a need for a good centre base...
>
> Jillian (professional): I think there are day services where people are just going out to hang around shopping malls...
>
> Helen: Yes.
>
> Jillian: ...and that sort of thing, that is not...
>
> Helen: I think that some of the things are being misinterpreted I think from the Same as You? report. Accessing outside is all very well but not just going out for the sake of going out.

The group also recognized that being involved in "everyday activities" did not always mean that people were being socially included. They emphasized that inclusion was a two-way process and that environmental and attitudinal issues both needed to be tackled:

> Pauline (professional): I think as well that the community isn't ready.
>
> Helen (Faye's mother): No (nod of agreement).
>
> Pauline: I mean our experience as well is that you know re-provisioning day care services for people who are more able isn't too difficult in terms of accessing community resources but when you require specialist equipment and specialist staffing and also there is the privacy and dignity aspect as well...
>
> Helen: Yes, absolutely.
>
> Pauline: ...that none of our community resources are really equipped...

> Helen: No (agrees with Pauline).
>
> General agreement.
>
> Pauline: It is also about discrimination as well, because you know in terms of... to be equipped in terms of equipment but also in attitudes...
>
> Helen: Yes, that's right.
>
> Pauline: ...you can't set people up to go into somewhere where they are not going to be welcome.
>
> Maureen (Simon's mother): We have just had a wee taste of that, we were going into somewhere like for a Christmas meal, a bar lunch, people at another table objected to our ones sitting there, wanted them moved.

Various studies and reports (Enable, 1999; Mencap, 1999, 2001 November; Scottish Executive, 1999) show that people with learning disabilities and their families experience discrimination and prejudice, both from people providing services (see pp. 271-272) and from the public:

> I went shopping in Tescos and a woman said "fancy bringing someone like that in here."
> (Mencap, 2001 November, p. 17)

The Mencap report on people with "profound and multiple disabilities" found that families tended to be socially isolated, not because people were deliberately unkind, but because they lacked insight and understanding. The SAY Report recognizes this and recommendation 19 (p. 72) aims to promote public awareness about learning disability and raise the profile of people with learning disabilities in communities.

However, people with profound physical and intellectual disabilities, because of lack of mobility and communication difficulties, rely heavily on others to initiate and maintain social contact. Therefore Hogg (1999) argues that for this group to be socially included, communication and understanding need to occur and this means that "patterns of social interaction have to be significantly modified with respect to their content, form and timing" (p. 39). This is endorsed by McConkey (2000) who maintains that improved communication with people with "profound and multiple disabilities", collaborative working amongst professionals, families and communities and the creation of an "opportunities culture" (see Chapter 2, Table 11, p. 90) are needed to ensure that this group of people are included in society. Uditsky (2002 May) further argues that to achieve inclusion for people with learning disabilities a new way of working needs to be adopted, one which turns existing practice upside down. He advocates that service provision should focus firstly on people with the most "profound and complex disabilities" in our society. He argues that if we can meet their needs, then including other people with learning disabilities in society will be more easily accomplished. This new way of working would mean that people with profound physical and intellectual disabilities are not last in the long wait for the services and support they require to lead a good quality of life.

This debate over the balance between specialist services and inclusive services continues (see Chapter 2). At present there appears to be an increasing balance in favour of generic social, educational and healthcare services. Parents feel there needs to be a complementary input from specialist services so that their young people with profound physical and intellectual disabilities can have an enhanced quality of life. However, research (Sutcliffe & Jacobsen, 1998b) also indicates that close collaboration amongst education, health, social services, voluntary/private sector agencies and young people and their families is an essential part of developing provision for people with "complex learning needs", especially at the transition from school to post-school provision (Byers et al., 2002). Joint working and funding has already been discussed in Chapter 6.

The family carers involved in the nominal group discussion felt that quality of service was also linked to staffing levels and training and this is discussed in the following section.

Staff

The family carers regarded staffing as an important issue, seeing staff as being "more important than adapted or accessible buildings". The parents also felt that they should be involved in the recruitment and appointment of staff (Table 38, p. 364, item 19) and that it was important that good relationships were established with staff working with their young people (Appendix N, p. 734, Table 43, item 12).

Staffing levels were regarded as of paramount importance in the provision of day services to people with profound physical and intellectual disabilities (see Table 38, p. 364, item 13):

> Maureen (Simon's mother): Staffing levels <u>must</u> at <u>least</u> be one to one (nods of agreement) and on quite a few occasions it has to be two to one for changing etc.
>
> Helen (Faye's mother): I think the European laws...
>
> Maureen: The European standards...
>
> Helen: It has to be two to one isn't it for some, for like hoisting, there is supposed to be two people.
>
> Roger (Geri's father): Yeh, it has to be two.
>
> Jillian (professional): That's for staff, it doesn't apply to parents though.
>
> Maureen: No unfortunately, no.

> Pauline (professional): I think linked to that is the thing about having good back up as well. If somebody goes off sick you have got somebody equally skilled to step in.
>
> Maureen: Yes, back-up.
>
> Jillian: And also access to some kind of expertise if you encounter a particular problem.
>
> Pauline: Or if they can't tackle something.
>
> Jillian: Or if they meet a problem that they are not equipped to deal with.

This is re-iterated in Hubbard's (1999) report. She argues that staffing levels are crucial in order to ensure that individual needs are met and to enable young people with "complex needs" to achieve personal development and "move on" in their lives. She emphasizes that services must be delivered in a way that supports the young people so that they are:

> ...fully engaged and the activity or resource is meaningful and relevant. There must be no token participation, lack of choice, passivity and lack of stimulation. This has direct consequences to the numbers of people employed in the delivery because to achieve active participation there has to be frequent, unhurried 1:1 "sessions".
> (Hubbard, 1999, p. 9)

Training for staff in educational and developmental aspects, as well as health and social care procedures was also given high priority (see Table 38, p. 364, item 3) in developing day opportunities and services for young people with profound physical and intellectual disabilities. This was also stressed by the "Enhancing Quality of Life" project (Maudsley, Dee, Hayhoe, & Byers, 2002). It recognized the need for staff development in this field, arguing that:

> Even staff who have been trained and are experienced in working with people with severe learning difficulties require additional training in how to respond to the distinct needs of those with profound and complex learning difficulties... There is a specific requirement for training which involves staff from different agencies learning together. Staff from all sectors many need help from others with formulating and planning flexible programmes based on the principles of person-centred planning which move away from traditional notions of course-based provision.
> (Maudslay, et al., 2002, section 3)

Hopefully, the newly formed national network on "profound and multiple disabilities", set up following the SAY Report (Scottish Executive, 2000, recommendation 29, p. 93), will be able to provide information, advice and training to staff working with people with profound physical and intellectual disabilities.

In the previous chapter the group stressed the importance of lifelong learning and education for this group of young people, including the provision of therapy services. This was raised again in the nominal group discussion (see Appendix N, p. 734, Table 43, item 9) and indicates that the group envisages staff as having a diverse range of skills and expertise but also having access to a wide range of professionals who will also work with the young people on an individual or group level, such as physiotherapists, speech and language therapists, music therapists and so on. It also suggests that the group recognizes that the young people's needs should be looked at holistically and that professionals from different backgrounds and disciplines play a valued role.

This concurs with Seed's (1996) further education model (see Chapter 2); the "Enhancing Quality of Life" project (Byers et al., 2002; Dee, Byers, Hayhoe, & Maudslay, 2002; Maudslay et al., 2002); Hubbard's (1999) paper on the development of services for school leavers with "complex needs" (see Chapter 2) and Hogg's (1991) paper on further education for adults with "profound intellectual and multiple disabilities" (see Chapter 2). Indeed, there are similarities between Hogg's core curriculum and the items generated by the nominal group (Table 41).

Table 41. Similarities between Hogg's core curriculum and the items generated by the nominal group

Hogg's areas	Items generated by the group
Cognition	5. Continuity of education
Communication	9. Speech therapy
Social behaviour	5. New opportunities, the chance to experience new things (personal development). Experiences outside the centre or home e.g. attend college. 11. Access community resources
Movement	9. Hydrotherapy, physiotherapy
Choice	6. Provision has an individual lifestyle plan which is on-going and developed by person-centred planning ~~specifies~~ based on needs and interests.
Affective experience and development	9. A range of therapies and creative activities individually prescribed e.g. aromatherapy, reflexology, hydrotherapy, physiotherapy, music, art, speech, occupational therapy. Able to use ~~alternative~~ complimentary therapy or medicine.

However, for people with profound physical and intellectual disabilities to live full and active lives they need to have their healthcare needs met. This is the topic of the next section.

Healthcare needs

Although my study did not focus on the healthcare needs of the young people at the transition stage, this was an important issue for the parents involved in my study (Appendix N, Table 43, p. 734, items 5, 7, 9, 14) (see also pp. 264 & 313). This is hardly surprising as access to adequate and appropriate healthcare is crucial to the young people's survival, their life expectancy and their quality of life. In addition, failure to meet their healthcare needs often results in their exclusion from services such as day services and short break opportunities (Espie, Curtice, Morrison, Dunnigan, Knill-Jones, & Long, 1999; Morris, 1999b) as well as access to leisure and educational pursuits. As shown in the first part of this chapter, the post-school provision that the young people in my study were attending could not meet all their complex healthcare needs and parents were "on call" to administer medical procedures such as nebulisation and the replacement of feeding tubes.

In order for people with profound physical and intellectual disabilities to live full and active lives they need to receive services which will keep them healthy, enable them to reach their potential and access services and community resources. For the young people in my study this involves accessing not only generic health services but specialist health services (Chamberlain, Guthrie, Kettle, & Stowe, 1993; Kerr, 1998). However, research shows that this is not happening:

> Currently, the services received by the vast majority of these young people are unfocused and fragmented. Multidisciplinary, effective inter-agency working is rare. The evidence is that these young people have many preventable medical problems and a poor quality of life, and often fail to reach their potential.
> (Chamberlain et al., 1993, paragraph 6)

Similarly, studies indicate that people with learning disabilities do not receive the same levels of preventative health, including routine screening and health checks, as the general population (McCulloch, Sludden, McKeown, & Kerr, 1996; Pearson, Davis, Ruoff, & Dyer, 1998; Stein & Allen, 1999). Moreover, often their healthcare needs go undiagnosed, unrecognized and untreated (Espie et al., 1999; Howells, 1996). This was also highlighted by the members of the nominal group in my study (Table 38, p. 364, item 7). They stressed the need for improved access to primary healthcare and regular health checks for people with profound physical and intellectual disabilities. Of particular importance to them was the provision of practical nursing support, especially in the home in event of a family crisis:

> Jillian (professional): ...and practical support, emphasised. Practical help in capital letters.

They also stressed the importance of family carers receiving on-going training in healthcare procedures:

> Anne (facilitator): ...so that is training in healthcare procedures was it...
>
> Jillian (professional): For carers, training and support, sort of ongoing really, updating.
>
> Helen (Faye's mother): Instead of, you have been shown it once and hope you get it right the rest of the time.
>
> Jillian: Exactly. And not being told about new techniques, new drugs, new pieces of equipment.

Young people who need continuing nursing care should be covered by health authorities' criteria for the provision of continuing care. Nevertheless, a report by the Department of Health (1997) found that most authorities focused on older people and on people leaving hospital and rarely mentioned young people with continuing nursing care needs (Morris, 1999a, 1999b). "Promoting Health, Supporting Inclusion" (Scottish Executive, 2002) recognizes this and if implemented, could provide the practical help and training the young people in my study and their families need. Similarly, the recently published Health Needs Assessment Report (Scottish Executive, 2004) may help to provide this group with the health services they require.

The group also stressed the need for health and therapy services to continue into adulthood:

> Maureen (carer): ...the continuity of care that they have had throughout their childhood must still carry on, it is a must. It (the need for continuing healthcare) doesn't automatically stop when they leave the school.

The lack of continuity between children and adult health services for people with disabilities was discussed in Chapter 6 and has been well documented in other studies:

> Everything happened when she left school. Everything changed. You're not prepared for all the big changes. I mean, everything's going nice and smoothly and then all of a sudden dentists don't want you, the children's hospital don't want you and you know, I think people don't know how horrendous it is when they leave school.
>
> (Cohen et al., 1999 March, p. 26)

Mencap (2001 November) and Morris (1999a, 1999b) noted how young people with "complex needs" often lose contact with specialist health services when they cease to use paediatric services. Cohen et al. (1999 March) also found that sometimes young people with "profound physical and multiple disabilities" received treatment from an adult specialist for one aspect of their healthcare but remained with paediatric services for another. Sometimes there is no equivalent adult service for young people with profound physical and intellectual disabilities to move on to (Blum, 1991). Chamberlain et al. (1993) found that frequently these young people moved into general services which did not have sufficient knowledge or understanding of their particular needs.

Current research (Chamberlain et al., 1993; Espie et al., 1999; Department of Health, 1997; Morris, 1999a) on the experiences of health services across a wide range of different groups of young people concurs with this and highlighted two general problems:

> - very patchy provision of health services specifically geared to those in transition to adulthood
> - a lack of specialist provision for some groups of adults with health care needs and/or inadequate and variable access to the specialist provision which exists.
>
> (Morris, 1999b, p. 93)

Several researchers (Chamberlain et al., 1993; Cohen et al., 1999 March; Pownceby, undated) highlight the need for liaison, support and follow-up work during the transition from child to adult services. They propose that:

> ...a dedicated community-based team with specific responsibility for this transition be set up. The team should include health and social services professionals.
>
> (Chamberlain et al., 1993, cited in Morris, 1999b, p. 94)

Others (Cohen et al., 1999 March; Forth Valley Primary Care NHS Trust, 2002 September; Southampton City Council, undated) suggest that a healthcare transition plan be drawn up for each young person to co-ordinate the transfer of information at handover from child to adult services.

Research also shows that there are difficulties with continuity of therapy services. Morris (1999b) found that often physiotherapy stops when the young person leaves school, or sessions are reduced or geared to "rehabilitation". Surveys and research (Morris, 1999b) show that the majority of young people and their families (96%) felt that they needed physiotherapy and were either not getting it, or not getting enough of it (Disability Now, 1999 February, cited in Morris, 1999b, p. 103) and some young people felt their health and/or physical ability was deteriorating as a result. This was also echoed by the parents (see Chapters 5 & 6) and by the members of the nominal group who took part in my study. They stressed the need for a range of therapies to be included in the young people's day service activities (Appendix N, p. 734, Table 43, item 9). They also wanted the same level and quality of healthcare and therapy services that their young people had experienced at school (Appendix N, p. 734, Table 43, item 5) to be provided by adult services. This deterioration in services has also been documented by other reports (Mencap, 2001 November; Morris, 1999b):

> Paediatric services are good but it seems that adult services don't have a client-led focus. They don't seem to think through what you will need – you have to ask for it.
> (Mencap, 2001 November, p. 30)

As already noted (Chapter 5) failure by day services to meet all of the young people's healthcare needs meant that the family carers in my study were "on call" to carry out certain medical procedures. Therefore because of the lack of nursing staff, or appropriately trained staff, the parents were anxious that procedures should be written down to cover emergency situations:

> Roger (Geri's father): ...pre-agreed procedures/protocols, pre-agreed between staff and carers in the event of an emergency or crisis. I guess in that situation it would be where carers couldn't be contacted.
>
> Helen (Faye's mother): ...even if they can contact us we might not get there in time, so they have to have procedures to follow.
>
> Roger: A lot of it is commonsense but I would be happier if it was written down.

This failure to meet the needs of people with profound physical and intellectual disabilities has resulted in many parents being reluctant to trust their offspring to services on a full-time basis (Mencap, 2001 November). This is reflected in the interviews I conducted with the families (see Chapter 5). They wanted to continue to look after their offspring in their own homes:

> Joyce (Geri's mother): My hopes and dreams for Kylie's future is for Kylie to stay healthy and me to have Kylie forever, as long as really as the eye could see and be on a daily basis cared for like she is the now.

but only because no viable alternative existed:

> Helen (Faye's mother): ...if there was a good group home and a place in a group home for somewhere in the future but I don't know where in the future that would be, it would be nice to know that Faye was settled and you know that we wouldn't have any worries if we weren't here.

These parents have no choice. Yet choice was one of the themes identified from analysis of the data from the nominal group discussion. This is the topic of the next section.

Choice

As discussed above "moving on" was not a subject the families in my study liked to think about. Like the families in the Mencap report (Mencap, 2001 November), their experiences of using the services had not given them confidence that their offspring would be well provided for. However, the professionals in the nominal group highlighted this issue:

> Pauline (professional): I was also going to say that you know after school it may be the case that the young person wants to leave home or as a natural stage that the family would want that but you know somebody reaches 18 to 20 when they normally would be thinking about leaving home, well why can't they? If they want that to happen.
>
> Jillian (professional): Yes I don't think we have mentioned community housing at all have we, it is an important thing to get done.
>
> Maureen (Simon's mother): Need to consider all viewpoints, family carers etc.

The family carers agreed that independent supported accommodation should be provided for young people with profound physical and intellectual disabilities but stressed the need for it to take place in a small homely setting with sufficient staff support (Appendix N, p. 734, Table 43, item 18):

> Jillian (professional): Supported living scheme, we may start to address that.
>
> Maureen (Simon's mother): It's expensive supported housing.
>
> Jillian: Yes I know but that is their problem isn't it (laughs).
>
> Maureen: Well they should have the choice, they should have the right to move on to like every young person does and it should not be institutional.

However, Morris (1999b) found that the likelihood that young people with "complex needs" will access appropriate accommodation and support "depends very much on whether housing and social services authorities recognize the nature of their needs and respond appropriately" (p. 73). She argues that despite legislation such as the Chronically Sick and Disabled Persons Act of 1970 and the Housing Act of 1996, few young people with "multiple impairments" are likely to live independently in supported accommodation. Instead they are more likely to move into residential care mainly because of a dearth of good quality supported accommodation in community settings for people with high support needs (Esmond & Stewart, 1996; Ryan, 1998). Nevertheless, she argues that these young people have the same needs as everyone else – to live in their own home and participate in their local community. However, they also require support. Cunningham, Wilson and Whiteley (1998) argue that to provide such support, services need to have:

- expert knowledge of the impairment/condition
- provide specialist support; have an understanding of the difficulties experienced by people with "complex needs"
- be able to co-ordinate services

- offer advocacy and a person-centred approach
- help people engage in their communities.

However, as highlighted by Maureen above, the cost of providing such supported accommodation is high. Thus Esmond and Stewart (1996) found that health and social services providers tended to look for "economies of scale" and were reluctant to consider even small-scale group homes for people with high levels of support. As a result many families with young adults with profound physical and intellectual disabilities continue to carry on caring for them at home as shown by this study. However, families also recognize that there may be a time when they cannot carry on doing so and this causes them major concerns.

Choice of services and provision was also regarded by the members of the nominal group as being important in the delivery of home, day and short break services (Table 38, p. 364, items 8 & 10 & Appendix N, p. 734, Table 43, item 4):

> Pauline (professional): I think it is about recognising that every family situation is different (nods of agreement) and designing a choice of high quality resources... I was thinking of things like respite care which is different for each, or can be chosen differently, some people want it at home, some people want it while they are away, some people want it at week-ends, some people just want it for a month a year, you know in a block, so it is about designing them so they are flexible to meet the needs... everyone is different (nods of agreement). So some families would choose say to want to be able to buy care themselves, whereas others don't want that, so I think it is kind of flexibility, choice, in each family situation. And to be able to buy them themselves if they wish, to organise and purchase themselves, if they wish.

The group recognized that the development of Direct Payments (The SAY Report, recommendation 5, p. 24) and the Independent Living Fund (ILF) would go some way towards offering young people with profound physical and intellectual disabilities and their families more choice, flexibility and control over the services and support they needed (but see Chapter 2, p. 89). However, Mencap (2001 November) found that many day services and short break services cannot meet the particular needs of people with "profound physical and multiple disabilities". This is echoed by Riddell's (1998) research in Scotland which suggests that alternative services do not exist for most people with "learning difficulties". Therefore new services need to be developed before families can use these systems.

There was also a recognition by the group that it was important that the young people should experience choice in the way services and the support they require is planned and delivered. They emphasized the need for individual lifestyle plans to be developed at the transition stage using person-centred planning (Table 38, p. 364, item 6) and for individually tailored creative activities to be provided at day service provisions (Appendix N, p. 734, Table 43, item 9). This is endorsed by the professionals in Cohen et al's (1998 December) study:

> ...we shouldn't plan for students – instead professionals should offer them options and support them in making their own decisions.
> (Cohen et al., 1998 December, p. 15)

Whilst giving choice to young people with learning disabilities was seen as important in theory, as seen in Chapter 6, Cohen and her colleagues found it was rarely put into practice. This is endorsed by Riddell, Baron, and Wilson (2001) who argue that recent Scottish Executive policies, together with a trend towards the "professionalisation of the field of learning difficulties" (p. 198) will lead to increased regulation of the lives of people with learning difficulties:

> The professionalisation of the workforce is thus increasingly surrounding the person with learning difficulties with a set of people, including lay advocates, with a uniform approach to the issues of learning difficulties and the mandate to define needs and appropriate services accordingly. While these services may vary from those currently on offer the informal regulation of people with learning

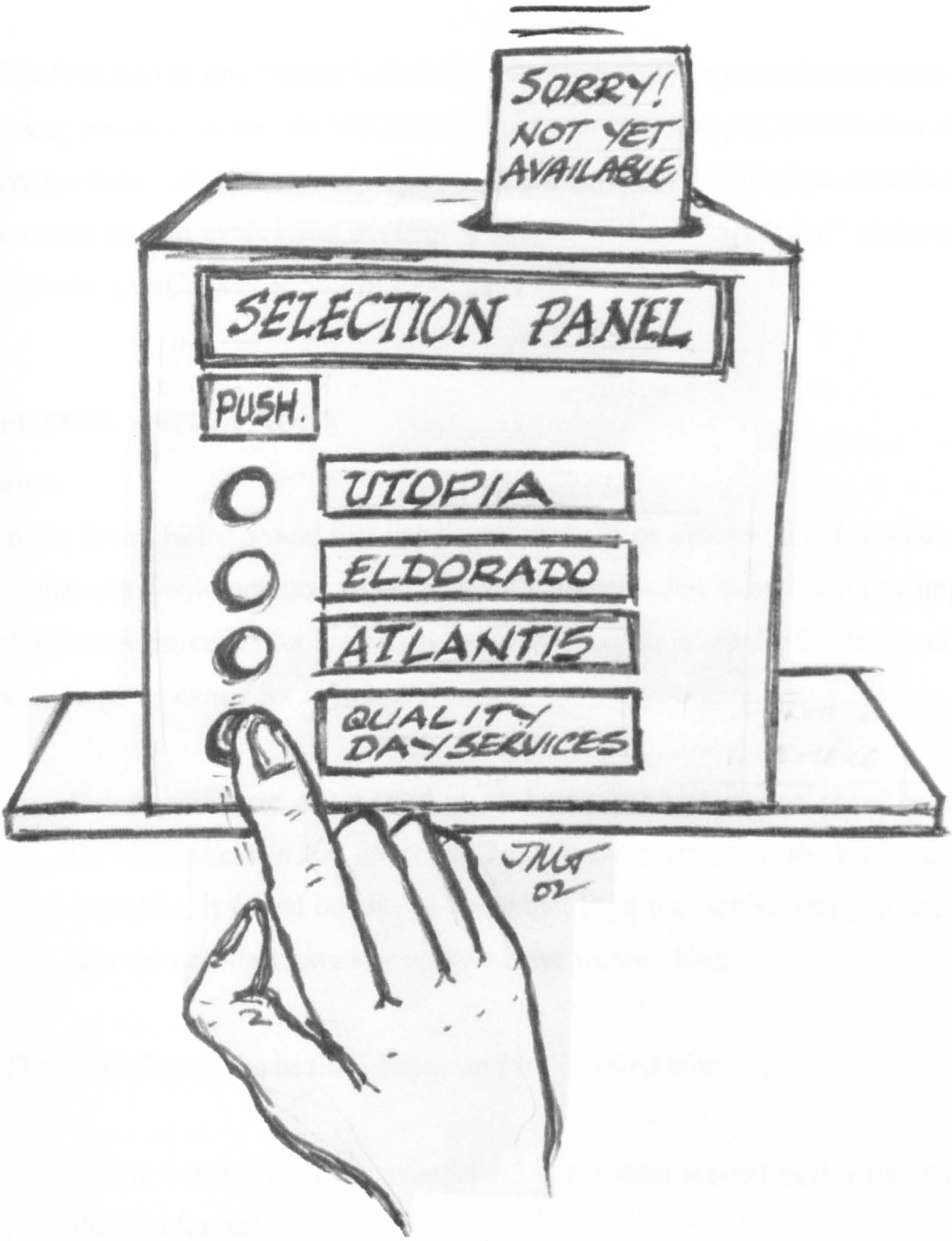
> difficulties seems set to increase as "joined-up policy" impacts on their lives.
> (Riddell et al., 2001, p. 199)

Looking at young people with "complex needs", Morris (1999b) found little evidence of this group being given the opportunity to make choices about their lives. However, research has shown that people with "multiple disabilities" are capable of communicating their preferences and making choices (Green & Reid; 1996, 1999; Ivancic, Barrett, Simonow, & Kimberly, 1997; Kennedy & Haring, 1993; Lancioni, Oliva, Meazzini, & Marconi, 1993; Sanderson, 1998). Lancioni, O'Reilly, & Emerson (1996) and Hogg (1999 October) also point out that:

> ...our right to exercise choice is dependent upon learning how to do so in a responsible manner, and that learning about choice making is an essential part of the total curriculum.
> (Hogg, 1999 October, p. 17)

This is endorsed by Hubbard (1999) who stresses that it is not always appropriate for young people to say exactly what they want to do because they have not had the experiences to enable them to make informed choices. They argue that the young people with learning disabilities need to experience certain situations and develop skills and strategies in order for them to make appropriate decisions and choices. Moreover, staff also need to develop more negotiated approaches to teaching and learning such as using alternative and augmented methods of communication; interactive approaches (Collis & Lacey, 1996; Nind & Hewett, 2001); response contingent learning (Ware, 1996) and by encouraging staff to "learn to listen" and develop mutual relationships (Dee et al., 2002). Like Hubbard, the members of the nominal group in my study favoured a person-centred planning approach. This process places the individual at the centre of all planning and acknowledges his/her rights, choices and aspirations. This is in line with the SAY Report which recommends "personal life plans" (recommendations 3 & 26, pp. 22 & 85).

However, despite legislation and the development of new empowering initiatives to help people with profound physical and intellectual disabilities access their human rights, this study, like previous ones, suggests that they are still being denied choices in their lives. Morris (1999b) suggests that "there is not enough awareness of how services need to be changed in order to bring this about" (p. 80). I would argue that for these young people and their family carers to have choices they need a range of services. As this study shows often there is either no service available, or the service offered does not meet the particular needs of these young people. There is no viable alternative, no real choice.



There is an urgent need to improve the quality of services to people with profound physical and intellectual disabilities so that they can have real choice in the way they lead their lives. Perhaps we should adopt Uditsky's (2002 May) idea and turn the way that services operate upside down so that people with the most profound and complex needs in our society have their needs met first. This presents a considerable challenge to the way in which services are run now. Moreover, it requires a change in values – to the recognition that people with profound physical and intellectual disabilities can and do make a positive contribution to their families, their community and society as a whole.

The final part of this chapter looks at the family carers' hopes and aspirations for their young people's future. As McConkey and Smith (2000) argue, information about this groups hopes, aspirations and experiences are essential if education, social and health services are "to evolve and develop in accord with the "needs-led" philosophy they espouse" (McConkey & Smith, 2000, page 3).

FUTURE ASPIRATIONS

Faye

In the future Helen would like Faye's provision to be able to meet her medical needs so that she would not have to be constantly on call. She would also like appropriate short break provision for Faye as at the moment none is provided. Helen and Gordon want to go on caring for Faye but:

> Helen: ...if there was a good group home and a place in a group home for somewhere in the future but I don't know where in the future that would be, it would be nice to know that Faye was settled and you know that we wouldn't have any worries if we weren't here.

They want Faye to be healthy, happy and well looked after:

> Helen: I don't want compromises, I don't want second best, I just want the best for her...

Simon

For the future, Maureen and Stuart hope things will continue as they are doing now. However, eventually they feel Simon would benefit from a residential placement:

> Maureen: I feel that he is now at the age that we are now looking for his future, his future needs as well, to move on like any young adult would move on with their lives, they don't want to stay with their Mum and Dads for the rest of their lives and I feel that he should be entitled to the same as every other young adult, to move on in life.

Kylie

Looking to the future, Joyce and Bobby would like to see Kylie stay healthy and happy. They want to continue to look after her at home but feel they need a five day a week placement for Kylie:

> Joyce: I still want her to go to day care because that gives us, me, well sort of half my life back and it gives us a chance to, as parents, as a mum to go out and about and do some normal things like shopping and visiting or pictures during the day. So my hopes and dreams for Kylie is a continuation of her life the now.

Geri

Looking to the future, Catherine and Roger want Geri to be happy and have a full life:

> Catherine: We want her to meet lots of people, we want her to be highly stimulated. We want her to have a good day centre, we would like Geri to go to a centre that we thought was suitable for Geri's needs for the rest of her life. We would like Geri to have a social life so that would mean respite care. We would like Geri to have holidays. We would like Geri to, wherever she went and the people that she was with, we would like them to enjoy her company and not be afraid of her and we would like

> the help and support that we need for Geri to have the life that we want her to have.

All the parents in my study want their youngsters to be healthy, happy, lead a full life and to be well looked after. Geri and Faye's parents would like provision for their daughters which meets all their medical needs so that they would not have to be on call. In addition, they would both like appropriate "respite care" for their daughters:

> Helen (Faye's mother): ...all we have been offered is a nursing home and that is just not... it is not an option.

Both families see short break services, not just as providing a break for the family from their caring role, but as a way of developing their young person's independence and autonomy and widening their social life.

All of the families want to continue in their caring role but they also want help and support. Some have looked further into the future and would like group homes to be set up for their offspring; others have not thought about the future as "getting through day to day is a battle some days." As already seen, research (Morris, 1999a, 1999b) suggests that young people with "multiple impairments", particularly those who require high levels of personal care and have communication problems, are more likely to move into residential care when they reach adulthood. Often professionals assume that these young people will have to live in nursing homes and indeed, Morris (1999b) found that young adults with high levels of nursing care needs are more likely to live in nursing homes than children with the same level of care needs. Furthermore, she found that health authorities' continuing care policies tended to focus on services for the elderly and hospital discharge (Department of Health, 1997) and rarely referred to young people with continuing nursing care needs. She argues that unless the needs of these young people are more adequately addressed they are "in danger of experiencing a transition to social exclusion" (Morris, 1999b, p. 138).

However, "respite care" or short breaks for this group is not the remit of my study. Likewise, neither is the transition from child health care services to adult services or the provision of accommodation and housing in the community. Nevertheless, a more integrated approach to the transition period involving education, social work and health services might lead to better services for these young people.

The final part of this chapter looked at the family carers' hopes and aspirations for their young people. They are similar to every parents' hopes for their children – health, happiness and a full life. The parents of these young people are only asking for their rights as human beings. Sadly, this group is often denied human rights.

SUMMARY

In Morris' study moving into adulthood for young people with "complex needs" was described as "hurtling into a void". This chapter asked family carers and professionals involved with young people with profound physical and intellectual disabilities what kind of services and provision they would like to see for this group. They described the kind of day, short break and healthcare services they wanted, stressing the importance of choice, flexibility and joint working in the planning and delivery of services. The items they generated in the nominal group discussion suggested that they wanted good quality, practical "hands on" services. Whilst some of the services could be provided in the community, they also stressed the need for specialist services and for ring-fenced funding for this group.

Although the SAY Report acknowledges the existence of people with "profound physical and multiple disabilities", like its English and Welsh counterparts (Department of Health (DOH), 2001), it fails to set a framework for the delivery of better services. People need to listen to young people with profound physical and intellectual disabilities and their family carers, they need to increase their understanding of this group's abilities, disabilities and needs and they need to value these people and acknowledge their rights. Only then will services for this group of young people improve:

We live in a society that sees people like my daughter as worthless. Why, then, would it be one that delivers high quality services?
(Mencap, 2001 November, p. 3)

Chapter 8 Conclusion

In this final chapter I consider the implications of my study in terms of theory, research methodology and service provision.

IMPLICATIONS FOR THEORY

In my study I used a transactional model of disability to increase understanding of the 'real life' experiences of young people with profound physical and intellectual disabilities and their family carers during the transition stage from school to post-school provision. Llewellyn and Hogan (2000) describe models of disability as representing:

> ...a particular type of theory, namely structural, which seeks to explain phenomena by reference to an abstract system and mechanism... It is important to remember that models may help to generate an explanation in some way, but they do not themselves constitute an explanation... models cannot be 'true' but are merely representations that are not in themselves based upon data collection or methodology. One of the essential features of a model is the application of one (better understood and developed) system to another (less well understood and developed) system... The advantages of the use of a model is that models enable us to represent information in a way that may aid understanding.
> (Llewellyn & Hogan, 2000, p. 157-158)

Although I chose to adopt a transactional model as I believe it fitted the young people's experiences more than the individualistic medical model or the social model, I do not dismiss these models completely.

As Llewellyn and Hogan (2000) argue, the individualistic medical model has increased clinicians' understanding of impairment and disability. Moreover, its emphasis on the medical and functional aspects of disability, is important in identifying the services which the young people in my study require, for providing criteria about what an impairment and impairing conditions are and for preserving their rights. Reindal (1995) argues that:

> Without any definition based on individual criteria of impairment and disability, disabled people's rights would be difficult to exercise. This would also be true if an individual definition was the only tool, because of its limitation to explain disabling structures.
> (Reindal, 1995, p. 67)

He recounts an incident in Norway where an association, representing unintentionally childless couples, applied for membership of the Norwegian League of Handicap Organizations. The association was refused membership on the grounds that it did not "fulfil the criterion of being impaired in a substantial way" (p. 67). Reindal argues that whilst the individualistic medical model has little explanatory value as a social theory, its applicability is relevant when encountering examples such as the one described above. Furthermore, although the individualistic medical model is now recognised as incomplete, examination of its limitations has resulted in an increasing emphasis upon social factors in the maintenance of disability, and consequently, the development of a social model of disability.

Whilst recognising that the social model has redefined disability in terms of a disabling environment and resulted in people with disabilities being seen as citizens with rights, I believe that, like the individualistic medical model, it is also incomplete. I have argued elsewhere (Chapters 2 & 3) that the social model fails to recognise the impaired body, impairment effects and the 'lived out' experiences of people with profound physical and intellectual disabilities. Although there has been what Goodley (2001) describes as a 'turn to impairment', both in terms of epistemological assumptions about impairment (French, 1993; Crow, 1996; Thomas, 1999) and postmodern critiques of Cartesian distinctions between biology and society (Corker, 1998; Corker & French, 1999; Hughes & Paterson, 1997) (see also Chapter 2), there has been a lack of focus on people with learning disabilities, particularly on people with profound physical and intellectual disabilities, and their experiences. Some writers (Walmsley, 1997; Chappell, 1998; Goodley, 2000) contend that people with learning disabilities have been tagged on to the social model of disability as an afterthought and that they are often excluded from the wider disability movement. They argue that although the social model of disability has influenced research that investigates the experiences of people with physical and sensory impairments, the social model is often overlooked in research and writing about learning disabilities (Chappell, Goodley & Lawthom; 2001). Indeed, Aspis (1997) maintains that there is a tendency among people with disabilities to identify the problems of people with learning disabilities as inherent to their impairments, rather than resulting from issues of access and social barriers:

> People with 'learning difficulties' face discrimination in the disability movement. People without 'learning difficulties' use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without 'learning difficulties'. We want concentration on our access needs in the mainstream disability movement.
>
> (Simone Aspis of London People First, cited in Campbell & Oliver, 1996, p. 97)

The young people in my study have profound physical, sensory and intellectual impairments. Therefore any model used to increase understanding of this group needs to consider the ways in which the physical, material and social organisation of society promotes inequalities and withholds rights and resources to this group, as well as impairment effects, the social character of impairment, the importance of people with disabilities as social actors and the attitudes of non-disabled people to impairment and disability. In addition, such a model needs to recognise that whilst impairment and disability are discrete entities, they also interact. Davis and Watson's (2002) comments about their research work with children with disabilities seems relevant here:

> We cannot write the body out of disabled children's lives, yet in recognizing the importance of impairments effects we should not assume as... those who work within the medical model do, that the meanings of impairment are pre-given. Indeed many children resist identities foisted onto them by others that relate to stereotypical views of impairment.
> (Davis & Watson, 2002, p. 166)

I believe that the transactional model, which I developed for my study, goes some way to meeting these requirements. In addition, this model enabled me to increase my understanding of the specific difficulties encountered by young people with profound physical and intellectual disabilities and their families during the transition stage from school to post-school provision; to investigate ways of reducing these difficulties and to suggest ways of developing their potential and increasing their quality of life. However, this model needs to be developed more fully and 'tested out' in subsequent research. It should be judged in terms of its utility to inform research and clinical practice. It is not a theoretical system, neither is it a theory of disability and it does not provide an explanation of every aspect of disability. As Llewellyn and Hogan comment:

> There is always the danger that if one model fits an individual's experiences more than another model, it is but a short step to confusing the model with truth and denying the validity of other models. Indeed, in this instance it is argued that the use of model may preclude further investigation; researchers may look for confirming evidence, and thus reject or fail to seek out disconfirming evidence. For this reason it is not appropriate to talk about the supremacy of any particular models of disability, particularly as a model as opposed to a more specific theoretical proposition cannot be so readily disproved. This can lead to

> fruitless debates about the relative value of models that can detract from a focus on strengths of their usage in both clinical and research work.
> (Llewellyn & Hogan, 2000, p. 163)

Llewellyn and Hogan further argue that in disability studies, the individualistic medical model and the social model have tended to be viewed in terms of theoretical systems rather than models to aid understanding. They define a theoretical system as:

> ...a general theory in the grand sense, it seeks to describe what the subject of study is about, as well as commenting on the methods that should be employed to research into it. A system then, needs to be inclusive in that it seeks to account for a wide range of phenomena, organises the available data and offers an account of them. The completeness of a system is carried over into the fact that it serves to establish, even dictate what types of question can be asked and indeed what forms of question cannot be asked.
> (Llewellyn & Hogan, 2000, p. 164)

They maintain that the term model, as it is currently used in disability studies, is misleading and that disability research needs to take greater care in distinguishing between theoretical systems and models. I agree with this and suggest that disability research needs to recognise that neither the individualistic medical model, nor the social model, are appropriate in helping to increase understanding of the lived out experiences of people with profound physical and intellectual disabilities. Perhaps it is time to move away from a social model of disability towards mutually inclusive theories of impairment and disability which include <u>all</u> people with disabilities.

IMPLICATIONS FOR RESEARCH METHODOLOGY

Researchers, such as Abberley (1987) and Oliver (1992), argue that most research associated with people with disabilities has been influenced by the individualistic medical model and has resulted in the oppression of people with disabilities, rather than their liberation. Indeed, Oliver (1992) maintains that for people with disabilities research has been:

> ...a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life.
> (Oliver, 1992, p. 105)

He argues that research has failed people with disabilities because of the social relations of research production. He urges researchers to engage in research which is transformative and relevant to the lives of people with disabilities. In addition, he asks researchers to join with people with disabilities in their struggle against oppression and to put their expertise and skills at their disposal (p. 102). He argues for a more enabling or "emancipatory" form of research activity.

As already stated, most research associated with people with learning disabilities has tended to be influenced by the individualistic medical model of disability and has favoured an interpretive paradigm and an enlightenment model (see Chapter 3, Figure 5 , p. 104). Such research usually focuses on experiential and service issues. The researcher is seen as someone who is able to empathise with the participants and use his/her skills as a researcher to tell people's stories and influence service provision (Chappell, 1998; Goodley & Moore, 2000). However, towards the end of the twentieth century, researchers, influenced by normalisation ideas, began to view people with learning disabilities as active contributors to the research process (Walmsley, 2001) and participatory research methods began to be adopted (see Chapter 3, Table 14, p. 105) This involved researchers working in partnership with people with learning disabilities and including them in the research process in a meaningful way. However, according to Zarb (1992), this is not enough; people with disabilities need to be in control of all the aspects of research – from the formulation of questions to the dissemination of findings. This involves adopting an emancipatory research paradigm (see Chapter 3, Table 15, p. 106). According to the social model of disability, people with learning disabilities can take a lead role in research design, data analysis and dissemination of findings, provided that certain disabling barriers are overcome (Stalker, 1998). However, as seen in Chapter 3, not all researchers believe that the principles of emancipatory research can be applied to all studies involving people with learning disabilities (Chappell et al., 2000; Riddell et al., 1998). Moreover, Walmsley (2001) argues that:

> The inclusion of people with learning difficulties in research projects has led to some creative, even empowering projects. It has also, I would suggest, acted as a strait-jacket, hindering researchers in the inclusive camp from crossing words with others, for fear of 'speaking for' people with learning difficulties without their consent.
> (Walmsley, 2001, p. 189)

In Clough and Barton's (1998) book "Articulating with Difficulty", several researchers highlight the difficulties they have encountered in giving people with "learning difficulties" a voice. Corbett (1998) maintains that "the issue of *voice* in emancipatory research is complex and multi-layered" (p. 55). Firstly, there is disagreement over which discipline or model is given prominence in setting the framework and key issues for the research. Secondly, there is the problem of selecting a sample and deciding how to listen and what to hear. Dyson (1998) points out that people do not always speak with a single voice or see themselves belonging to particular groups. Moreover, voices are not always coherent and interpretations are difficult to validate as informants are more likely to acquiesce than to contradict (Sigelman, Budd, Spanhel & Schoenrock, 1981). As Booth and Booth's (1996) study shows informants are often inarticulate, unresponsive, have problems with time and thinking in abstract terms. Nevertheless, their study shows how these problems can be tackled. The study also stresses the importance of "listening" to what goes unsaid:

> Fluency is not the only key to communication. Silence may be as telling as talk.
> (Booth & Booth, 1996, p. 57)

Thirdly, there is:

> ...the need to provide a means of expression beyond the conventional which most accurately conveys the perceptions and experiences of vulnerable people whose apparent ideas are open to interpretive distortion and abuse.
> (Corbett, 1998, p. 55)

"Articulating with Difficulty" (Clough & Barton, 1998) provides examples of how researchers have explored the concept of voice and investigated the perceptions and experiences of inarticulate informants. These researchers state their values and political positions and acknowledge the complexities of giving people with disabilities a voice "in principled and valid ways" (McIntyre, 1998, vii). Booth and Booth (1996) argue that too often researchers tend to view people with learning difficulties in terms of a deficit model rather than the limitations of their methods:

> Such a 'deficit model' of informant response is rooted in a view of disability as a problem of the individual. It serves to legitimate the exclusion of, for example, people with learning difficulties from a participatory role in narrative research in ways that mirror their exclusion from the wider society. The emphasis of research should be on overcoming the barriers that impede the involvement of inarticulate subjects instead of highlighting the difficulties they present.
> (Booth & Booth, 1996, p. 67)

The above concurs with Riddell et al.'s (1998) arguments that:

> ...debates on appropriate methods are not merely technical questions, but hinge on disputes regarding the nature of disability, the relationship between activists and the academy and on wider questions of epistemology concerning the basis of social knowledge and theory.
> (Riddell et al., 1998, p. 79)

However, the young people in my study have severe intellectual and communication impairments. They are unable to use language in any form. They have no speech, they are unable to sign or use symbols. They communicate at an early level using signals such as reflex responses, actions, sounds and facial expressions and sometimes it is difficult to interpret these signals in accordance with the young people's feelings or meanings. In addition, the nature of the responses are specific to the person. For example, Geri uses coughing to communicate. Sometimes her cough indicates a desire for interaction, at other times Geri uses a range of different coughs whose meaning is dependent on the context:

> Catherine (Geri's mother): It [coughing] can be displeasure if for instance she is listening to her music and it is finished and she is really interested in listening to her music, she can cough, that is saying 'Could you put my music back on'. If somebody puts pop music on and she really hates it, it's to cough to say 'Please just get that music off, I hate it'

As shown in Chapter 5, despite their severe communication impairments, the young people can communicate their needs and wishes, are capable of making choices and having at least some degree of control over their lives. However, it seems to stretch the meaning of everyday words beyond usefulness to suggest that the young people with whom this study is concerned can be involved meaningfully in the research process, engage in participatory or emancipatory research, or directly communicate their experiences and feelings about the transition stage. Therefore data was obtained indirectly through the young people's family carers. Porter, Ouvry, Morgan and Downs (2001) suggest that the involvement of family carers and others who are significant in the person's life, is essential for establishing how "people with profound and multiple difficulties" communicate and for validating interpretations of communications. As Jillian, one of the professionals involved in my study, comments:

> It's also crucial to be very sensitive... to the ways in which the person concerned communicates and again I think you have to be guided by the family in this because you can't possibly pick up in the

> same way as they do how the person is going to express choices, preferences, happiness, unhappiness.

However, studies (Garth & Aroni, 2003; Thomas & O'Kane, 1998) show that often young people and their parents have a different perspective and understanding of experiences. In addition, some researchers with disabilities (Oliver, 1986; Shakespeare, 1993), as well as some people with disabilities, question able-bodied people's abilities to discuss disability when they lack the experience of being disabled:

> As a disabled person and academic, I am in favour of academic debates about the nature of disability, what concerns me about this one is that it is yet one more example of people with abilities attempting to speak authoritatively about us.
> (Oliver, 1992, p. 20)

This raises two questions: who has the authority to speak about disability; and who should research disability. Unlike Oliver and Shakespeare, Reindal (1995) argues that experiences of disability are comparable to other personal experiences and further argues that:

> To criticize another's view by appealing to a lack of personal experience, or giving personal experience the status of a special validity that excludes critique on an intellectual basis, is to abolish the criteria for common ground...if the criterion of discussion is that it is restricted to personal experience alone, it deprives people of the right to ethical commitment to social problems which they have not personally experienced. A consequence of this could be that several weak groups would lack spokesmen.
> (Reindal, 1995, p. 60)

In the case of the young people in my study, their family carers are their spokespeople. They are their voice:

My voice is usually my Mum's
She can speak for two,
I've heard her shout for this and that
Even for a loo!

To silence family carers' voices on the grounds that they 'speak for' their young people without their consent, present their own perspectives and make assumptions about their young people's best interests, is to further marginalise and exclude this group. Moreover, the argument that they have not experienced disability has been disputed by several researchers. Reindal (1995) argues that being closely related to a person with disabilities might be a personal experience of disability at one level (p. 59) and Dowling and Dolan (2001) argue that families containing children with disabilities are disabled – they themselves experience disability.

Therefore I would argue that researchers need to accept that people with severe intellectual and communication impairments cannot be meaningfully involved in participatory or emancipatory research. This does not mean that this group should be excluded from research or the research process. Their family carers and others who play a significant part in their lives can be their 'voices' until we develop the ability to overcome obstacles to effective communication with this group.

IMPLICATIONS FOR SERVICE PROVISION

Difficulties experienced by the young people and their families

This study has looked at the transition stage from school to post-school provision for young adults with profound physical and intellectual disabilities. It has highlighted the difficulties and problems encountered by the young people and their families through this particularly emotional and stressful time (Table 42, p. 405). Not surprisingly, the study showed that the young people and their families' experiences are similar to their peers with less severe impairments and disabilities and their families (McConkey & Smyth, 2000). However, they are less likely to receive effective support in transition than other groups of young people with disabilities. In addition, often services fail to meet their needs as they move into adulthood. There are very few options, if any, open to young people with profound physical and intellectual disabilities when they leave school. Where services do exist, they are often not always delivered in an effective manner. Usually they are not age appropriate, flexible or of a sufficiently high standard. Often they are unable to meet the young people's medical needs. Thus the family carers who took part in this study emphasized the importance of healthcare, therapeutic services and continuing education for their offspring. Currently, life-long learning for this group, as advocated in policy documents is not happening.

Table 42. The difficulties encountered by the parents during the transition stage

1. Information
    a) Family carers are not given enough information about the Future Needs Assessment (FNA) and transition processes.
2. The FNA process
    a) FNA meetings do not always involve all the agencies who could contribute to the assessment process or the delivery and provision of services.
    b) The people involved in the FNA process do not always have sufficient knowledge and/or information about the young person, their needs, or the services available.
    c) Little progress is made between meetings.
3. The transition period
    a) Arrangements for a smooth transition from school to post-school provision were difficult to plan and organize as either no placement was identified, or a placement was not identified soon enough to allow a period of transition.
    b) Placements offered and accepted by the young people and their families were later withdrawn as it was subsequently found they could not meet the young person's needs.
4. Post-school provision
    a) Little or no provision available to meet the young people's needs.
    b) Where provision is available, it cannot always meet all of the young person's needs, especially their medical needs.
    c) Often the provision offered is of an interim kind and the young people and their families are left uncertain of future provision and services.

What needs to happen?

Young people with profound physical and intellectual disabilities and their families should be able to expect that:

- Information is given to them about the whole transition process – the FNA process, their legal rights, service systems, educational opportunities, health services, social work services, community and housing services and social security benefits

- Professionals have sufficient training, skills and knowledge of the transition process, specialist and non-specialist services and resources

- The transition process places the young people and their families at the centre of planning for the future and that this planning takes into account their needs, gifts and aspirations

- They will have available to them a consistent person who will answer their questions, act as advocate for them, offer help and support when dealing with statutory and voluntary organisations, co-ordinate the whole transition process and future transitions

- The transition process is co-ordinated between all agencies and professionals

- The transition process starts well in advance of school leaving age so that professionals have time to get to know the young people and their families, help them to prepare and plan for the future, and explore and develop choices

- The transition from school to post-school provision is a smooth one, with appropriate service provision being identified in advance

- Service provision is designed around the informed choices and needs of the young people and includes access to specialist and generic services

- A range of options and choices are available to the young people on leaving school.

The family carers and professionals involved in my study stressed the importance of a transition co-ordinator to oversee the whole transition process. They also saw person-centred planning, in the form of an Essential Life-style Plan, as being necessary for this group, so that the needs, interests and aspirations of the young people and their families are taken into account. They also felt that person-centred planning approaches would help to improve agency co-ordination. However, the family carers and professionals also recognised that organisational, administrative and resource issues also needed to be addressed to improve the transition stage. This would involve:

- The development of further education provision for the group to address their continuing learning needs

- A recognition and action by health authorities that they have a responsibility to meet the healthcare and therapeutic needs of people with profound physical and intellectual disabilities, so that they can reach their full potential, enjoy a good quality of life and be fully included in society

- Making it a legal duty on agencies to implement the recommendations of the FNA process

- The Scottish Executive setting out clear objectives for services for people with profound physical and intellectual disabilities and their family carers, as well as identifying the group as a critical priority when it comes to funding and the allocation of resources

- The development of joint transition policies, which specify aims, identify the roles of agencies, departments and professionals and have joint agency structures, procedures and protocols to ensure policies and procedures are implemented, developed and monitored

- Joint training, joint funding and agencies, professionals, family carers and people with profound physical and intellectual disabilities working together in partnership.

However, in tackling these organisational and administrative problems, it must be remembered that the key issue is not just to achieve administrative smoothness, but to provide better support to people with profound physical and intellectual disabilities and their family carers, so that their lives will be significantly changed for the better, as the Mencap Report states:

> There is an urgent need to deliver practical hands-on services to these families... [and] to improve the standard of services so that people with profound and multiple learning disabilities have real choice in how they live their lives.
> (Mencap, 2001 November, p. 41)

Although my study looked at the transition from school to post-school provision for young adults with profound physical and intellectual disabilities and focused on educational issues, the findings suggest that there are also problems surrounding the transition from child health services to adult services, short break services, accommodation and community housing. Although some of these aspects have been looked at by other studies (Forth Valley Primary Care NHS Trust, 2002 September; Morris, 1999a, 1999b), they have not focused on people with profound physical and intellectual disabilities. Access to adequate and appropriate healthcare is crucial to survival, life expectancy and quality of life for the young people in my study. Moreover, failure to meet their healthcare needs can lead to them being excluded from day and short break services and leisure and educational opportunities. They are in danger of social exclusion rather than inclusion.

The provision of services for this group also requires a change in values and attitudes:

> There are some clear messages about what is needed to achieve real improvements in the quality of life of all members of these families...
> But the clearest message of all is about values and rights.
> (Mencap, 2001 November, p. 2)

Only when society has a better understanding of people with profound physical and intellectual disabilities, values their contribution to society, recognizes their rights as individuals and citizens and accepts responsibility to provide services to enable them to reach their potential and have a good quality of life, will services for this group improve.

This will involve increasing society's awareness and understanding of people with profound physical and intellectual disabilities. Currently in our society, people with profound physical and intellectual disabilities tend to be viewed in terms of the personal tragedy theory (see Chapter 2). This viewpoint regards education for this group, especially after eighteen, as a waste of time and resources. It reflects the human capital perspective which regards investment in this group as unlikely to generate significant economic returns. People with profound physical and intellectual disabilities are seen as lesser human beings for whom society has a duty to care (MacKay, 2001 June). Other members of society are more optimistic, seeing all disabilities as curable. I would suggest that this view is unrealistic and ignores the complexity of this groups' impairments and disabilities. Others argue that everyone is disabled and regard being tall, short, gay (Corbett, 1997; Shakespeare, 1992 September) or infertile (Byggfosk, 1993, cited in Reindal, 1995, p. 67) as being disabled. In my opinion this is insulting to people with profound physical and intellectual disabilities and their families when such difficulties are compared to the profound disabilities experienced by this group. In contrast, others deny the very existence of disability. As shown in Chapter 2, the existence of people with profound physical and intellectual disabilities is only just beginning to be recognized.

There is still no widely agreed term for this group. Often they have been included in the term "complex needs" perhaps because society finds it too awful to acknowledge the severity of their impairments or finds it too difficult to meet their needs. MacKay (2001 June) argues that:

> Existence is allowed recognition when something can be done about it within existing resources, or when it fits prevailing dogma.
> (MacKay, 2001 June, p. 4)

This applies very much to young adults with profound physical and intellectual disabilities. Their existence is often "forgotten" and their needs go unmet. There is still uncertainty surrounding the curriculum content and teaching methods for this group. Moreover, the current philosophy of social inclusion is difficult to achieve for this group given the reluctance at both national and local levels to commit funding for services for this group. Even within the disability agenda and the currently favoured social model of disability, people with profound physical and intellectual disabilities have tended to be ignored (see Chapter 2).

SUMMARY

Research to further our knowledge and understanding of people with profound physical and intellectual disabilities is still in its infancy. Moreover, there are few substantial pieces of research which have focused on the experiences of this group of young people and their family carers during the transition period from school to post-school provision, from their perspective. Hopefully, this study has added to the limited literature currently available into the needs, experiences and aspirations of this group.

My study has also suggested that a transactional model may be a more useful tool in helping increase our understanding of people with profound physical and intellectual disabilities than the individualistic medical model or the social model. Moreover, it has also argued that, at present, we are a long way from 'Damascus' (Zarb, 1992) when it comes to emancipatory research methodology with people with profound physical and intellectual disabilities. Until we can overcome barriers to effective communication, we will only be able to access this group's experiences, feelings and thoughts indirectly through their family carers and people who know the youngsters well. However, this does not mean that we should not continue trying to find new ways of communicating with this group. Indeed, we must guard against adopting an individualistic medical model approach which sees these communication difficulties residing in the individual.

Imagine if you can
How it feels to be me
Trapped in a body without a voice
And longing to be free.

We must help these young people to find a voice, even although, at present, it is only through others.

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