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Parents' Views of Moves Towards Independence by their Adolescent and Young Adult Offspring with Learning Disabilities.

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ABSTRACT

Families supporting a young person with learning disabilities through the transition from child to adult services have been identified as one group of carers with priority needs (Department of Health, 2001a). While parents of young children with disabilities have received much attention, there is a dearth of literature concerning the needs of parents of adolescents and young adults with disabilities. They have rarely been considered even though their needs and difficulties may be very different from those of families with young children with disabilities (Dale, 1996). A better understanding of the needs of these parents is needed so that professionals and parents are able to work together as effectively as possible and to ensure that any support offered is appropriate to the needs of young people with learning disabilities and their families.

A key aim of learning disabilities services under current policies is to support young people with learning disabilities in developing increasing independence and choice. In contrast, research has suggested that parents of such young people may struggle to promote their children's independence (e.g. Card, 1983; Urey & Viar, 1990). This study explored the views of parents regarding moves towards independence during adolescence as well as parents' experiences of the support offered by services during this stage. The study focussed on three key areas of independence namely 1.) attainment of adult roles 2.) relationships 3.) leaving home and the future. These three areas were chosen as they have been identified in the literature as areas where conflicts may arise between parents and professionals in relation to the promotion of independence versus continuing dependence (e.g. Darling, 1983; Urey & Viar, 1990).

Semi-structured interviews were carried out with 14 parents who had a child with a learning disability between 18 and 25 years old. Interview transcripts were analysed utilising Interpretative Phenomenological Analysis (Smith, 1997). In addition, three quantitative measures were utilised to examine the impact of the young person's level of functioning, challenging behaviour and family resources and stress on parents' views and attempts to promote their children's independence.

Parents highlighted the huge investment that they have in their child, possibly leading to conflict with professionals who may underestimate this. The majority of parents described a sense of shock and anger during the transfer to adult services due to lack of planning, lack of resources and changes in service ethos. They frequently appeared to experience intense dilemmas arising from concerns for their child's safety, juxtaposed with their awareness of their child's desire for more independence. The themes of vulnerability and risk of abuse were raised throughout. Parents were open to talking about their child's sexuality and said they would like more open discussion with professionals. High levels of challenging behaviour, perhaps surprisingly, appeared associated with higher levels of independence. Younger age of offspring, professional involvement of a family member with learning disability services and greater material wealth seemed to result in greater input from services and in turn higher levels of achieved independence. The hopes and fears of these parents had many similarities to parents of non-disabled children, but there were also a few striking differences. The implications for services are discussed, as are the limitations of the study.

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CHAPTER 1

INTRODUCTION

Overview and Background to the study

While parents of young children with disabilities have received much attention, there is a dearth of literature concerning the needs of parents of adolescents and adults with learning disabilities. They have rarely been considered even though their needs and difficulties may be very different from those of families with young children with disabilities (Dale, 1996). Card (1983) highlighted the often painful and distressing adjustment parents of children with disabilities must make to a new and more separate relationship during adolescence. Despite parents' frequent concerns about their child's future provision, most wanted to continue caring for their offspring for as long as possible (Card, 1983). Parents wanting to preserve this relationship often find themselves in conflict with professionals who wish to develop independence in the young person (Dale, 1996).

It is essential that service providers are aware of parental views so that professionals and parents are able to work together as effectively as possible, for the benefit of adolescents and young adults with learning disabilities. Also it will help ensure that any support offered is appropriate to the needs of people with learning disabilities and their families. The present study explores the views of parents regarding their child's moves towards independence during adolescence as well as parents' experiences of the support offered by services during this stage. Parents' experiences concerning their adolescent offspring will be studied by focussing on three key areas of independence, namely: attainment of adult roles; relationships; and leaving home and the future. These three areas have been chosen as they are areas which have been identified in the literature as key aspects of adolescence, yet areas where people with learning disabilities and their parents may struggle to move towards greater independence. In addition they are areas where parents' and professionals' views are likely to clash (e.g. Urey & Viar, 1990; Darling, 1983).

Over the following pages I will first present definitions of learning disability, adolescence, transition and independence and review the context within which the parenting of adolescents with learning disabilities takes place. I will then focus more on the literature pertaining to adolescence generally and its relevance to the experiences of young people with learning disabilities and their parents in particular. The learning disability service context will then be presented.

Definitions

Learning Disability

People with learning disabilities do not constitute a homogenous group. However, related to diagnosis and classification there are several features of learning disability, "which have gained widespread acceptance across professional boundaries within the UK and America" (British Psychological Society, 2001). There are three core criteria for learning disability:

- Significant impairment of intellectual functioning;
- Significant impairment of adaptive/social functioning;

- Age of onset before adulthood.

Throughout this study research is only referred to if the participants meet this criteria. The participants in this study also all had a child with a diagnosed learning disability.

Adolescence

This term is commonly employed to refer to the transition between childhood and adulthood and the Lifespan developmental model highlights that adolescence is a continuation of childhood development (Coleman & Hendry, 1999). Adolescence is thought of as the period of development marked at the beginning by the onset of puberty and at the end by the attainment of maturity in several areas, including sexuality, emotional and cognitive functioning and a notable degree of practical independence. It is important to note that the term adolescence is perhaps less precise than it appears since both the onset of puberty and perhaps even more so the attainment of maturity are difficult to define or specify and tend to change in line with historical, social and economic changes. For the purpose of this study puberty is thought to start when females begin menarche and when males start to shave, in agreement with other research into young people with learning disabilities.

Much of the learning disability literature looking at the transition period between childhood and adulthood tends to study participants between the ages of 14/16 years and 25 years (Carpenter & Lindsey, 2002). Use of an extended age range, compared to studies of non-disabled "adolescents" reflects the fact that the move from childhood into adulthood is often extended or delayed for young people with learning disabilities (Vetere, 1993). For those young people with learning disabilities who acquire a significant level of independence, such as leaving home, establishing intimate relationships, or entering some form of employment, this does not often occur until they are in their early twenties or even later. Throughout this study the terms adolescents and young adults will be used to denote the age range of the study sample. However, it should be stressed that many of the issues individuals with learning disabilities may deal with in their early twenties could be regarded as part of the developmental stage of "adolescence".

Transition

This is a concept frequently utilised within learning disability services. There are many different transitions throughout the life course, for example receiving a diagnosis of learning disability, however the main use of the term associated with people with learning disabilities relates to the move from child to adult services. This is seen as a major transition and is meant to be planned several years in advance. Recently there has been an increased awareness of the importance of transition periods for people with learning disabilities and their families and the difficulties that they often have at these times.

Independence

As discussed later independence is a key aim for the Government's modernisation agenda (Department of Health, 2001a). After a thorough literature review the following key indicators of "independence" were utilised.

- Living situation, for e.g. living with family or residential placement.
- Frequency of activities involved in i.e. during the day as well as during the evenings and at weekends.

- Number of friendships and "love" relationships such as boy/girlfriend. The quality of these relationships was also briefly discussed.

Although these indicators are comparable for young adults without learning disabilities, it is also important to recognise that young adults with learning disabilities will need varying degrees of support to achieve independence. Associated with this is the availability of support and whether assistance is accepted.

Experiences of Parents of children and adolescents with learning disabilities.

Early research regarding families of children with disabilities was largely approached from a pathological perspective, tending to assume psychological impairment in families as a consequence of the child's disability. More recent research has revealed variations in parental caregivers' experiences, and highlights the importance of identifying those parents who are adapting successfully to the caring role as well as those who are not, and factors which contribute to this process (Walden et al., 2000). The presence of positive outcomes of caring reinforces the view that care giving is an activity of mixed valence for caregivers as opposed to the "pathological" view of care in earlier studies. The amount of stress any family member may experience is individual and will change over time (Bromley, 1998).

Most researchers and clinicians now recognise that a pathological perspective is not helpful and that collaboration with parents and building on their resources is essential. For example McConachie's (1994) transactional model of stress and coping in childhood disability suggests that stresses, including child characteristics and problems, life-cycle stages and life events, are mediated by parental perception, coping style and access to resources (e.g. social support, family interactions, utilitarian resources and service provision).

It has been suggested that vulnerability factors leading to family stress relating to the child include severe levels of disability, extreme levels of activity, the existence of behaviour problems, poor sleep patterns, and the presence of physical health problems. Vulnerability factors relating to the parents and family include: social isolation, economic difficulties, marital problems, lack of family closeness, a high number of life events and the use of more passive coping strategies such as wishful thinking or avoidance (Bromley, 1998). Sloper & Turner (1993) studied 107 families of children with severe disabilities and showed mothers to be at high risk from psychological distress and 67% of mothers at "critical" levels of stress. Factors that appear to improve resilience to stress include: having a supportive social network, meeting parents who are in similar situations, marital satisfaction, material wealth and resources, good health within the family, good communication between family members, an ability to maintain a positive outlook and the use of good problem-solving techniques and more active coping strategies, such as asking for help and support from services when it is needed (Bromley, 1998).

Within such a framework family difficulties are not denied, but the emphasis shifts to identifying which aspects of caring are most stressful, risk factors and resources families develop (Wirz et al, 2000). Such an emphasis also shifts the focus onto services and how these should be targeted to offer effective support to children with disabilities and their families. It is important not to forget that only thirty years ago parents of children with learning disabilities were being encouraged to place their children in institutions and to have very limited expectations of their child's abilities and had to fight hard for any support (Quine & Pahl, 1985).

A key issue in current literature focuses on promoting independence in young people with learning disabilities. This is also a key aim for the Government's modernisation agenda. Although it is recognised that individual needs will differ they suggest that the "starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this (Department of Health, 2001a, p.23). This reflects the wishes of young people with learning disabilities who frequently complain "of boredom at home, a wish for employment, accommodation of their own and personal relationships leading to having a family of their own" (Mental Health Media, 1998 cited in Mir. et al., 2001, p.25). Although this research focused on Black and Asian young people with learning disabilities, similar findings have also been found with other groups of young people. The concept of independence can be problematic as often service providers assume that a Western approach to independence will be shared by all people from different ethnic groups. However, despite this independence appears to be high on the priority list in services for young people with learning disabilities. Possible barriers to independence have been highlighted and includes restrictive expectations by carers, families and society, a lack of information about opportunities and poverty (Mir et al., 2001).

Experiences of Parents of young people with learning disabilities, including the transition from child to adult services.

It is important to note that the vast majority of the literature has looked at young children with learning disabilities and their parents, but has largely ignored adolescents and their parents. Much of the research looking at adolescence and transition has been undertaken in the United States with a very different configuration of services. Research has highlighted that the needs of families from ethnic minorities, with a child with learning disabilities, are quite different (Mir, Nocon, Ahmad & Jones, 2001). Recent studies in the United Kingdom tend to have accessed white participants only and often select sub-samples of these which do not necessarily represent views and needs of all families with an adolescent family member with learning disabilities.

For example Redmond (1996) interviewed seventy-eight parents (where possible both the mother and the father) who had teenage daughters with moderate learning disabilities, aged between 12 and 18, attending special schools in Dublin. Results showed that parents were generally supportive of the development of independence in their offspring, but had many concerns. Parents described evenings, weekends and long holidays as the "forgotten hours" and were concerned about the isolation and lack of friendships their daughters often experienced. In this regard they described difficulties in integrating the teenagers into appropriate leisure activities. Parents tended to underestimate their daughters' capabilities in terms of employment possibilities, as their views were contrasted with teachers. Parents reported continuously worrying about the future, when they would no longer be able to care for their child, but were not aware of alternatives and few had made any plans. Sexual exploitation and abuse were also grave concerns for the majority of the parents and the need for sex education was raised. A sense of anger and frustration with services was common and many parents talked about having to fight services and apply constant pressure simply to obtain adequate services (Redmond, 1996). The importance of services working closely with parents to achieve independence was highlighted. Although useful, this research is limited in that it concentrates on white, Irish families with daughters aged between 12 and 18 years. Also like many other studies the research focused on a particular level of disability i.e. moderate learning disabilities, which limits the ability to generalise the results.

In addition to the above findings Ferguson et al. (1988) studied the perspectives of American parents on transition from school to adult life for their offspring, aged between 15 and 23, with severe learning disabilities. Parents raised abandonment by professionals and lack of services when leaving child services as key issues. Ferguson et al. also found that parents were forced to become "experts" themselves so that they could fight for better service provision, after being abandoned by professionals. This meant that parents either worked within learning disability services or were very knowledgeable about provision for people with learning disabilities. Engagement with professionals varied, but largely seemed to fall at opposite ends of a continuum, parents either reported working enthusiastically and constructively alongside professionals, or more hostile relationships with professionals and being their child's advocate. Ferguson et al. (1988) conclude that "normalisation suggests the need for a weaning away of the individual from the daily protection and restrictions of parental control. Reality suggests the need for even greater parental advocacy and oversight when the individual faces the tremendous inadequacies of adult services" (Ferguson et al., p.187, 1988).

Similarly to the previous research Thorin & Irvin (1992) studied concerns and stresses at transition experienced by American families with a young adult with severe learning disabilities aged between 12 and 25 years. 42 members of 19 families were interviewed. The most frequently mentioned concerns were those associated with their child such as friendships and getting along with others, self-care capabilities, responsible behaviour and sexuality. Concerns rated as most stressful were associated with services, such as quality and availability of services, dealing with service providers and family financial problems and disagreements.

Another American study looked at parents' perspectives and needs during transition to adult services, for their offspring with mild to severe learning disabilities (Hanley-Maxwell et al., 1995). Parents reported needing support in caring for their offspring in areas including developing support networks for their children, filling their children's leisure time, finding possible residential alternatives to living at home, and providing vocational experiences and choices. All the parents interviewed indicated that they were tired and ready to let go of the task of being the main carer and several feared life-long burden. This is in contrast to the findings of Card (1983) who found parents wanted to continue to care for their offspring for as long as possible. It is not clear from these papers why there is such a difference in parental views. However, perhaps it reflects that over a decade parents have become more aware of their options. Many barriers to families needs being met were also highlighted, such as lack of accessible and high quality services that address all aspects of adult life, provision of home-like residential resources, few support networks for the adolescents and their families and a need for flexible services that respond to individual needs (Hanley-Maxwell et al., 1995).

Sittlington (1996) completed a major review of 41 studies related to the transition process for young people with mild learning disabilities. The review focussed on aspects of adult life other than employment and post-secondary education. These included maintaining a home, becoming involved in the community (including recreation and leisure activities), and experiencing satisfactory personal and social relationships. This review highlighted that out of 41 major studies, employment and education was referred to in all of them, whereas only 24% referred to leisure, 44% relationships and only 24% to housing. This ties in with the following findings of Heslop et al. (2001) that several key aspects of their offspring's life had not been addressed during the transition process.

A recent large scale UK project entitled "Bridging the Divide" studied 283 parents with sons and daughters aged between 13 and 25 with a learning disability (Heslop et al., 2001). This postal survey focussed on the effectiveness of the transition planning process in line with current legislation. Frequently parents reported that several key aspects of their adolescent offspring's life had not been addressed, such as opportunities for further education, independent living skills, adult relationships and sexuality, employment and leisure and social opportunities (Heslop et al., 2001). This study revealed that only 75% of the young people had a transition plan despite the legal requirements. Approximately 50% of the young people had had some meaningful involvement in the planning of their future. The main reasons for the other 50% not being involved in the plans were perceived difficulties in facilitating the person in the process, and the lack of choices actually available to these young people as they get older.

Respondents frequently said that they would like more information about leisure and social opportunities, information about benefits, future housing options and opportunities for further college education. In general some families reported positive experiences of transition often due to the efforts of certain individuals and/or the recognition that transition planning should be a process and not a one-off annual event. In contrast other families experienced little co-ordination between different services and no input into transition planning apart from at annual reviews. For many of the families the most negative element of the transition process was the lack of real options to move on to and uncertainty and confusion seemed to be common reactions (Heslop et al., 2001). 97% of the people in the survey were white and the authors acknowledge that the results are skewed to a predominantly white client group, which does not reflect the ethnic mix in the population generally.

Transition Legislation

The lack of co-ordination between child and adult learning disability services has been widely recognised for a long time. Organisational fragmentation makes it difficult for professionals and services to provide the type of co-ordinated assistance most likely to promote a positive transition experience (Routledge, 2000). Child and adult services also tend to be organised in very different ways and have very different cultures, which further complicates the transition for families. The policy response to the fragmentation of services has emphasised the need for more and better planning for each individual (Heslop, et al., 2001).

The Special Educational Needs Code of Practice (Department for Educational Employment, 1994) require that any young person who has a statement of special educational needs should also have a transition plan. This plan should be drawn up by the Local Educational Authority (LEA) at the first annual review of their statement after their 14th Birthday. Generally the guidance is comprehensive and helpful and "although the system of planning is to be driven by schools and LEAs it makes clear that transition planning is a continuing process that should be concerned not simply with leaving school, but should look at the move to adult life" (Heslop et al., 2001). The guidance also highlights the importance of involving the young person with the planning as well as creating partnerships with agencies like social services, careers services and parents. Despite this legislation research indicates that young people and their families are frequently not benefiting from effectively organised transition plans (Morris, 1999, 1995, 1996, 1997). Difficulties recognised at transition include a lack of co-ordination between child and adult services and unmet parental expectations assuming adult services could match the high levels of care provided in children's services. Also there are minimal services for adolescents with learning disabilities and a lack of choices and opportunities in areas such as employment, living arrangements, leisure and health. The Strategic Framework also highlighted a lack of respect from services concerning parents' views and expertise and parents felt that they were often asked their opinion, but never listened to.

Disparity between Professionals' and Parents' views

Much of the research has suggested that frequently parents' and professionals' views differ as to what the needs of the young person are. The researcher has observed frequent disagreements within clinical settings and disputes between parents and services are also common. A partnership is needed between professionals and parents to create an environment that best meets young people's needs (Dale, 1996). There is some evidence of clear differences between parental and professional views on needs for services, although none directly concern adolescents and their families. Wirz et al. (2000) utilised semi-structured interviews to collect the views of 20 parents of children with congenital learning disabilities aged 2-5 and postal questionnaires from 20 professionals, nominated by parents, as individuals whom they felt understood their needs. They found that only just over half of the parents felt that when they approached professionals with concerns about their child, before they were informed of their child's disability, were they listened to and supported appropriately. Furthermore the majority of the parents interviewed felt that they were given insufficient information concerning their child (Wirz et al., 2000).

With regards to parents of children with severe physical disabilities, Sloper and Turner (1991) found that unsatisfactory contact with professionals can actually exacerbate stress in the parents, especially where service provision is poorly structured and badly co-ordinated. This is confirmed by Wirz et al. who studied parents with 2-5 year olds with learning disabilities. They note that "differences in perception (between professionals and parents) may become difficulties in themselves, triggering hostility or ineffective targeting of services, such that needs are not met despite significant input" (Wirz et al., 2000, p.8). Although similar research has not been carried out with adolescents with learning disabilities and their families, similar findings may well be likely.

Wirz et al. (2000) studied the influence of possible complicating factors in the partnership between professionals and parents, including communication difficulties, inaccurate assumptions about needs and conflicting perspectives. Two main themes emerged namely the differing "world-views" of parents and professionals, and the complexity of the service network. Urey & Viar (1990) found that professionals tended to overestimate needs and continue to have negative expectations of family resources (cited in Wirz et al., 2000).

Far from being a homogenous group parents who have a child with a learning disability represent a cross section of the population, for example in terms of income, age, employment and cultures (Redmond, 1996). The needs of the stereotypical family with a disabled child do not exist, as there is such a large range of individual differences. Despite this, research reveals that common themes emerge from parents' experiences and this needs to be acknowledged by services and professionals if appropriate services are to be designed and developed. Informing parents that they are not alone in their views may also lead to greater confidence in them playing an active role in service development (Redmond, 1996). Research has also indicated that care managers tend to overestimate possible conflicts of interest between family carers and their offspring, suggesting that interventions may even be at risk of undermining family coping strategies (Grant & Ramcharan, 2001).

Adolescence

Adolescence is a dynamic period of change over several years, not only within the individual person, but also within their whole social structure (Durkin, 1995). It is a time of major change biologically, cognitively, psychosocially, sexually and behaviourally. External changes also occur such as changes in responsibilities, shifts in others' expectations, less nurturing and more emphasis on independence (Coleman & Hendry, 1999). Core tasks therefore need to be negotiated for adolescents to move successfully into adulthood including physical maturation, development of sexuality, emotional autonomy from parents, identity development and development of rational thought. These changes are effected by important contexts, including family, school and peers.

Adolescence: Storm and Stress?

From about 1900 in Europe and the U.S. adolescence has been thought of as a period of "storm and stress" (Hall, 1904). Highly influential writers suggested that normal child development almost invariably results in a tumultuous and problematic adolescence (e.g. Blos, 1962; Freud, 1958). "According to many, adolescents are portrayed as troubled with fluctuating emotions and hormones over which they have little control. The "typical" adolescent is assumed to be out of control, in constant conflict with his or her family, and incapable of rational thought" (Offer & Schonert-Reichl, 1992 p.1003).

More recently it has been argued that adolescence may be challenging but not necessarily problematic (Coleman & Hendry, 1999). At least for non-disabled adolescents most changes are in a positive direction giving the adolescent more capacity for individual functioning. (Coleman & Hendry, 1999). However, "children who enter adolescence already vulnerable psychologically or socially are likely to experience a more difficult adolescent decade under challenging social circumstances" (Petersen & Leffert, 1997).

It is also useful to consider adolescence from historical, societal and cross-cultural perspectives to highlight the large range of variation. Adolescence appears to be distinctly different in modern technological society and "our increasingly complex societies have made it even more difficult for adolescents to understand what kinds of adults they are to become and how they are to accomplish this" (Peterson & Leffert, 1997). The few publications which research the experiences of Black and ethnic minority young people have emphasised that concepts of what adolescence means can vary from one culture to another (Morris, 1999).

Puberty

During adolescence a growth spurt occurs which concludes at the end of adolescence. Until adolescence the rates of growth for boys and girls are thought to be comparable. However, girls tend to enter this period of growth one or two years earlier than boys (Carr, 1999). During this period young people develop primary sexual characteristics i.e. menstruation in females and capacity to ejaculate in males, and secondary sexual characteristics i.e. auxiliary hair, breasts and voice changes

(Carr, 1999). The average age in the US for the emergence of primary sexual characteristics is 12 years for females and 14 years for males (Carr, 1999). Hormonal changes have also been researched and their effects seen in both males and females. In females higher oestrogen levels are associated with positive moods and increased activity, while lower levels are associated with poorer moods (Alasker, 1996). In males raised testosterone levels contribute to male aggression and dominance (Alasker, 1996). Puberty in young people with learning disabilities has been found to be similar to those without a learning disability. However some evidence has shown that females with severe and profound learning disabilities may have delayed or absent menarche. The main difference in puberty between young people with learning disabilities and those without, is the management of menarche and masturbation, as sometimes there are difficulties in these areas (Craft, 1994).

Adolescence and people with learning disabilities

There is little research concerning adolescents with learning disability, in contrast to the extensive literature on the needs of children with disabilities and particularly their parents. There is some evidence that particular groups of people are less likely to receive effective support during transition, including young people from minority ethnic communities and young people with learning disabilities (Routledge, 2000; Cohen et al., 1998a & b; Morris, 1999b; Pearson et al., 1999). There is a lot of literature claiming to study "young people with learning disabilities", but in fact participants are of low ability or have specific learning difficulties, rather than a generalised learning disability. The following summary represents the limited information available that specifically covers adolescents who have a generalised learning disability (see definition on p.8).

Beart et al. (2001) studied leisure opportunities amongst 16 to 30 year olds with learning disabilities. Five focus groups were held within a variety of specialised services for people with mild to moderate learning disabilities. 29 people took part and the aim was to find out what community leisure activities they already accessed and what barriers stopped them from accessing more leisure opportunities. All five groups identified lack of transport and carer/friend support as barriers to accessing leisure opportunities. Only two of the five groups thought money was a major barrier. Leisure opportunities were shown to be segregated from the community as a whole as the majority of activities were organised by day centres. This research is useful as it highlights that support and limited access to the community appear to be the main barriers, not simply lack of money. However this was a small local project and whether an activity requires transport or money could be seen as a somewhat arbitrary categorisation, as it depends on the activity as well as individual circumstances.

The vast majority of young people with learning disabilities live with their families. Even in adulthood around 60% of people with learning disabilities continue to live with their families (Department of Health, 2001b). Davies & Jenkins (1993) interviewed 60 young people with a learning disability aged between 17 and 28 and their families. As noted in more recent studies the majority of the young people i.e. 87% were still living at home with their families. Often the young adults' opposition to other living arrangements was based on a misunderstanding of what that might entail or a lack of knowledge about alternatives. The parents interviewed were nearly evenly divided as to whether they would like their son or daughter to live away from home one day. A willingness to consider other options often appeared due to the realisation that the parents would not be able to provide care indefinitely. Other parents were clearly distressed at this idea as they felt nobody would care for and respect their son or daughter as they did. Davies & Jenkins conclude that one of the ways young people with learning disabilities can achieve a more adult lifestyle is by moving out of the family home, as they would be more likely to access evening and weekend leisure activities and would have peers to socialise with. This study is useful considering that Heslop et al. (2001) revealed that parents frequently wanted more information about future housing options, but these areas were often ignored. This suggests that "leaving home" as a future option is on the transition agenda for many parents with a young adult with learning disabilities.

Ryan (1997) investigated in-depth what issues and concerns are most pertinent to young people who have learning disabilities and their families as they move from school to adult life. The study was based on contact with 36 young people and their families from six different local authorities in England and Wales. Experiences around leaving school were very mixed and expectations and hopes were similar to young people without learning disabilities. Several families raised the benefit trap, which in many cases prevented the young person from finding employment. With the exception of some older parents leaving home did not seem high on the agenda. Some families felt they had received adequate information and advice, while others felt very let down by professionals. It was also highlighted that formal meetings presented difficulties in enabling young people with learning disabilities to have their say. The author also recognised that young people need to make choices through experience and there were very limited opportunities for this, as well as limited options in general. Ryan poses the question whether "without access to housing, support and the very things that can come from such independence such as status, dignity, relationships and self-esteem, will people with learning disabilities ever make the transition to what they perceive as adult life?" (Ryan, 1998, p.18). In 1994 a survey of young disabled peoples' experiences and a comparison with their non-disabled peers revealed that between 30 and 40% of them "find great difficulty in attaining a degree of independence in adult life comparable to that of young people in the general population" (Hirst & Baldwin, p. 110, 1994).

Morris (1999) also looked at transition to adulthood for young people with complex health and support needs, including people with physical and learning disabilities. Interviews were held with 14 young people and 2 sets of parents. It was revealed that young people with disabilities would benefit from health services specifically geared towards the transition to adulthood. However there is very patchy provision of services across the country. These young people were seen to be vulnerable to failure of health and social services to meet their needs during the move from child to adult services. Young people wanted accessible information given to them and not only their parents. They also recognised that peer support was very important to them. Morris concluded that for those people interviewed to a large extent the scope for any personal development had ceased. This study revealed important findings, although similarly to other learning disability research the numbers are small which causes difficulties for generalising the results.

The Service Context

"Valuing People: A new strategy for learning disability for the 21st Century" (Department of Health, 2001a).

The government White Paper for learning disabilities identified two areas relevant to adolescence as in need of major improvement, transition into adult life and supporting carers. It states that "disabled young people and their families often find the transition to adulthood both stressful and difficult. For many, there has been a lack of co-ordination between the relevant agencies and little involvement from the young person. Some young people are not transferred from children's to adult services with adequate health care plans, which results in their exclusion from adult services. This is likely to affect young people with severe learning disabilities and complex health needs in particular. Starting adult life should be a time of opportunity for young people. The Government wants to see more young people taking part in education and training, which will help them lead productive adult lives and find employment" (Department of Health, 2001a, p.41-42).

Providing adequate support for parents is of great importance in ensuring a fairly smooth and successful transition to adult life for young people with learning disabilities. What happens to young people during adolescence and early adulthood to a large extent can determine the quality of the rest of their lives (Morris, 1999). There is a real lack of choice for young people with learning disabilities leaving the education system. For many there may be nothing suitable available and tends to also be a time when people become "lost" to services (Department of Health, 2001b). There is also a lack of housing or residential options for young people with learning disabilities. Families can be accused of not letting their children leave home, which although may be true in some circumstances, the reality is that often families are keen to promote independence in the young person with a learning disability but are hindered by the lack of suitable options (Department of Health, 2001b).

The White Paper stresses the needs of carers with regards to: their need for more comprehensive information; improved access to support services such as day services and respite care particularly for those with more severe disabilities; and being treated as valued partners by local agencies, not as barriers to their son's or daughter's greater independence. Life long carers have to cope and adjust to many transition challenges such as being told their child has a learning disability, deciding on what educational opportunities are appropriate for the child, adolescence and moving from child to adult services, and leaving home. As all of these transitions are an inevitable part of the life course, it is crucial that services take a long-term view of planning with and for people with learning disabilities, to help minimise the stress and anxiety that people experience (Department of Health, 2001b). Carers that are supporting a young person through the transition from child to adult services have been highlighted as a priority. Many parents feel that they have not been adequately prepared for this transition and the change comes as a profound and unwelcome shock.

Services for Adolescents with Learning Disabilities

Farran et al. (1986) noted that "there are no universally available services for children at a single age and no comprehensive set of community services covering the family's and the child's needs as they grow older" (p.150). They have also noted that traditionally services have been fragmented, with no co-ordinating body and parents have rarely received the proactive help they need. It has since been recognised that the lack of continuity in services at the transition point from school into adulthood, with a loss of relationships and support is of major concern. It is easy to understand how confusing this transition can feel to a young person and their family and the potential difficulties that can result (Routledge, 2000). The possible loss of services and lack of appropriate adult provision is, understandably, also a major worry for families. In response, in many areas, specific teams have been set up over the past decade to focus on offering support during the transition to adulthood. As noted, there have also been changes in legislation which, theoretically, should result in improvements in service provision for this group.

The fragmentation of services and transition support has frequently been linked to disappointing outcomes for young people with learning disabilities as they leave school. Ryan (1998) noted "For most of the participants of this project, at least, the money and status associated with employment which they aspired to had eluded them. The majority either attended or were planning to attend college, with some having their part time college week 'topped up' with attendance at day or training centres…It is therefore fair to say that, despite the planning that has been brought about by legislative changes, not a lot of change has occurred in relation to providing people who have learning disabilities with access to real employment and choice in their lives" (Routledge, p. 20, 2000). People with learning disabilities have also been linked with several other "poor outcomes". For example it has been found that the rate of psychiatric disorders may be higher in people with learning disabilities. Perhaps this is unsurprising considering their likely life experiences, such as birth trauma, institutionalisation, stigmatisation, isolation, lack of friendships and intimate relationships (Caine & Hatton, 1998).

"Poor outcomes" may be associated with the nature of learning disabilities, but are also likely to be linked with poorly co-ordinated services. Across the country a range of approaches are being developed to improve the coherence of professional work in transition. These include: transition steering groups, joint or integrated transition teams representing the focused investment of time and resources for transition, transition co-ordinators and measures to ensure improved communication and information sharing between professionals (Routledge, 2000). The importance of listening to young people with learning disabilities and their families and empowering them has been recognised. This includes more effective methods of informing young people about choices through direct experience and accessible information aids such as videos. However, this type of practice is still rare and only available in very few services. The use of advocacy, independent advice and support, person-centred planning, creative methods in involving young people with their reviews and inclusion of families from all backgrounds and cultures are aims that should be strived for (Routledge, 2000). These encouraging developments hopefully reveal the continuing battle to improve the experience of transition to adult services and more effectively meet the needs of young people with learning disabilities and their families. To meet needs more effectively it is perhaps more important that professionals really listen to parents and are flexible in the way they respond to each individual family over time, rather than inventing new service structures (McConachie, 1986).

Summary

The previous review of the literature highlights the gaps in the research, which led to this study. A key issue in current literature focuses on promoting independence in young people with learning disabilities and is also a key aim for the Government's modernisation agenda (Department of Health, 2001a). Independence was therefore chosen for the focus of the study. "Parents views" and the "period of adolescence" were chosen as families supporting a young person through the transition from children to adult services, "have been highlighted as a group of carers who have priority needs and require particular attention" (Department of Health, 2001b, p.29). Heslop et al. (2001) studied the effectiveness of transition planning, in line with current legislation and found many discrepancies and parents dismayed at the lack of co-ordination between services. Also the majority of young people with learning disabilities are still living at home with their parents and they are therefore likely to have a large impact on their child's achieved levels of independence (Department of Health, 2001b).

Young people with learning disabilities have frequently complained of boredom at home and the wish for employment or fulfilling day time activities (Mir, et al., 2001). They also talk about the importance of friendships and the wish for intimate relationships perhaps leading to families of their own (Morris, 1999). Young people have also raised the desire for accommodation of their own and the opportunity to love away from home like other young people without learning disabilities (Davies & Jenkins, 1993). This study therefore aimed to explore factors that promote independence and those that appear to act as barriers to independence.

Qualitative methodology was chosen as the majority of research to date is based on surveys or questionnaires and the researcher wanted to attempt to understand parents' individual stories.

Aims of Present Study

This study has two main objectives: 1.) to explore parents' experiences of caring for their adolescent offspring with learning disabilities during the move towards adulthood and potentially greater independence; and 2.) to explore the role of services in this process.

Research questions

The research questions are as follows:

1.) **How do parents' view moves towards independence by their adolescent son or daughter?** In particular the following areas of independence have been chosen for the reasons outlined above. Three areas of independence will be explored i.e. the attainment of adult roles including day time activities like employment and leisure opportunities; relationships including peer and sexual; and the future including the complex issue of leaving home.

2.) **What are parents' experiences of services during this period?**

3.) **What factors seem to have an impact on parental views and experiences in this area?** In particular the study wanted to look at factors that promote independence and those that appear to act as barriers to independence. Quantitative measures will be utilised to measure family resources and stress, level of adolescent's functioning and level of challenging behaviour as these have been shown in the literature to have a possible impact (Dale, 1996). Family demographics will also be collated including age of the young person, diagnosis, ethnicity, marital status of parents, presence of siblings, involvement of family members in learning disability services and material wealth. All these factors will then be compared with each young adult's achieved levels of independence.

N.B. Cautious analysis will be made concerning the possible impact of different factors (for example family demographics) on parents' views, mindful that the study is essentially qualitative and the associated small sample size.

CHAPTER 2

METHOD

Overview

Fourteen parents with an adolescent son or daughter with learning disabilities participated in the study. Parents completed three standardised questionnaires, which were measures of their adolescents' challenging behaviour, level of functioning (e.g. skills and participation in daily life) and family resources and stress. Parents were subsequently visited in their own homes and interviewed using a semi-structured interview schedule (see appendix 4). The interview collected information about family demographics and composition and looked at adult roles, leaving home and the future, relationships and support from services during adolescence.

Participants

Participants were recruited from two healthcare trusts in London Boroughs. The inclusion criteria for participants in the study were being parent to a son or daughter with learning disabilities between the ages of 16 and 25 years. Parents were included regardless whether their offspring was still living with them as this would hopefully result in a varied sample with different levels of achieved independence. All levels of disability were included and participants were recruited from the learning disability registers in both boroughs. At least one parent had to be fluent in English due to the financial constraints of the project, although it is recognised that this may have excluded the voices of many parents. The aim was obtain a rich and diverse picture of the experiences of parents of an adolescent with learning disability.

There were fourteen participants in total, consisting of 11 mothers and 3 fathers. The offspring being discussed ranged from 18 to 25 years old; half were daughters, the other half sons. Thirteen of the young people had moderate or severe learning disabilities and one was described as having a mild learning disability. Four of the young people had Downs Syndrome, four had Cerebral Palsy, three had Autism (for two of the young people this was an additional diagnosis), four had a diagnosis of moderate learning disability and one had a rare genetic disorder. Half of the young people had additional health needs such as physical disabilities related to Cerebral Palsy. Six of the participants were White British and one was White Irish. The other seven participants were Black African, Black Afro-Caribbean, Asian, Middle Eastern or Mediterranean. Please see Table 1 on next page for a summary.

Table 1 Participants 1-14: Demographics

Participant number **MO= mother** **FA=father**	**Age and Sex**	**Level of Learning Disability as Described by Parents**	**Additional Diagnoses**	**Ethnicity**
MO1	23 F	Moderate	Downs Syndrome	White British
FA2	21M	Moderate	Cerebral Palsy	Black African
MO3	23M	Moderate	Autism	Black African
MO4	19M	Severe	Cerebral Palsy	British Asian
MO5	24F	Severe	Cerebral Palsy and Autism	White British
MO6	23F	Moderate	Downs Syndrome	Black Afro-Caribbean
MO7	23F	Moderate	Cerebral Palsy and Autism	White British
FA8	18F	Moderate	N/A	Middle Eastern
MO9	23M	Moderate	N/A	Mediterranean
MO10	18M	Moderate	Downs Syndrome	White British
MO11	18M	Moderate	N/A	White British
MO12	22M	Moderate	Visual Impairment and Epilepsy	White Irish
FA13	25F	Severe	Rare genetic disorder	Mediterranean
MO14	18F	Mild	Downs Syndrome	White British

Demographics

In accordance with factors identified in the literature as potentially relevant to parents' experiences, information on the following demographic characteristics of both the parent and the adolescent with learning disabilities were collected:

- Age of the adolescent with learning disabilities
- Age of parental carers
- Ethnicity of parents and adolescent with learning disabilities
- Whether parents are employed
- Whether parents experience financial difficulties
- Marital status of the parents
- Any diagnosis and if applicable diagnosed level of learning disability
- Whether in contact with similar families or not

Recruitment Process and Procedure

Contact was made with a Consultant Clinical Psychologist in both of the NHS Healthcare Trusts involved in the project. These Psychologists facilitated liaison with the people in charge of the Learning Disability Registers in both of these Trusts. Information letters were sent to eighty parents in each borough i.e. all parents who had a child between 16 and 25 and were registered. The researcher did not have access to the families' personal details due to strict rules of confidentiality.

On the information letter (see appendix 1) sent to parents, the researcher's telephone number was given which parents could ring if they would like more information or would like to participate. The researcher then discussed the project with the parents, arranged an interview time convenient for them and posted the three standardised questionnaires and consent form to their homes to be completed. The researcher visited the parents at their home. The purpose of the study and confidentiality of the interview and the information obtained from it, were re-iterated to parents at the beginning of the interview. If participants had not felt comfortable filling in the three questionnaires before the interview then they were incorporated into the interview schedule. The interviews lasted between 2 and 4 and a half-hours.

Ethical considerations

Ethical approval for the project was obtained from both the NHS Healthcare Trusts Research Ethics Committees (see appendices 2 & 3). The information letters sent to parents gave an outline of the study and what it entailed. This information stated that the study was independent of services or input the family was receiving and their decision to take part or not would not affect any of the services they were currently receiving or might receive in the future. Parents were aware that their participation was voluntary and they were free to withdraw at any time. Parents were also reassured that all information would be strictly confidential and would only be used for the purpose of the study. Before the interview participants signed a consent form. The option of feedback concerning the results of the study was discussed with the parents and if they were interested they were informed that in due course a summary of the results of the study would be sent to them.

Researcher's Perspective

The impetus for this research arose through the researcher's previous clinical experience within the field of learning disabilities. Employment as a Nursing Assistant, Assistant Psychologist and Trainee Psychologist resulted in extensive experience working alongside families with a member with a learning disability. The researcher was struck by the impressive coping strategies that families developed and the way they negotiated complex service frameworks. Work in adult learning disability services also highlighted the needs of young adults and the seeming lack of acknowledgement of "adolescence" by services.

Measures

Data was collected using both qualitative and quantitative measures.

Aberrant Behaviour Checklist (ABC: Aman & Singh, 1986). Appendix 5

This is a 58 item scale assessing irritability, lethargy, stereotypic behaviour, hyperactivity and excessive speech in adolescents with learning disabilities. The scale was designed for use with people with mild, moderate, severe and profound disabilities. It is an informant rater tool and can be filled in by parents with no special training being required. Questions are asked about the adolescent's behaviour over the last four weeks. For each item participants rate whether the behaviour specified is a problem and respond on a four point scale, (0 = not at all a problem; 1 = behaviour is a problem but slight in degree; 2 = the problem is moderately serious; 4 = the problem is severe in degree). According to the authors it is suggested that when subscale scores exceed the 85th percentile for his/her normative group they meet "extreme" criteria. There have been several psychometric studies of the ABC. Interrater reliability has been found to be moderate (Aman et al., 1987; Freund & Reiss, 1991). Criterion validity also appears to be adequate to very good (Rojahn & Helsel, 1991). Examination of the psychometric properties of the scale show that it performs well and is both a reliable and valid instrument (e.g. Aman, Singh and Field, 1985; Newton and Sturmey, 1988).

Short Form of the Resources and Stress Questionnaire (QRS-F: Friedrich, Greenberg and Crnic, 1983). Appendix 6

This is a 52 item self report questionnaire, which measures the impact of a learning disabled, physically handicapped or chronically ill family member on other family members. The scale is composed of four sub-scales: Parent and family problems (20 items); Pessimism (11 items); Child characteristics (15 items); and Physical incapacitation (6 items). Each item is a statement to which participants respond 'true' or 'false'. For example "I worry what will happen to _____ when I can no longer take care of him". A response of 'true' for this item is scored as 1 and a response of 'false' is scored as 0. Scores within each sub-scale are summed to provide four sub-scale scores. Scores on all items are summed to provide a total score, which ranges from 0 to 52, a higher score indicating a higher level of parental stress. There are no guidelines recommending what scores represent "extreme" or "cut-off" scores.

Information available regarding the psychometric properties of the QRS-F indicate that the internal consistency is high (coefficient alpha ranging from .92 to .95) (Friedrich et al., 1983; Scott, Sexton, Thompson & Wood, 1989). The internal consistency is approximately the same for parents of disabled children (coefficient alpha = .89) as for parents with non-disabled children (coefficient alpha = .88), suggesting that the measure can be usefully applied in experimental and comparison groups (Scott et al., 1989). Friedrich et al. (1983) described the correlation between the four sub-scales and other independent measures (e.g. Beck Depression Inventory) as indicative of good concurrent validity. However, the authors do not provide any figures to demonstrate this. Scott et al. (1989) suggested that the QRS-F has good construct validity.

Caregiver Information Questionnaire (CIQ). Appendix 7

This asks questions about a disabled child/adolescent's skills, participation in daily life and problem behaviours. Parents are asked to answer the questions in a way that reflects how things are, rather than how they might be if the situation was different. The CIQ can be used to plan educational programs for children and obtaining resources that are needed. If utilised on a subsequent occasion it can be used to help evaluate progress.

Initially the Disability Assessment Schedule (DAS: Holmes, Shah and Wing, 1982) was going to be used as a brief screening device looking at an adolescent's level of functioning. The DAS has been extensively utilised in research and its psychometric properties have been widely published. However the researcher had concerns about some of the questions and the way it might be perceived by parents, possibly even alienating the parents from the study. A researcher at Lancaster University (Personal Communication) also advised the researcher that both measures had been used in studies and parents generally scored at the two extreme ends of the scale on the DAS, while the CIQ appeared to have greater face validity with parents. Initial studies being carried out, suggest that the CIQ has good reliability and validity. However, there are currently no norms available for the CIQ.

To identify the most appropriate measure for the purposes of the current study, a copy of both the CIQ and the DAS was given to six parents who had a child with learning disabilities between the ages of 16 and 25 years. All unanimously stated that they preferred the CIQ. Comments were made such as the CIQ appeared to allow more positive observations to be recorded about the child and parents found some of the DAS items excessively negative. Due to its apparent greater acceptability to parents, the CIQ was chosen for this study.

Analysis of Quantitative Data

A Table was designed that contained all the scores from the Aberrant Behaviour Checklist (ABC), Caregiver Information Questionnaire (CIQ), and Questionnaire for Resources and Stress (QRS-F). A correlation was carried out between the Aberrant Behaviour Checklist (ABC) scores and the Questionnaire for Resources and Stress (QRS-F). All the scores from the quantitative measures (ABC, CIQ and QRS-F) were compared to levels of achieved independence as described by the parents during the interviews. For the ABC norms were used to identify "extreme" scores. The CIQ and the QRS-F were analysed by ranking all the scores for each measure, for each individual and comparing the highest and lowest scores to levels of independence. Occupations for both parents were categorised using the Standard Occupational Codes (S.O.C., 1999) from the Department of Work and Industry. These codes were then used to look up gross annual incomes for each individual and the highest earner in each household was utilised in the analysis. Earnings were then also compared to levels of achieved independence.

Semi-Structured Interview Schedule. Appendix 4

The semi-structured interview schedule was designed using literature by Jonathan Smith (1999) who developed Interpretative Phenomenological Analysis (IPA). In designing the schedule the researcher was informed by findings reported in the literature regarding parents' experiences and concerns about the transition from child to adult services. Areas that have been largely ignored within the transition literature, such as questions around sexual relationships, were also incorporated into the interview. Background and demographic information was first obtained from the participant. Three topic areas were covered and under each topic area information was asked about the support received from services: 1.) Adult roles (further education, employment, leisure), 2.) Relationships (peer and sexual), 3.) Leaving home and the future. The questions were designed to elicit interviewees' own conceptualisations of their experiences of being a parent to an adolescent with learning disabilities.

The interview was developed utilising feedback from several clinical psychologists in the field and consulting six parents of adolescents with learning disabilities during construction of the questionnaire. The schedule was designed as a flexible interview guide, which would allow adapting the order of questions and topics in line with the interview process. The interview questions were modified depending on the age of the young adult. For example the question "how much of the typical teenager do you see in x?" was re-phrased as "how much of the typical teenager *did* you see in x?". At the end of each interview participants were asked for feedback on how they found the interview. All the parents felt that questions referring to "teenagers" or "adolescents" were still relevant to them even when their offspring were in their twenties. Parents also frequently said that their child with learning disabilities behaved similarly during adolescence compared to their other children without learning disabilities.

Analysis of Qualitative Data

All interviews were recorded and then transcribed verbatim. Transcripts were analysed following the principles of Interpretative Phenomenological Analysis (IPA, Smith, 1997). Please see Appendix 9 for an excerpt of an interview transcript.

Rationale for using IPA

IPA was designed specifically as a psychological research method. It is a phenomenological approach and is therefore interested in the world as experienced by individuals within certain contexts and at certain times as opposed to being interested in discovering objective truths. Unlike grounded theory, IPA is not attempting to develop comprehensive theories about the phenomena under investigation from individuals' accounts. Instead IPA is interested in gaining understanding and insight into individuals' experiences and it is these accounts that become the phenomenon with which the researcher engages. Also IPA is still a relatively new and developing research approach and it is not associated with debates and controversies that now surround Grounded Theory (Willig, 2001). Although IPA literature provides clear accounts of how to carry out analysis in a structured way it still invites the researcher to explore the data freely and with creativity.

IPA "is concerned with an individual's perception or account of an object as opposed to an attempt to produce an objective statement of the object or event itself" (Smith et al, 1997). It acknowledges that people's cognitions are not transparently available within an interview situation, but hopes to understand what a person thinks or believes by engaging in an analytic process. IPA explicitly recognises that the researcher's conceptions influence the process of making sense of the transcripts. IPA acknowledges this dependency and "complication" and states that the themes derived from the IPA process are a reflection made by both the researcher and the participants (Smith, 1996).

Each of the transcripts were read and re-read and the emerging themes were coded. Major themes were then identified and ordered into a structure of Domains (Higher order categories) and themes (Lower order categories). The data was organised using a computer package called QSR NVivo, specially designed for

Qualitative analysis. This package allows the researcher to categorise and organise transcribed interview data very efficiently. The package does not automatically sort data and needs instruction for every aspect of the data organisation. Coding is therefore supported but not dictated by QSR NVivo. Interviews can be coded in many different ways and when a theme needs to be reviewed this information can be easily produced. Once themes were identified they were then reapplied to the transcripts and adapted as necessary. This process was cyclical and continued until a final list of domains and themes were created that reflected all of the transcripts. Two other researchers also examined the transcripts initially for potential themes and later on to check the fit of the evolving themes to the original data. Their feedback was utilised to modify the themes. These procedures were used to ensure that the themes reflected the interview well and helped to increase the validity and reliability of the final themes.

Information from the interviews was also collated to reflect the levels of achieved independence of each young adult. Three qualitative indicators of independence were utilised i.e. living situation of offspring, day, evening and weekend activities, and relationships including peer and whether they have been in a love relationship (had a boyfriend or girlfriend).

CHAPTER 3

RESULTS

Overview

1. *Questionnaire Results* (Table 2)

Table 2 presents overall scores for the Caregiver Information Questionnaire (CIQ), Questionnaire on Resources and Stress (QRS-F) and the Aberrant Behaviour Checklist (ABC). A correlation was carried out between the ABC and the QRS-F as it was hypothesised that there would be a positive correlation as the presence of more challenging behaviour perhaps leads to greater stress within families. The ABC and QRS-F were found to be positively correlated as expected ($r = .62$, $p = .01$). Please see appendix 8.

Out of the five young adults who require the most supervision, three have a diagnosis of Cerebral Palsy. Three of the four young adults who have the highest functioning and therefore the least support have a diagnosis of Downs Syndrome. The four young adults who have the highest functioning also have the lowest scores on the Questionnaire on Resources and Stress (QRS-F) and on the Aberrant Behaviour Checklist (ABC). Five of the six individuals with the highest scores on the QRS-F also have the highest ABC scores. The other very high QRS-F score (i.e. total = 40) is not associated with a high challenging behaviour score, however this high score is likely to be associated with this young adult's very complex physical health needs, such as severe visual impairment, severe epilepsy and an unknown life expectancy.

Table 2 Participants 1-14: Scores for Caregiver Information Questionnaire (CIQ), Questionnaire on Resources and Stress (QRS-F) and Aberrant Behaviour Checklist (ABC)

Participant number MO= mother FA=father	*** CIQ Child Functional Skills**	**CIQ Supervision** *1=constant 4=very little*	**QRS-F** *Higher scores=greater distress*	**ABC** *Higher total scores= more challenging behaviours.*
MO1	1.18, 1.2, 1, 1	4	6	0
FA2	3.73, 2.6, 3.5, 3.25	1	31	40 Subscale 3#
MO3	1.54, 2.6, 3.25, 2.75	2.7	28	52 Subscale 5#
MO4	4.09, 3, 4.5, 2.25	1	16	**
MO5	2.36, 3, 1.5, 2.25	2.3	28	46
MO6	**	**	**	**
MO7	4, 2.8, 2, 2	1	19	47 Subscale 5#
FA8	1.91, 1.4, 1.5, 2	2.7	22	31
MO9	2.18, 3.2, 3,2	1	41	73 Subscales 3, 4, 5#
MO10	1, 1, 1, 1	4	6	3
MO11	1.64, 2.6, 1.5, 2	3	32	45
MO12	3.09, 2.8, 1.5, 1.25	2	40	17
FA13	4.18, 3.8, 4.75, 3	1	26	15
MO14	1.54,1.4,2,1.5	3.3	26	8

Key:

* Self-Care Skills. Interest in Activities. Communication skills. Social Skills. (1=very well needs little help/very often – 5=cannot do this, 4=rarely or never).

** Incomplete data set.

Subscales scores that exceed the 85th percentile for his/her normative group and meet 'extreme' criteria according to the authors. Subscales: 1=Irritability, 2=Lethargy, 3=Stereotypic behaviour, 4=Hyperactivity, 5=Inappropriate Speech.

1.1 Levels of Achieved Independence (Table 3)

Table 3 presents qualitative indicators of level of independence achieved for each of the 14 adolescents studied, as described by their parents. This summarises information from the interviews such as living situation for their offspring, day, evening and weekend activities, and relationships including peer and whether they have ever been in a love relationship (had a boyfriend or girlfriend). Ten of the young people were still living at home. Two of the young people were in group homes, one was at residential college a long distance away and one was at a residential school.

The results suggest, not too surprisingly, that the more activities these young people are engaged in, the more opportunities they seem to have to make friends, except for one who had a diagnosis of Autism. Also of the 5 young people, who had been in a love relationship, four were not living at home or had lived away from home for several years. Three of the five young people who were engaged in the largest number of activities also had the highest Aberrant Behaviour Checklist scores. Two of these are 23 year old males who also need almost constant supervision. These two families despite significant service input and supported activities still reported very high stress (QRS-F) scores. The other two young adults in this group had a diagnosis of Downs Syndrome and need very little supervision. Employment for both parents was categorised using the Standard Occupational Codes (S.O.C., 1999) from the Department of Work and Industry. Parents who received the highest earnings appeared to have children who reached the higher levels of achieved independence.

Table 3 Participants 1-14: Levels of Achieved Independence

Participant number MO=mother FA=father	**Living Situation** f/t = full time p/t = part time	**Current Activities** f/t = full time p/t = part time	**Relationships**	
			Friendships	Boy/Girlfriend
MO1	Home	No outside activities and services	None	No
FA2	Home	Day Centre f/t	Very few	No
MO3	Home	College f/t + Work Experience + Regular weekend sport activities + Evening Clubs (4 x per week).	Very Few	No
MO4	Home	Day Centre f/t + Weekend Activities, Paid carer.	None	No
MO5	Home	Day Centre f/t	None	No
MO6	Group Home	Day Centre f/t	Few	Yes
MO7	Home	Day Centre f/t + Weekend Activities, Paid carer + Evening Clubs (3 x per week)	Few	Yes
FA8	Home *Hopes for weekly boarder at residential college*	Special School f/t	Few	No
MO9	Home	College f/t + Weekend Activities, Integrated Sat. Club + Evening Clubs (1 x per week)	Very Few	No
MO10	Home *Hopes for College.*	Special School p/t + Work Experience + Evening Clubs (2 x per week)	Many	No
MO11	Residential College f/t	College f/t	Few	Yes
MO12	Home	Day Centre p/t + Work Experience.	Few	Yes
FA13	Group Home	Day Centre f/t	Few	No
MO14	Weekly Boarder at Special School.	Special School + Work Experience + Evening Clubs (2 x per week) + Weekend Activities, church.	Many	Yes

2. *Qualitative Analysis of Interviews*

In the following section the qualitative analysis of the in-depth interviews with parents is presented. This part of the analysis aims to present a detailed account of the experience of being a parent of an adolescent with learning disabilities and how parents view and support their offsprings' engagement in adult activities, relationships and leaving home. The analysis also examines how parents cope with negotiating with services and, in particular, the move from child to adult learning disability services. Despite participants being recruited from two different services, the results from both were very similar. This was perhaps surprising as one borough had separate child and adult services and the other had a joint child and adult learning disability team. One would perhaps transition experiences to be more positive for the parents in the borough that had a joint service. Table 4 shows how these experiences have been organised into "Domains" and "Themes", in line with the principles and methods of Interpretative Phenomenological Analysis (Smith, 1999).

Table 4

Domains (Higher order Categories)	**Themes (Lower Order Categories)**
2.1 Parents' Experiences of Child's Puberty	2.1.1 Physical Characteristics and mood 2.1.2 Comparison with siblings 2.1.3 "Typical Teenager" 2.1.4 Challenges of Puberty
2.2 Moving from Child to Adult Services	2.2.1 Shock 2.2.2 Anger 2.2.3 Concerns 2.2.4 Positive Experiences
2.3 Hopes and Fears	2.3.1 Hopes for the Future 2. 3.2 Concerns about the Future
2.4 Independence	2.4.1 Relationships 2.4.2 Leisure Activities & Employment 2.4.3 Leaving Home

Domains are higher order categories and were largely determined by the areas covered in the interview and partly by what participants spontaneously spoke about. Themes are lower order categories and were largely determined by what participants spoke about and partly by the structure imposed by the interviewer. For example the themes 'shock and anger' are lower order categories and emerged from parents' experiences of 'moving from child to adult learning disability services', a higher order category. One way of understanding this distinction is by viewing domains as categories organised and driven by the interviewer and themes as categories whose organisation was driven more by the participants themselves.

Excerpts from the transcripts that appear in the results section have, in some cases, been edited to capture the most important information. Where material has been edited this is represented by three dots, "…". Where dialogue is presented, "I" refers to interviewer and "R" refers to respondent. Each quotation indicates which interview it has been taken from, MO representing mother and FA representing father, followed by the number (1-14) of that participant. These numbers correspond to the numbers in Tables 1, 2 and 3.

2.1 Parents' Experiences of Child's Puberty

This theme captures parents' experiences of their son or daughter's puberty. Frequently parents compared their child with learning disabilities to their other children. While they described many instances of being a 'typical teenager', they also noted significant differences which often could result in real dilemmas and tensions for both parents and their children.

2.1.1 *Physical Characteristics and Mood*

The interviewer indicated that puberty started when menarche began for females and when males began to shave. Parents felt puberty began earlier for their daughters, i.e. between 10 and 14 years and between 17 and 18 years for sons. This is similar to the general population. All parents mentioned physical changes such as the growth of body hair, the need to shave and periods.

I: So when do you feel puberty started for him?
R: About a year ago. I would have said just before Christmas last year. He would have been just over seventeen.
I: Some people say that starting to shave is the onset of puberty. Do you think that was the start of puberty?
R: Yes, I think it was with P. because he started growing body hair and started getting a really hairy chest and legs and things, so I think it probably was. **MO10**

Changeable moods were described by 5 of the 7 parents of daughters, which they linked with pre-menstrual tension.

R: I reckon she started puberty when she was about 11, but she actually had periods starting when she was 14, usual time, quite normal. But she hit puberty, God, with avengeance...She was a right moody cow when she, oh what a bitch, you know just like my eldest one. No different, no different to any other woman, all the same old problems. Typical teenagers! It was no different to her sister except worse. (laughs) **MO5**

Parents talked about seeing signs of frustration and anger in nearly all of the sons. This was frequently noted to start in their early teens and increase with age. Parents often attributed this to their sons' lack of verbal ability and the frustration they must feel.

He has grown and he looks older, but there hasn't been a lot of change as he's still very much like a young child. Except that he is growing up and he has all these screaming and temper tantrums. These have got much worse over the last couple of years. He might do this once or twice a day depending on his mood. Anything you might say just starts him off; he doesn't like being told off. At these times I now try to ignore him and he calms down after a while. I think he likes to get it out of his system, as he can't express himself in any other way. He puts his hands up and shouts out a lot and he just doesn't want to be disturbed. I think the main problem is his frustration. **MO4**

2.1.2 *Comparison with Siblings*

Generally parents felt that their children were very similar to their other children in the way they expressed puberty and being a "teenager". However obvious differences were also described. Differences were especially noted concerning masturbation by the sons and nearly all of the parents concerned raised this as a difficult behaviour to manage. Two parents also said their daughters masturbated, but guiding them to the bedroom or toilet had not been a problem. The embarrassment, fears (for e.g. masturbating in public) and humour in different situations were described by parents.

I: When do you think puberty actually started for him?
R: When he started masturbating.
I: And how old was he then?
R: About fourteen again. Maybe a little bit before. I found it very difficult at first, (a) because you're only just about coping, hanging on by your nails, and then (b) you think, 'Oh, for God's sake, not something else!' And that's a horrible way to be about something natural that gives pleasure... So, you know, you have to make sure he does it in his bedroom, because also I've got three girls in the flat. So now I have to stop going into the bedroom and, you know, we've had some serious incidences where he's had a fit and fallen out of bed and jammed himself but I can't go in and check in case he's in the middle because I've got to give him some privacy. You know, if you want to have a wank, have a wank. Maybe it's the nearest thing you're going to get. If it comforts you, boy, you do it. It's not a problem for me like that, I just feel sorry for him that he's never going to go on from that. You know, it would be normal with a normal boy and then he would progress to women or, men. But whatever. But that's not going to happen, so if he's got that, then good luck to him. **MO12**

It seemed poignant that this mother was quite convinced that her son would never engage in intimate relationships. This would clearly have psychological and emotional implications for both mother and son. In this case the mother is also faced with the dilemma of wanting to respect her son's privacy and her fears around his safety due to his severe epilepsy.

2.1.3 *"Typical Teenager"*

Three of the parents felt that there had been no change for their child during their teenage years, as they did not have any opportunities to rebel and engage in activities commonly associated with becoming a young adult, at least within a Western culture, for e.g. going to the pub and staying out late.

Things haven't changed a lot except of course that gradually her brother and sisters left home and these were difficult times for her. **MO1**

Parents also often expressed their intense sadness at their child's lack of opportunities and isolation from their peers and wider society.

I: So what do you think is very different about being a teenager for her?
R: The independence, the friends, she's isolated, that's the worst part for these young people, the isolation from normal society. Until we integrate fully in schools this is never going to change. Until there are no special schools and especially units, no specialist units and the people at the school gate are the same people she's going to see in the clubs. Sweden, eat your heart out. They've got it right. One of my son's friends couldn't believe that my daughter didn't have a normal life. He didn't understand why she didn't go to the youth clubs after school, didn't have lunch with them. He didn't even know what a special school was. Utopia... She has so much frustration and she'd see her brothers and sisters all going out, all dressed up to do things and it used to break my heart. **MO5**

Some parents talked about the difficulty of not associating all difficulties to their child's disability, but considering typical teenage changes as a cause.

You know she used to be really mega horrible sometimes. And a friend said to me, you know underneath all of that she really is just an ordinary teenager. But you tend to forget those things and because I had never got a problem with my other daughter...whereas X is a bit more fiery like me. And my friend she said to me one day I actually think that if X was a normal child, she would probably be quite fiery and she would be like you and she would, you know, be quite difficult, quite a strong character, which she is. But you see you forget all that. You don't see that at the time, you just see this problem child that has got this disability and everything is blamed on the disability... And I've thought about this a lot since and I've thought to myself she'd be a right little rebel if she was normal. If she was normal she'd be like "cor I'm not coming in at that time, no I'm not doing that and completely different from her sister." **MO7**

Nearly all of the parents felt that their child with learning disabilities was still very much a "typical teenager".

Exactly the typical teenager, going from one phase to another. The only thing he has left is staying out late and piercing his ears and his nose because he can't do it! **MO9**

Interests and activities described by parents were often quite similar and included: T.V. soaps, pop music, shopping, clothes, parties, sports and so on. Obvious differences between their children and teenagers without learning disabilities were also talked about.

There are little things, like when he was eighteen we went out to a restaurant for a meal and I said to him, 'Why don't you have a beer? You're allowed to now'. Whereas any normal teenager would be saying, 'Oh, great! Can I have a beer, Mum?' And he's going, 'No, I don't like beer. I want orange juice, thank you.'

So he's not really into things like…whereas a normal teenager can't wait to legally go out and be able to buy a drink. But he's not aware of that sort of thing. So things like that. **MO10**

2.1.4 *Challenges of Puberty*

Six parents talked about their offspring's need to start recognising their limitations, as they perhaps felt too independent. A dilemma was apparent for parents to perhaps continue to protect their children when they were showing a desire for more independence. One father talked about his son approaching everybody in the street with his new found confidence and desire to chat to different people. However the responses he received were often not pleasant as the public were often afraid of his advances and would respond in anger.

He's pretty much independent, and the older he's got, especially since he was eighteen, he's now saying to me: 'I'm going to go to school on my own, on the bus.' And I'm saying to him, 'P, you could do it, but let's not do it in the winter'. 'I'll take the torch, if it's dark,' he says. But it's more like, 'Well, I'm eighteen now, and I want to do everything on my own now'. And he does go out on his own…So it's little things like that. He's got to learn what his limitations are. He thinks he could just go out and rule the world on his own. And it's like, 'Well, I'm eighteen, why can't I do it?' **MO10**

Parents often talked about their own disrupted social lives and how inappropriate behaviours by their child, as they had got older, were becoming more difficult to manage in public. Their child's lack of understanding about sex and masturbation was a concern for several of the parents, especially those with sons.

A lot of things have happened that he doesn't understand. There is the sexual things, then he started feeling his body and it is an awkward situation. He can't really ask his brother. When you can talk, you can ask, you can tell friends. But with him, of course, it is very difficult. **MO9**

2.2 *Moving from Child to Adult Services*

The experience of transition was described in detail by all parents and the majority still clearly felt very strongly about the whole transition experience. The move from child to adult learning disability services appears to have been fraught with difficulties and evoked strong emotions for the majority of parents.

I. Did you really worry about the move from school?
R: Of course. The school is like an institution, like you have been in prison for all the years and all of a sudden, they open the doors and they tell you, you are in the big wide world, so you feel there is no life after school. When you are in somewhere for endless years and then you say Oh my God, what is after school?
I: And all the things you worried about, did it come true?
R: In school, you are so protected and all of a sudden they send you to the college where they tell you, you have to behave in a certain way and things are not acceptable and you have to integrate. Suddenly, from severely disabled school you are moving into an integrated life and it has not been done gradually. It is just in with normal people. You know, all teenagers are cool. They can make fun about them so it is really hard. **MO9**

Five of the parents felt that their transition experience into adult services had been generally good. They viewed this as linked with good, advanced planning and good school policies. Three of these parents were heavily involved in services for people with learning disabilities. For example one was a teacher, one ran a Mencap club as well as being on the committee at their child's special school and the other had a daughter who also worked, as a teacher in a special needs school. Three of the parents who felt the transition went well admitted to being very worried before, but with hindsight realised that this was unnecessary. Two of these parents also talked about their determination to fight to get what they wanted.

In the end he got a day centre place, after all the struggle. We wrote to the GP and the MP's and all of that to get heard. We wrote to explain our position, as we didn't know what to do. We got responses. I think the MP might have influenced something as we got a place in the end. We had to do that all in the end as it was getting out of hand. You have to fight, otherwise you are ignored. I think if it had been better planned it wouldn't have been such a fight. **MO12**

In contrast two parents felt that their transition experience had been very stressful and generally badly organised. In both these cases their sons were left with no services for six months due to waiting lists for respite care being closed and the local day centres saying they were full and did not have the resources to meet everyone's needs. Both parents talked about the terrible stress they were under at the time and how hard it was to cope with employment and the rest of their families' needs. Both of these parents said their reviews were too late and nobody took on the role of co-ordinator to monitor the transition process. Despite one of these parents having an allocated social worker they felt that this did nothing to ensure the smooth running of the transition process.

What we did have a problem with was when he was due to leave school and go to a daycentre, that was a fight. We had difficulties during the summer holiday about his care before he was due to go. We were told that he did not have a place there and no other options were given. In a sense as he was not offered a place at the Day Centre we had to ask for someone to spend some time with him. We got some help at home, but obviously we were being charged for it. We said to them if you can't provide a day placement then surely the alternative is they should provide some home care. Then they insisted that we pay for it and said due to staff shortages at the Day Centre they didn't want to take him or any school leavers on...It was awful. I said if you are not able to provide a service then there has to be an alternative. But apparently that was not the way it was supposed to work out. Then finally of course they said yes we will take him on in a few weeks. But I had to start my work as the school holidays were over, so I said no and I wanted someone to come and help. I tried to fill in as much time during the day caring for him because my father-in-law could not cope or manage by himself. So to relieve the pressure on him I paid for more care. And then of course they took him on and he went for just 5 induction days. At the beginning he had lots of temper tantrums and then finally he got used to going. We had a lot of problems though. I don't know whether it was the organisation of the school or the social workers or what. **MO4**

Eight of the parents talked about having to fight services in order to get what they wanted. These families felt that transition had both good and bad elements. However, they felt that the reason why everything had turned out well was purely because they were determined, had a good understanding of the system and therefore knew how to fight to have their and their child's needs met. Most of them said that they would have liked to have access to an individual within services that could support them.

> *I'm lucky because my situation is fairly good: I'm white, middle class, fairly well-off, able to access resources if I want, fairly articulate, and even I have a hard time. But it's nothing compared to other people. And I get so upset... I sometimes find I can't cope with the emotional strain over fighting for stuff for my son as well as looking after my other 3 and working. And I need people for support, who will actually say, 'Look, I'll do these enquiries'...And this is the sort of thing that families need.* ***MO11***

The four parents whose children were 18 years old and had not yet moved to adult services all talked about being concerned about not knowing what the future held. None of these families had an allocated social worker, which they felt would lessen their anxiety.

2.2.1 *Shock*

This theme was labelled as 'shock' as many parents utilised this term and it seemed an appropriate label of their experiences. Nearly all of the parents described experiencing a sense of shock during the move to adult services. Although four of the offspring were only 18 years old and had not yet transferred to adult services, three of these parents anticipated experiencing a sense of shock associated with the transition in the immediate future. This anticipation seemed to be partly from discussing their situation with other parents and partly because they were already feeling anxious about the imminent changes.

> *It's a big shock. And as many people know about it as about going to school, but there is a whole ground swell and expectations about going to school; and in a sense, because they're still yours, and a bit small, you go along and you're part of the process. Then, all of a sudden, adults don't listen to parents because they're adults. And there's things to do with capacity to consent.* **MO11**

The ethos, rules and expectations of services appeared to change overnight without preparation for the family or child.

She went to bed a child and then she woke up a woman and then the very next day went to a day centre. It was the same in school, she went from being a little girl to a big girl, overnight she was going to transfer to a different class, and it wasn't appropriate for her to have her pickles (dolly) in school and I said, and if you want the truth, bollocks she will have her pickles at school if she wants them. She didn't change overnight the rules changed overnight, not X, her needs were still the same as they were when she left school at 4 o'clock yesterday and her needs will be the same when she comes in today, so you let her take pickles with her. I've never ever compromised my daughter's needs for other people's rules. **MO5**

The move was a huge upheaval for the family and many felt their child was unprepared for being thrown from safe institutions to integrated life in the real world. Many parents, especially those whose children also had physical disabilities and complex health needs were astonished at the lack of handover to adult health services. Parents felt they often had to fight the system to simply receive services that for years had automatically been provided.

The transition was pretty awful really, because when you hit that sort of age, the funding thing starts to go out of the window and, once they don't have a legal obligation to provide you with anything, you've got to literally stand up and fight for it, and kick. **MO12**

Well you see you get this great shock when you go from you know, child services to adult services, you don't get all the things that back it up when you are in child services, you get this in child services, you get that in child services, but when my daughter needs a new walking frame ooooohhhhh (made out that's an unusual thing to be asking for). I rang the local hospital, the physio department to get her K-walker (a walking frame). So I rang them up and said I need to order a frame and they said we don't provide those. Well I said why not?
I: Until that point had they always provided the frame?
R: Yes, but of course she was a child then, but when you are an adult when you need one, then suddenly nobody knows what they are. **MO7**

2.2.2 *Anger*

Most parents expressed anger at the way transition between services was managed. One mother talked about her anger at the lack of clarity in the transition process and argued that the process needed to be more transparent and accorded much higher priority. She also highlighted the need to start the process even before the age of 14 years.

*R: Transition needs to be more prominent. It has to be more prominent. With children and families getting their act together more, even though they're still not there, there is an expectation on the part of the families and adults, in the next five years are going to get really hammered because you've got all these vocal parents with expectations and they are going to be hammered by the fact that a lot of these children are going to fall by the way because they don't meet the criteria. The process should be more transparent. There are several stages of transition which people don't realise. It's from when you first have a diagnosis, and then there's from home to nursery, less so from nursery to statutory schooling, then from primary to secondary is a major thing and these are the transition things, and also the group things. And that's what not recognised. So there's lots of transitions, but no one ever sees it because it's all statutory and you just go on the treadmill. And at the age of sixteen, you are suddenly dropped off the treadmill. And you think, 'What the f*** is going on?' Then they put you on another treadmill, which is very thin and you're going to fall off it anyway. It just wobbles a bit. And it gets wobblier from there on!... At least until then you've got the statutory stuff, and afterwards it doesn't become statutory and they just try and throw things at you willy nilly. And there's more people to deal with and a longer time-span. But I think transition should be well and truly established by the age of 14. You can't start at 14. The process starts at 14, but people have to be aware because we weren't aware of what the 14 plus was supposed to be and how important it was.* **MO11**

The changes in ethos and practice provoked much anger as parents felt adult services appeared less keen than child services on parental input and they were suddenly excluded. One mother talked about her experience of professionals assuming she was an overprotective mother as she asked them to hold her 18 year old son's hand while walking, despite her apparently sound reasoning for this.

He (social worker) said you've got to put X's interests first. Well, what do you imagine I have been doing all these years? What do you think? Don't talk to me like that. It's so insulting! Do you imagine I haven't been putting my son's interests first? What? I put my interests first? What am I doing? It's so irritating. You try to explain to these people how hard it is to manage...So they (professionals) said, 'We will just walk him to the corner of the road.' And I said, 'Well, make sure you hold his hand'. So he thinks I am overprotective? I don't know what he thinks. They walk along, he is not holding his hand, he *has a fit, falls down and cracks his head on the phone box. So you think, 'Listen to me because I know from experience what I'm doing.' I might not have always analysed why I am doing it, but probably because it works. I am not always aware of why I am doing things, but there is usually a damn good reason for it. But I don't need my son cracking his head open to prove a point.* **MO12**

Parents described a lack of communication within adult services and missing the close contact that schools generally kept with them. One mother talked about the anger at adult services when they refused to allow her daughter to use her walking frame as she might knock over other elderly users of the service.

So she went from school to the adult day centre and I said that you know she's got her walking frame and we need to keep her exercising because of her weight blah de blah. And then I'm told that all of a sudden, after she is now at the day centre, we don't actually think her walking frame is a good idea. Of course I just went ballistic, what on earth do you mean it's not a good idea? They said well we have got a few clients here that we are concerned that she is going to bump into, we have got one with brittle bones and we don't think it's a good idea that she uses her walking frame and blah, blah, blah. And so I said I'm very sorry, but you accepted her to come with her walking frame and I said this is not good enough. I said it's a bit like me turning round to you and saying well I am going to cut your legs off today, you can't have no legs, you've got to sit in a chair for the rest of your life. **MO7**

Parents described their anger at professionals, as they felt that they themselves were the "experts" when caring for their child. One mother said she refused to call them "professionals" as she had little respect for the majority of professionals, due to past experience. This same mother refused to accept her child's statement when she 14 years old as she felt it did not reflect the needs of her child. She interviewed again everyone involved, rewrote the statement herself and submitted it to the Education Department. Several parents talked about meeting their child's needs for life whereas professionals simply do it as a job. One mother was angry that her son had not even been referred on to adult services and when she contacted them they did not know he existed. Another family experienced a social services assessment as extremely intrusive for six months, due to numerous interviews and telephone calls, eventually resulting in no services or input.

At one point a friend said to me you need a social worker, so I wrote a letter and eventually a social worker came and his needs were assessed, which I thought was the most disgusting process I have ever come across. They intruded in our lives for six months. They interviewed me and my husband separately, all the children separately, and us as a family, and my husband and I as a couple. Six months process; they did this huge report, and at the end of the day, said they were closing the case. I was so incensed. **MO11**

2.2.3 *Concerns*

Some parents seemed aware in advance that adult services were deemed by parents to be less efficient than child services. Other parents talked about their experience of suddenly everything stopping at age 19.

R: It's like 14-19 we will be taking care of you, not everything, but at least some help and then, oh, sorry. You are 19; you are on your own now.
I: And did you know that was coming?
R: I was lucky, because the social worker started telling me. But however she prepares you for it, it was just a shock. And how can you prepare my son for that?
I started talking to him and that he will leave the school and he asked the question: 'Why? I do not want to go to a day centre, I prefer the school. And then he would call me on the phone from the day centre and say he wanted to come home, and why are you sending me there. It was very tough. **MO9**

Parents felt that resources were extremely limited and there was no one available to talk through their concerns.

The trouble is you are aware that you need more services, but there doesn't seem to be anybody that can help. It doesn't matter how many times you phone the duty social worker as they are different people every time and they just say they can't help and always seem to be in a hurry. There is nobody that knows you and your family that you can sit down with and simply talk through your worries. **MO7**

Two parents also felt strongly that the needs of their other children were never taken into account by services and that this was very unfair on them.

If you want to do anything innovative, forget it. Just the fact that I'm entitled to get the train fare reimbursed from picking him up at half-terms and at the end of terms. Yet when I said that I had three other children and to take them it was much cheaper and easier for me to go *up by car, social services were completely thrown by the fact that I said I wanted to get my expenses paid. And they said I couldn't. They simply ignore the fact that you are the sole carer for other so called 'normal' children. They soon won't be as services could drive me insane. They do little to help my son with difficulties and don't care in the slightest for my others.* **MO11**

Parents felt concerned that there was not a single person co-ordinating the experience of transition and felt like they were moving alone into what they described as "the great unknown". Many parents were aware they might need to fight for their child's rights and were also aware that they would be labelled by professionals as 'difficult'.

I shout at them (professionals)! I think I learnt years ago I am not in this to be popular. I don't particularly care if you think I am a raving lunatic or a difficult mother, or what the hell label you want to give me. I don't care. If I scream and shout and it makes you shift, I will scream and shout. I don't care what you think. It doesn't bother me any more. It used to, it's very difficult to change the attitudes you have been brought up with and to stand up to, you know,.... To my mother, doctors were gods. Whatever tablet they handed to you, you took it. I have now learnt there is good and bad in everything. And there is good and bad and you wait until you judge whether they are good or bad. You give everyone a fair shot and then tell them they are bad! [laughs] **MO12**

One parent described how having a child with learning disabilities had negatively effected her confidence and experiencing grief at every new transition point regarding what her child was unable to achieve. She said that each transition was therefore a vulnerable and difficult time for her as the limitations of her disabled child were again highlighted.

Your self-confidence is knocked when you have a child with special needs, and it doesn't stop, it goes on. You grieve for every developmental stage you either go through or don't go through because they're different from what you expect, the normal life patterns of other children. Other children go through developmental stages that he never does. And I grieve; though I don't necessarily know that that's what I'm doing. You know, you get angry, you go off the rails, you do all sorts of things. Children with special needs and disabilities cost, on average, three times more to bring up than a mainstream child. Then you've got the added burden that most families with children with special needs and disabilities are single parents. And all sorts of things like that. I'm sorry, I just get quite irate about it! MO11

This could possibly be linked with the apparent need for each parent to talk through the experience of receiving the diagnosis i.e. the first major transition, without being prompted by the interviewer. The impact of this experience was very clear.

You see when I had her I didn't know what Downs Syndrome was for a start and she was premature, they thought she wouldn't make it as she wasn't even seven months, she was less than that. That Dr. he always told me make sure you stick up for her, keep good for her and I think that was very good for me, as I didn't know anything about what a Downs Baby even looked like. And he knew it and I was streaming (mimed crying) and he came to my bed and even asked me when he realised and he said well she can stay here and you can come and see her, because there is nothing you can do she is being fed and they had everything round her head, you know tubes and stuff. **MO6**

Concerns were also raised about the lack of respite for the young person and the parent. Parents reported that, in many cases, they had found waiting lists for adult respite places closed due to over subscription. Parents also complained about the lack of other breaks, such as leisure activities during school or college holidays.

They (professionals) don't understand. These kids are 23,24, but the brain is still just a small child. They want good play schemes and they want to enjoy life. But after they are 19, they say, 'Excuse me, you are an adult now and we can't offer you anything'. **MO9**

This mothers use of the term "play scheme" (a term used by councils for 5-12 year olds) perhaps suggests that she still views her 23 year old son very much as a child. This again could reflect a possible conflict between parents and service perceptions. One mother talked about her concern that her daughter would be placed with others of an inappropriate age and would be vulnerable to exploitation and/or abuse.

I thought Oh my baby, with all those sort of you know inappropriate adults, inappropriate age groups and stuff. And I thought I can't have this, I was not impressed. I wasn't impressed that my beautiful daughter was going from children's to adult's and it's not age appropriate and lets face it in normal life you would not be in a room with a 50 year old man or woman you would be in your own peer group and that is the thing I object to very strongly. And I objected to that at School as well and I wasn't having her being touched up at the Day Centre by some, well young man old man whatever, because they think it's OK and there's all dark corners and so that's one of the reasons she didn't go there. **MO5**

Four parents talked about their sense that services seemed to want them to get to a crisis point before they would intervene. They stressed how much money parents are actually saving services by providing care, and juxtaposed this with the lack of respect and help they were given when they admitted they were not coping well.

Parents perceived services as unwilling to help unless they became sick or experienced a breakdown.

And parents, or carers whatever they like to call us, they're so unsung, and there's too little recognition of what they do, there is none. But we save the health service, we save society, we're out there saving millions upon trillions of money but no-one ever recognises it. "We must do something for the carers, they say". What? (laughs) What are they supposed to be doing, because I haven't seen it. You get invalid care allowance and that's it. Just go away and do it. MO12

2.2.4 *Positive Experiences*

Some parents admitted that their concerns, with hindsight were unnecessary.

My concerns were found to be unnecessary. The integration into her Day Centre regime was a happy one with happy relationships with peers, thanks to a good school policy. **MO1**

We chose for her to go to the college near Leeds as they came and did a presentation at the school and we attended all the presentations about her future. I was worried about the move, but it all worked out so well. **MO6**

He went to school until 19 and the social worker talked to us about the change. In the last year he used to go twice a week so he got used to it. I felt we had choices, but we just wanted him to go somewhere nearby. **FA2**

Most parents summed up contact with services and professionals as both good and bad at different times. Parents talked about professionals listening and being sympathetic, but not being able to follow through with immediate action, often due to a lack of resources. Most parents also felt that professionals attempted to understand what it was like for them, but that they could never fully understand unless they too had a child with learning disabilities. Several parents identified particular individuals who had helped them through difficult times, or conversely, left them feeling very unsupported.

Four years ago I lost the best social worker in the area, an autism specialist, as I was told she didn't need a social worker any more. How ridiculous, these people's difficulties don't go away. That social worker was fantastic and helped us get what we wanted. **MO5**

I: Have you ever had a social worker?

R: Not quite, I haven't really had one. Not in that way as I did things myself. You know that Dr. (Psychiatrist) he never put me down and said that's not good or told me my way was not right. He was really supportive. **MO6**

The changing over to day care services was also an issue, as at that time I had got a social worker who was absolutely useless. Up until that point I hadn't had a social worker for several years and I'd had this girl who was a community nurse, come psychologist, come social worker all rolled into one and she'd worked with children for many years and she was fantastic and if this girl said that she would get something done she would do it and get it sorted. Then she left the area and I was eventually given this social worker partly for the transition and leaving school as my daughter was 18. The social worker might as well have not taken on the case, as she was a complete waste of time. Prior to her starting I had already gone through the plans with the community nurse, we had gone through the motions of thinking where my daughter should go and had talked to the school about what was suitable and that and everyone had given their input. **MO7**

Several of the parents talked about how useful it was to receive a diagnosis, both in helping them to understand their child's difficulties and in accessing the right services when their child moved to adult services. For two parents their daughters received a late diagnosis of autistic spectrum disorder at 18 years old. Although at the time they were very distressed about feeling they had not met their child's needs fully for the previous 18 years, they felt it made finding appropriate specialist adult services easier.

2.3 *Hopes and Fears for the Future*

This domain covered parents' hopes and concerns about their children's future. Where possible the hopes and concerns will be contrasted with parents of non-disabled children as similarities and differences were apparent.

2.3.1 *Hopes for the Future*

All parents expressed hopes for their children's future, which were similar to those of parents of non-disabled children. One parent talked about wanting her son to find a suitable job and one parent talked about wanting her son to find a partner. However, while other parents may be hoping for their children to be successful in various areas, these parents' hopes seemed at times to focus on much more basic "human rights". In this vein many parents talked about wanting their children to be well looked after and treated with respect and dignity. Other parents' aspirations were very different to what you would expect from parents with non-disabled children. One parent talked about wanting more opportunities for his son such as simply being able to go swimming once a week. One mother wanted her son to have a 'calm mind' as his frustration, anger and constant swearing was limiting his ability to integrate into the community.

When talking about their "magic wishes" three parents stated that their main wish would be for their child to be 'normal'. This wish seemed to reflect more a wish for some form of solution to all their child's difficulties, rather than indicating a non-acceptance of the child's disability, or indeed the child.

I: If you had 3 magic wishes what would they be for his future?
R: I wish he could get normal, nothing else. This covers everything. If he was normal he could be independent and live a normal life. **FA2**

The majority of the parents talked about wanting their children to be happy and healthy and for many physical health was very important. Again this is what many parents with non-disabled children might say. One mother whose son has severe physical (including facial palsy) and sensory difficulties relating to a brain tumour talked about her wish to simply see her son smile.

I want him well, physically well. Physically well would do me. If he could smile. If I could see what he would have been before he got ill.[sighing]...To see him smile. Yes. Just that. That's all I would ever wish. You could give me six and a half million off the lottery, they're looking for a winner today, and I'd give it to you. Big lesson, big, huge lesson. Things aren't important. If I had the world, I'd give it to you to make him better, but that cannot happen. **MO12**

Two parents talked about their hope to be around for as long as possible, to ensure their children would get everything they need. This again seems to be related to hoping that their children's "human rights" would be met. One mother also talked about the need for her daughter to have an advocate once she could no longer take that role.

Number 1 She needs a representative to fight on her behalf, so she needs a social worker. Number 2 she needs security, not necessarily financial as that side of things is ok, but somewhere she can be safe and happy, her happiness is so important. Number 3 I think her happiness could be improved if more people asked, "why is she doing that?" No one addresses why she's doing things; they are more likely to ask how do we deal with it. I just want more people to ask why? **MO5**

Some parents talked in detail about their careful planning to ensure financial security for their child, such as making a will, ensuring that their other children have full control over the finances and that their money would not disappear in inheritance tax. These parents said they had worried about these things for years before they had formally organised their financial affairs in case of their deaths. Two parents talked about close friends who suddenly died leaving their children, including one with a learning disability, with no financial security and how this had caused the children additional trauma.

2.3.2 *Concerns about the Future*

Parents talked readily about their fears for their child's future. Many parents talked about their concerns about what would happen when they were no longer around to care for their child. Parents were concerned that their child should reach their full potential and that all their needs should be met. These concerns seemed quite different to how parents might feel about their non-disabled offspring. Although these parents may even think about the future in terms of their offspring making sure their parents needs were met. Two parents were especially concerned that their son's learning should continue throughout life and not suddenly end when they left college. Similarly some parents also worried that once residential college ended that their children would be forced to come and live back at home due to a lack of other options. These parents appeared more concerned about their children's levels of stimulation than the disruption to their own lives. In one case this had already happened and the mother concerned felt angry that her son had gone from being independent, living away from home with many friends and a girlfriend only to return to the family home. Eventually day activities were arranged for her son, but he could not access evening or weekend leisure activities due to the high levels of support he needed. The concern that services and education would suddenly stop is something that only people with a disabled child would be likely to face. For families without disabled children ongoing education and moving out of home long-term would both be options. All parents were concerned that the responsibility of caring for their child should not fall to their other children. Although they hoped that their children would continue to support their sibling, they felt that it was not fair to assume they would provide the same level of care as their parents had once these were too old or no longer alive.

Parents talked about being worried about abuse occurring in residential establishments and the fear around their vulnerable child's safety. This was a theme that was frequently mentioned by parents in relation to different topics. They felt strongly that their young adult was as vulnerable as a child, but the same level of protection was not available.

I: To your knowledge has she ever been involved in any sexual activity?
R: No and that is something that I worry a bit about. She is so vulnerable I am concerned for her safety as people could so easily take advantage of her. This would be my main concern if she went to residential accommodation where I could no longer keep a close eye on her.
I: Do you think you would feel the same about other people with learning disabilities?
R: I think everybody in the world is entitled to love and physical pleasure, but the trouble is depending on the person's ability level there is a fine line to abuse. I would worry if somebody say "normal" wanted a relationship with my daughter, as I feel this would be abuse.
I: Do you have worries or fears in this area we have not talked about?
R: No one has ever approached me or talked to me about these issues before. I don't have any problems with whether relationships are between two females or two males, but I do have a problem with abuse in relationships and I feel my daughter is very vulnerable to this.
MO5

In contrast to the majority of parents one father did not acknowledge having any concerns about the future. He said his son would find it extremely hard to go into a residential setting and he would have to visit every day for him to stay. This father lived alone with his son and was very committed to things staying that way. This father had taken early retirement to care from his son when he became divorced. Caring for his son had become his main focus and he admitted that he could not imagine his son not being around. He felt positive about the future as his son was at a good day centre and they were best friends.

All parents talked about their concern over the lack of preparation of their child towards independence. Several felt that although schools and day centres attempted to work on things like domestic skills, nobody worked on emotional maturity and understanding. For example, very few felt their child had been involved in Relationship and Sexuality Education and thought this was very important for the future. Parents often felt that important skills for independence such as managing finances would always be out of reach for their child. One parent felt angry at the way the respite care was managing the development of his son's independence. He felt that his son was left alone to carry out his own personal care as respite staff felt this was an important aspect of independence. However the result of this was his son came home unclean. His father felt that encouraging independence around friends and relationships was more important for his future, and this was even more unlikely to happen if he smelt bad and wore dirty clothes.

2.4 *Independence*

Three areas of independence were studied namely relationships, adult roles such as activities and employment, and leaving home. These three areas were chosen as they are areas which have been identified in the literature as key aspects of adolescence, yet areas where people with learning disabilities and their parents may struggle to move towards greater independence.

2.4.1 *Relationships (Friendships and Sexual Relationships)*

Friendships

Nearly all of the parents talked about their child's lack of friends. A dearth of leisure activities during the evenings and at weekends appeared to contribute to this and often parents felt they were unable to access the community. Another apparent difficulty was that parents were getting older and their young adult with learning disabilities no longer wanted to spend all their leisure time with their ageing parents. Parents were therefore finding it much harder to entertain their children during the evenings and at weekends, some described these as "the forgotten hours". One mother talked of her distress at the lack of her daughter's friends and the following quote perhaps highlights the difficult emotions evoked in her during her daughter's adolescence.

> *One day I sat there and I said to her, you've got friends and who are your friends and she said mummy, daddy... Well I sat there and I cried, I was so upset I really was, that's the first time I have actually cried, apart from when she was diagnosed and I was very upset, but that was more anger and frustration, but this was real sorrow. That my daughter was sitting there saying that we, her family, were her friends. We were all she had. I find that so sad, because she's not had anybody to volunteer to come and take her out or do anything for her, for the last four years.* **MO5**

Another mother talked about her sadness that all her son's closest friends had died in recent years. Due to his severe physical and sensory disabilities and unknown life expectancy he had tended to meet other young people who also had severe disabilities. For many of them malignant tumours had returned. His mother said that during the last year she had coped better by not asking why these young adults had died as it increased her anxiety about her son. Two mothers also talked about their children's distress when volunteers, keyworkers and carers had suddenly vanished, when they thought they were their friends. One mother expressed her sadness at her son's inability to keep friends. She thought this related to his poor social interaction skills, such as his tendency "to talk non-stop", which others found difficult to tolerate. He talks to her about being aware that he "gets on people's nerves" but is unable to understand why and gets frustrated and upset. Similarly another son had a habit of approaching people and pulling their hair, which made people react badly towards him and he was often hurt by their responses. Three parents said their children tended to gravitate towards adults and staff, possibly due to their difficulties with communicating.

In direct contrast with the previous parents, two parents felt their children had many friends, attended special schools, enjoyed work experience and attended several evening and weekend clubs. Understandably these parents seemed much more satisfied with their children's lives and opportunities. Both of them felt that they would not change anything if they could, as the support they were receiving was very good. One mother talked about a special relationship her daughter had with a severely disabled young woman.

> *There is one particular girl and she is in a wheelchair, but her care needs are much higher than my daughter (X). She can't do anything for herself, can't feed herself, she lays in one of those special chairs. But it was funny that X homed in on this girl and when she comes to the day centre X constantly takes care of her. My daughter is in her own wheelchair, but she will push her own wheels and then she'll get her into the right position. And then she will sit with her and hold her hand and she doesn't eat very well, but whenever she is with X it is always a day that she eats. So there is obviously a relationship, in their own way, I mean this other girl has no communication at all, but X will hold her hand and sit by her all day when she is at the day centre...They used to say to us, oh she's eaten today because your daughter has been with her so she has had a good day.* **MO7**

Sexual Relationships

11 of the 14 parents felt that their child was just as entitled to a sexual relationship as anyone else. Two parents felt so strongly about this that they had even considered getting a professional sex worker for their sons. All the parents said that nobody had ever spoken to them before about their views on relationships and sexuality and yet it was something they had spent time thinking about.

> *I did the parents' talk at the transition conference and I stood up and started talking about sex and people were uncomfortable about it. I said, 'My son is entitled to a sex life, but the big problem is there is HIV and Aids; there's sexually transmitted disease, there's abuse how does one manage all that?' People always remember me, because I always say stupid, outrageous things! I'm happy to talk about sex. I wish professionals and people around would be willing to. Nobody wants to talk about it and I need to...I want him to have sex, but I'm the mother of a son, not the mother of a daughter. And I can just imagine the implications. I can imagine him not getting a condom on, that sort of thing...plus the fact that I would like it to be a pleasurable experience for him...I have actually thought about should I get him a professional.* **MO11**

One mother said that although she hoped her daughter would one day have a sexual relationship she felt that her diagnosis of Autism may prevent this from happening, as it is hard to get close to her physically. One mother said she had spent quite a bit of time worrying about the possibility of her daughter getting pregnant and would like to talk through her options with somebody, but was not sure who to turn to. The same mother talked about a holiday when her daughter had thought a family friend was her boyfriend. She felt concerned that her daughter would be rejected and had told her it might be better to try and find someone else with Downs Syndrome. She did this by expanding on her daughter's knowledge about her "special differences" and how somebody else with Downs Syndrome would perhaps understand and love them more. Two participants felt that their daughters were of course entitled to have sex, but they were both concerned about the possibility of abuse.

Two parents (one mother and one father) did not feel that the issue of relationships and sexuality was relevant to them and their child as they felt their child was too severely disabled. They related this to the inability of their child to physically engage in a sexual relationship and their lack of understanding concerning sexual feelings. One mother said she was relieved her 23 year old daughter had not experienced a sexual relationship, as she was sure that she would find the experience "terrifying and distasteful".

2.4.2 *Leisure Activities and Employment*

All parents felt that more leisure opportunities are needed for people with learning disabilities. One mother said that all her son's evening activities had stopped when he was 19. By accident she met another parent who had children with learning disabilities. This mother and her husband were running a club for these young adults in the evening and she arranged transport for the other mother's son. He had been attending the club ever since and made many friends. His mother said that it was wrong that parents had to rely on chance meetings to get information about local activities. One mother talked about her son's love of watching sports on Sky and how she would love for him to do this with friends. She felt pubs were sadly unsuitable, as somebody would have to supervise and she and the other mothers had young children. The same mother said she did not mind what he did as long as he was occupied, rather than bored, and out of the house. She felt this was especially important as her son had already experienced living away from home and being more independent. 5 of the 14 young people were reportedly engaged in several evening and weekend activities. However the young man with the most activities was able to access these due to his mother dedicating her life to ensuring he was fully occupied. This resulted in her sacrificing every weekend in order to take him to activities and support him.

R: Saturdays he is busy the whole day. I spend the whole day with him as in the morning I take him to the leisure centre and there is a new club with his respite activity group. There are about 15 children there and from 11 to 11.45 for 45 minutes they do exercise. From 12.15 to quarter to one they do swimming. Then from 12.45 to 1.15 they play snooker. I then bring him home quickly at around 1.30 and he goes ball room dancing. So he goes to classes, which is another club, from 2.15 to 3.15. Every other Saturday there is a club under Mencap. That is alternate Saturdays. He is at this club until 4.30 after ballroom dancing. We come home after 4.30. So for the whole Saturday I follow him around and am just behind him. Sunday morning he goes to play badminton with his brother at the Social Club. Then in the evening he goes bowling again with Mencap which is just around the corner from here, Super Bowl. **MO3**

A few of the parents felt that transport was the main hindrance in organising evening activities. One mother had solved this problem by sharing the responsibility for providing lifts with several other families. Two parents talked about the difficulty of organising transport as their child was in a wheelchair. One mother described her repeated yet unsuccessful attempts to engage her daughter in suitable leisure activities, as well as her concerns about her daughter's safety.

I: Does she have any evening or weekend activities?
R: No she has nothing, which is what I am fighting for. I've got her name down for everything possible. For volunteers, anybody. And of course I have to lay myself open to all sorts of people that I don't know. And also I sometimes think that when you put too much demand for that kind of service that they could take in somebody who is inappropriate. The only thing is I find with adults that they don't feel the need to police check and my daughter is just as vulnerable as a five year old and if somebody is interfering with her, sexually or messing her brain up or abusing her in any other way, verbally or holding her up as an object of ridicule for the friends, how would I know, because she does not have the speech to tell me. So no the answer to that is she doesn't have any outside activities and I have been fighting for that since her last befriender left four years ago. **MO5**

Two parents talked about the possible benefits of having 'direct payments' in the future. They hoped that this government initiative would give them more control and access to better support and leisure facilities.

With regards to employment, half of the parents felt this was not applicable to their child due to their disabilities. All of these young adults were either at day centres or special schools full time and none of them had had any work experience opportunities. Two other young adults had completed work experience and attended college, but in both cases the parents felt work would be very unlikely due to the level of support they needed. Another concern was that the young person might not be paid and therefore taken advantage of, which made parents very wary of possible employment.

Four parents said their children had enjoyed their work experience and hoped they would find work in the future, although one of them stressed that she was more concerned about his lifestyle and where he might live rather than his "career". The same parents who were keen on their children working were also very keen to promote leisure opportunities, and leaving home in the future.

I: Have you got any thoughts for her, about work or other possibilities?
R: Yes, gardening is on offer for her for the handicapped. It depends a bit. In the next three years at college, they will give her every opportunity to try out things and then, where she shows interests and strengths, that is what they are going to say she can specialise...But she has had work experience now in the sixth form at the high school, first in laundry. She liked that very much. So, when we walk past the laundrette, she says, 'Mummy, I am going to work here!' Why not? In a way, these people, make life more simple. They don't have career ambition. As long as it is a right choice for you, you don't have to live up to expectations. **MO14**

2.4.3 *Leaving Home*

All the parents acknowledged how difficult the decision was to consider their child leaving home. Ten of the young people were still living at home - one of them had had to return home after his residential college placement ended at 21 years. One father talked about his mixed emotions when his daughter went into residential accommodation. Again the concerns related to vulnerability and abuse were raised.

Well, it was a mixture of feeling. I was concerned, obviously, at the beginning, because when you have a child, you tend to over-protect them and worry about them. It's exactly the same for my son. I mean, he's going to school and it's a long way to school and he's coming back late about 4.20 sometimes after four, it depends on the hours. So, if it comes to five o'clock, I have something to worry about. So it's exactly the same for her. It's a mixture of feelings that you have inside, is she going to be all right, but at the end of the day, she is well treated, she is well looked after. **FA13**

Another father talked about the huge sacrifice it would be for his family to send his 18 year old daughter away.

She is everything in our lives. She is everything: our happiness, even for my two sons, for me for my wife. She is everything. We cannot live without her, even one hour. But I was discussing with my wife the situation. I said, 'Look. I know we become older every day. I might die tomorrow; you might die tomorrow; you don't know. My boys might leave her when she becomes old. We have to discuss something for her life. She should be independent and we have to put her in this school because it is a very good school. We think we also have to do another sacrifice and we have to bring her on Friday and deliver her on Sunday. It will be hard for all of us. **FA8**

Three parents talked about how they don't like to think too long term so they either try not to think about the future at all or simply try to 'wait and see' and take each day at a time. One mother stated that she would go "crazy" if she even began to think about the future. One parent said that her religion helped her cope.

When she was born, I was horrified. I thought, 'This is not a life, this is a sentence for life!' I don't want to be a mother for life. When your children grow up, they say goodbye, and then they move on. But, of course, I've changed. I am a Christian and he (God) is changing me. **MO10**

One mother felt moving out of home would be 'a hell of a wrench' for her autistic daughter. She hoped that when her daughter left school within ten years she would be used to living away from home during the week, as by then her parents would be in their sixties. This mother was aware it would take a long time as her daughter refused to sleep in any bed except the one at home. At first she felt that professionals thought she was being ridiculous, but now 4 years on they agree, as her daughter still will not sleep in a bed at weekly respite care. Instead her daughter will stay up all night or sometimes lie on the floor in the lounge.

One parent said that her child would only go into care if her husband and herself could no longer cope. She said only then would her daughter leave home out of necessity, something that they "do not anticipate with any degree of pleasure". Another mother said she could not see herself letting go of her daughter until she died, but would then simply hope that her daughter would go into a Jewish home.

Parents whose children had already left home were satisfied with the care their children were receiving and were in frequent contact with staff. They felt that their children were receiving more opportunities than if they were still living at home, had more opportunities to make friends and to go out in the evenings and at weekends. All of these parents felt that residential placements had worked out well. The vast majority of the parents who still had their offspring at home said that nobody had discussed residential options with them.

CHAPTER 4

DISCUSSION

Overview

In this chapter the key findings of this study will be discussed in relation to the three research questions and the literature. The limitations and strengths of the study will be discussed and suggestions for further research will be made. Finally the implications of the findings for clinical practice and service provision will be considered.

Study Findings

This study aimed to explore 1. the experiences and views of parents in relation to moves towards independence by their adolescent son/daughter and 2. the experiences of service support during the adolescent period. As noted in the introduction, the study is very much based on a western perspective of 'independence' as a key marker of a successful move from childhood to adulthood. It is recognised that in some other cultures 'independence', as evidenced for example by leaving the family home, is valued much less than family and community cohesion. In discussing the findings any cultural differences with regards to parents' views will be reported. In addition, the study aimed to investigate whether a number of factors have an impact on parents' views, including the young person's level of functioning, challenging behaviour and family resources and stress. Throughout the author remains mindful of the nature (and limitations) of qualitative research and conclusions drawn will be treated as tentative, yet very important indicators in an under-researched area.

Research Questions 1 and 2 –

How do parents view moves towards independence by their adolescent son or daughter with learning disabilities and what are their experiences of service support during this period?

Based on the literature the researcher had expected that parents might be somewhat reluctant to discuss certain issues, for example their child's sexuality. In contrast, parents talked very candidly about even the most personal and difficult aspects of their experiences and their accounts were often charged with emotion. Their willingness to discuss their experiences and concerns with the researcher was perhaps not surprising in view of interviewees' frequent complaint that nobody had ever talked to them before about many of the issues raised during the interview. As such they may have perceived the researcher as a professional who was at last willing to listen, even if this would not result in practical outcomes. The finding that many parents, who have had very extensive contact with services, felt that nobody had taken the time to find out about their views and concerns in itself is very important. Unless services hear and understand what parents' needs and concerns are they are unlikely to ever work in true "partnership". In addition, in such a context notions of parents as "difficult" or "overprotective" which often pervade learning disabilities services can all too easily be perpetuated, without a good understanding of the motivations underlying parents' actions.

Parents' Investment in their Child

Every parent highlighted the huge investment they had in their children, both practically and emotionally. While this issue receives little attention in the literature, face to face with parents it was almost overwhelmingly evident throughout the interviews. This could perhaps lead to conflict with professionals who may fail to appreciate just how much emotional and practical investment parents have with their learning disabled children, even once these reach adult age. Many parents described instances when their intense love and concern for their child had led them to fight for their child's rights, frequently resulting in direct conflict with services. Several interviewees described how they thought they were perceived by others, particularly service providers, at such times, including as "aggressive", "stupid", "outrageous", "ridiculous", "demanding", "overprotective"- the list is endless. They seemed aware that they were at risk of alienating others and of being negatively labelled by services, but seemed to have accepted this as a "price worth paying" to assert their child's rights.

A few of the parents described how the first professionals they had contact with, such as the paediatrician, had told them they would need to stay strong and fight for their child throughout their lives. Parents often said that they had gradually become the fighters that they now were. After initially accepting what professionals had told them, parents appeared to have gradually realised that they were the "expert" on their child and with constant changes in service personnel there was no one person following the family and being aware of all of their needs. Several of the parents were employed in learning disability services and used their "inside knowledge" to get the best care for their children. Also several siblings had become involved with services providing care for people with learning disabilities, including training as social workers or special needs teachers. Ferguson et al. (1988) also found that parents were forced to become "experts" on learning disability services. This perhaps suggests that some parents become aware that people who are on the "inside" (for e.g. work for services), are more knowledgeable about services and are able to fight for better service provision.

The interviews suggest that parenting an adolescent with learning disabilities is by no means straightforward or that parental views can be easily categorised. Many parents seemed to experience new dilemmas once their adolescent son or daughter went through puberty - continuing to feel the need to protect their child, juxtaposed with their child's desire for more independence. It is possible that these dilemmas are similar for parents who have non-disabled children. However, it is likely, that parents who have a child with a learning disability perhaps feel a stronger need to protect their child due to their frequent concerns of vulnerability and abuse. Tension may arise from the tendency of parents to protect, or what services often perceive as "overprotect". The shock of adult services, lack of resources, lack of communication compared to child services and the change of ethos may all combine to raise parents' anxieties.

Vulnerability and Abuse

As one would perhaps expect vulnerability and protection from abuse were enduring themes for all parents and were raised at many different points during the interviews. Parents felt this was one of the major challenges of puberty, as they had to balance their concerns for their child's safety with the desire of the young person to become more independent. All parents raised vulnerability and the risk of abuse as a concern in relation to their child's future, especially when thinking about their son or daughter leaving home and no longer being around to protect them. Parents whose children had limited verbal abilities felt they were even more at risk, as they would not be able to let people know if they were being abused. Many parents talked about the possibility of abuse in residential settings and knew of examples where this had occurred. Concerns about vulnerability were also linked with employment and the possibility of their young adult being "taken advantage of". All parents also raised abuse as a concern associated with sexual relationships. Although the majority of parents said they were keen for their son or daughter to experience a sexual relationship, they were very concerned that abuse could take place, as well as contraction of sexually transmitted diseases and pregnancy. These concerns have been raised in several other papers (for e.g. Craft, 1994; Redmond, 1996).

For the parents interviewed this constant awareness of their child's vulnerability clearly acts as a barrier to more actively promoting and supporting their child's moves towards independence. Accordingly services may well need to pay much more attention to these fears and may need to find ways of reassuring parents more effectively. Failure to understand the intensity of parents' concerns about the risk of abuse is likely also closely related to interviewees' perception that services fail to listen to parents' concerns. An obvious practical improvement could involve making police checks for staff in adult learning disability services a legal requirement, rather than this only applying to staff in child services. Overall, service providers will need to think more broadly how to ensure that parents feel heard and that their concerns for their children's safety are responded to. At present there is impetus at national level to create more opportunities and choice for young people with learning disabilities (Department of Health, 2001a, 2001b). However, such efforts will often be fruitless if parents are too concerned about exposing their children to a significant risk of abuse to support them in taking up such opportunities.

Transitions and Life Cycle Theory

Transitions were highlighted as particularly difficult and painful times for parents in this study. The first transition raised was diagnosis and how traumatic this was for all concerned. With regards to the move into adolescence some parents talked about their intense pain and distress, which seemed to be associated with witnessing their child's lack of development and achievement of certain "adolescent tasks" or markers of a successful transition to adulthood. Parents often described their distress at the realisation that their young adult would never develop or have the same opportunities as others of their age. When talking about their children's sexuality and masturbation interviewees often expressed sadness that their child may never go on to experience a full sexual relationship. Many parents found thinking about their young adult leaving home very difficult to imagine and others simply wished their disabled offspring could say to them "I'm leaving home", like their other children.

One mother described her sorrow at her daughter having no friends and thinking of family members as her only friends. A lack of a social life was often linked to the limited leisure opportunities for young people with learning disabilities.

Beart et al., 2001 found that young adults with learning disabilities tend to take part in activities in day centre time, as opposed to genuine leisure time. Faced with a lack of safe and appropriate leisure activities, they most commonly engage in passive ways of spending time such as watching television, rather than more physically active leisure activities, which many of their non-disabled peers engage in (Messent, Cooke & Long, 1999). Adolescence seems to bring with it a further reduction in leisure activities for young people with learning disabilities- parents in this study often worried that as they were getting older their children were less likely to want to engage in activities with them. However, unlike their non-disabled peers many of the young people had no friends to spend their leisure time with and little access to leisure activities organised by services.

Qureshi (1995) described the post school period as a "crunch point" for families as a number of factors are likely to combine to increase the particular stresses upon parents giving care at home. For example, there is likely to be a decline in alternative sources of informal support as other children have left home and grandparents becoming elderly, perhaps even representing an extra demand. Due to the demands on their time as a result of caring for a child with disabilities parents are likely to be less well off financially compared to other families and their limited freedom negatively affects their social lives. Qureshi notes that, in addition, parents may face additional challenges in the aftermath of puberty- the young person is likely to have more physical strength, which can pose particular challenges with young people who also present with challenging behaviours, and sexuality may arise as an issue for the first time. As well as all these changes, families have to adjust to a whole new adult service framework.

Several authors have drawn on Family Life Cycle theory (Carter & McGoldrick, 1989) to understand the particular difficulties faced by families with a learning disabled member (Vetere, 1993; Goldberg et al, 1995). Carter and McGoldrick (1989) highlight that family stress is likely to be greatest during phases of transition between stages in the family developmental process. For families with a member with learning disabilities this can become even more complex as the transitions commonly experienced by families may be delayed or non-existent. Also when a member of a family has a severe disability the sequence of life events tends to be different to other families without a disabled member (Vetere, 1993; Goldberg et al., 1995). For example one of the sons in this study left home at 12 years old to attend a residential school but returned to live at home when he was 21 years old. The life-cycle stages therefore often occur in a different sequence to the one parents (and the young person) may hope for (Goldberg, et al., 1995).

It is perhaps during adolescence that transitions feel most out of synchrony for parents of a young adult with learning disabilities. For example the parent above was angry that her son left home when he was 12 years old and was forced to return when he was 21 years old due to lack of funding. Another parent in this study felt that the move to primary and secondary school felt okay, but leaving secondary school and entering adulthood was a very stressful upheaval for the family. Carter and McGoldrick view the beginning point for a new family life cycle as the stage of 'young adulthood'. They stress that this is a complex transition and involves the launching of a single young adult to eventually form a new family sub-system. For healthy development it is thought there need to be changes in the young adult's differentiation of self in relation to family of origin, a development of intimate peer relationships, and establishment of self in terms of occupation and financial independence. These areas have all been identified in this study as difficult changes for a young adult with learning disabilities to achieve. Difficulties in this process have been highlighted, such as parents encouraging continued dependency in their adult children out of a wish to protect them.

Recapitulation of Grief

A number of authors have highlighted the feelings of grief associated with a first diagnosis of a child's learning disability (Goldberg et al., 1995). Goldberg et al. (1995) suggest the initial feelings of grief over the loss of the hoped for "perfect child" may be re-evoked at subsequent transition points in the family life-cycle. Some parents talked about the grief they felt when they were given the diagnosis as they had lost the child they thought they would have. This is often referred to in the literature as the "perfect child" (Goldberg et al., 1995). At each major family life cycle it is thought that memories of previous loss and grief are remembered for each family member. Parents said that over the years their distress at the diagnosis had come at different times, especially transitions. None of the parents discussed how it effected other family members. Two parents adopted their children and they said they imagined their experience to be different to other parents as they had chosen to have children with learning disabilities. These parents did not talk about experiencing grief. There does therefore appear to be some evidence for parents experiencing recapitulation of grief.

Hopes and Fears

In discussing the hopes and fears of parents, one key question is to what extent these are similar or different to those of any parent. In this study many experiences and concerns described by parents are clearly very different to those of parents of non-disabled children. However, several of the parents' experiences concerning adolescence are strikingly similar. There appeared to be more similarities in parents' hopes for the future than parents' concerns for the future. Their hopes were similar with regards to, for example, wanting their child to find a partner and employment. Many parents in this study also talked in general terms about wanting their child "to be happy and healthy", which again is likely to be similar to the hopes of parents who have non-disabled children. However, in some respects the hopes of parents in this study seemed to centre more around basic human rights, than positive 'achievements' for their child. Several parents talked about wanting their child to be treated with dignity and respect and well looked after.

Parents' concerns about the future were frequently very different to what parents of non-disabled children might say. Fears around everything stopping at 19 such as education, college placements and even residential placements were very apparent. Interviewees also raised concerns about the lack of preparation for the future at school and the lack of focus on independence training. When it was carried out parents raised concerns over the way it was managed. This is likely to only be an issue for parents with disabled children as for other families on-going education options, leaving home forever and the gradual development of independence are more common. Also, as noted, parents in this study described intense fears about their children around vulnerability and the risk of abuse. This theme was much more common for these parents than one might expect for families without a disabled member, a finding which was also noted by Drury et al. (2000).

Sexuality

Parents talked openly about their child's sexuality, although all said they had never discussed this issue before with a professional. Craft (1994) stated that it is common practice for there to be no significant involvement of parents with professionals concerning the sexuality of their offspring. She suggests several reasons for this, namely either sexuality is seen as a non-issue, that is it is assumed to be irrelevant for people with learning disabilities, or it is seen as the exclusive province of either parents or professionals. Surveys of parental attitudes to the sexuality of their offspring are fairly consistent in their findings, although small scale (e.g. Kempton, 1979; Squire, 1989). Generally they note parental anxieties about the risk of being abused or exploited, daughters becoming pregnant, getting in trouble with the law (especially males) and about their child's frustration at not being able to achieve full sexual roles (Craft, 1994). In this study parents revealed similar anxieties, although none expressed concerns about possible conflict with the law.

Parents' willingness to discuss their children's sexuality and their frequently expressed wish that their child should experience a sexual relationship, stand in contrast to other studies which report that parents find it very difficult to think about sexuality, particularly if they have a child who is disabled (Drury et al., 2000). The findings of Drury et al. (2000) are perhaps effected by the fact their study was part of clinical work. However, this study involved confidential, lengthy, interviews separate from any clinical work. Finally, parents in this study were keen on Relationship and Sexuality Education, which is neglected in many schools when young people with learning disabilities are concerned (Craft, 1994).

Attitude surveys looking at professionals reveal a gradual change over the last two decades resulting in professional groups demonstrating a greater willingness to acknowledge and assist with the development of the sexuality of people with learning disabilities (Rose & Holmes, 1991). However despite this as stated before no parents in this study had discussed their concerns with professionals. Parents felt the subject had never been raised, but would welcome the opportunity to discuss their anxieties. Parents and professionals tend to work from very different time-scales, which may complicate how and when Relationship and Sexuality Education should talk place. Parents generally feel a deep and lifelong commitment to the wellbeing of their offspring and usually try to secure and approve a lifestyle for them to last beyond their own death. The time-scale for parents is therefore very long. It is perhaps not surprising that conflict sometimes arises between the short-term visions of a professional and the longer-term realism of a parent (Craft, 1994).

Experience of Services

Although the majority of parents talked about the difficulties they had experienced with services, they often said that their experiences were both good and bad. Two parents said that most of their dealings with services had been positive, although they were very aware of the lack of resources. Despite participants being recruited from two different services, the results from both were very similar. This was perhaps surprising as one borough had separate child and adult services and the other had an integrated child and adult learning disability service, incorporating health and social service professionals. In preparing the study the researcher anticipated that the experiences of parents in relation to adolescence and their child's transition from child to adult services would to be more positive for the parents in the borough with an integrated service. However, this was not evident in the results and perhaps reflects the different ethos between child and adult services (for example move from school to day centre) which can give rise to lots of difficulties and stresses, despite the integrated nature of the community learning disability team itself. This raises questions about the best way to structure services to meet parents' and service users' needs. Simply having joint learning disabilities services which cover the whole lifespan does not seem to guarantee that the move from childhood to adulthood is not marked with serious difficulties for the young person and their families.

Parents often talked about the sense that they needed to reach crisis point and have some kind of a break down before services intervened. This is very different to the apparent ethos and policies of services. Under current legislation the needs of children with significant learning disabilities, as one group of 'children in need' should be fully assessed and regularly reviewed, with greater support provided at times of increased need. However, the experiences of at least some parents in this study suggest that there is some way to go to ensure that services are needs led and preventative, rather than reactive to crisis.

Parents talked a lot about their feelings of anger towards services and how they saw themselves as the "experts" on their child's needs and care. All parents talked about their sense of "shock" in relation to the move to adult services. It is possible that this sense of "shock" contributes to parents feeling perhaps more anxious and therefore overprotective than they did before their offspring reached 19 years. Parents appear to lose faith in services after their child is 19 years old and are angry at the lack of opportunities, which often seems to stand in marked contrast to the range of opportunities offered during childhood. Several parents noted that the withdrawal of opportunities is especially difficult after their child had already experienced greater independence through school such as holidays, respite care, work experience and college placements. One mother, for example, was outraged that her son had had to return to live at home after experiencing an excellent residential placement full of opportunities and close peer relationships.

It has been suggested that where parents report low satisfaction with services this may be less a reflection of service efficacy, but more indicative of low expectations about services (Todd & Shearn, 1996b). This is very relevant for the parents in this study as they all seemed to have very low expectations about adult services and were aware of the lack of resources and therefore opportunities and choice. Despite being aware of limitations in adult services parents still described feeling "shocked" when actually involved with them. Todd and Shearn (1996a; 1996b) described parents with offspring with learning disabilities as either "captive" or "captivated". "Captive" parents are thought to be yearning for a post-parental lifestyle and are aware "of not being free". "Captivated" parents are thought to have a lack of awareness about alternative roles to parenting and free time is experienced as "waiting". It is thought that "captive" parents are more likely to be associated with higher levels of stress and anxiety. Most of the participants in this study fitted into either of these two categories and perhaps this provides some support for Todd & Shearn's model. Other parents did not fit neatly and seemed to fall in-between the two categories. For example one mother said she "sacrificed" her evenings and weekends to follow her son around and ensure that he was fully occupied. She also reported high stress levels and could be seen as a "captive" parent. A father talked about his life living with his disabled son. At no time did he suggest he wanted something different, appeared happy in his role and said his son was also his best friend. Stress levels also appeared to be low and this father could perhaps be thought of as a "captivated" parent. Todd & Shearn suggest that "captive" parents have more negative outcomes (e.g. higher stress, anxiety and depression) and "captivated" parents more positive outcomes. One needs to be cautious when suggesting that stress results from parents' attitudes and perceptions towards their role, as there are many other factors to consider. Todd and Shearn's research does not go as far as exploring the impact of this on parents' offspring.

Research Question 3 –

What factors have an impact on parental views and experiences in this area?

This question attempts to identify whether there are any mediating factors which influence parents' views and attempts to support their child in developing greater independence. Factors which were considered as potential mediators include parent and family factors, such as family resources and stress, marital status, employment status, ethnicity, presence of siblings, and child factors, including age, level of functioning, presence of challenging behaviour and any diagnosis.

Overall parents were more likely to want to explicitly encourage activities, friendships and sexual relationships than perhaps leaving home. Although several of the parents had managed this many felt there was a lack of safe options and they would find it incredibly hard to accept that their child had to go into a residential placement. Often this was again linked to the theme of vulnerability and abuse, for example in relation to mixed sex group homes with residents of all ages.

Levels of stress and challenging behaviour

Six parents had very high levels of stress and their child exhibited high levels of challenging behaviour, which were positively correlated i.e. the higher the levels of challenging behaviour the higher the levels of stress. Perhaps surprisingly the young adults with high levels of challenging behaviour also had many activities and comparatively good levels of achieved independence. Only one of them was at residential college, which indicates that the higher levels of opportunities were not simply the result of the setting. It appears that the higher the level of challenging behaviour the greater the service input which enables the young person to be supported in talking part in many evening and weekend activities which in turn provides respite for their families. However despite this high level of input, parental stress levels still remained high.

Levels of Supervision

The level of supervision needed for each young person did not appear to effect achieved levels of independence. The seven young people who needed the least supervision ranged from achieving high levels of independence through to very low levels of achieved independence. The same was true for the seven young people who needed the most supervision. This is perhaps linked with the above finding as even when a person needs constant supervision they may still have a high number of evening and weekend activities, including work experience.

Age

The young people who appeared to have the highest level of achieved independence were the youngest in the sample. All the 18 year olds had the highest independence levels, they were often living away from home in residential placements, participating in work experience and reportedly had many friends. People with learning disabilities are largely dependent on formal daytime and leisure activities to form and maintain friendships. This explains why some of the young people had no friends. The young adults aged between 21 and 25 years generally appeared to be less independent. This ties in with parents' views that services become very limited and opportunities for independence minimal. There is also much evidence that the vast majority of young people with learning disabilities live at home perhaps limiting their independence (Department of Health, 2001).

Diagnosis

No clear patterns emerged concerning diagnosis and level of achieved independence. However, the presence of physical disabilities seemed to have an impact on parents' views. In this vein, parents whose children had physical disabilities, for example related to Cerebral Palsy, were not particularly concerned about future employment opportunities, feeling that this was not relevant to their child. It is possible that these parents are underestimating their child's capabilities. However the amount of extra support required for people with physical disabilities is frequently not available and these parents are fully aware of this.

Ethnicity

Research into disability within minority ethnic communities has tended to focus on physical disabilities and on South Asian communities (Mir et al., 2001). Research has revealed high levels of isolation for families and high levels of carer stress, low up-take and poor access to services, high levels of unmet needs and receipt of lower amounts of benefits amongst family carers of people with learning disabilities from ethnic minorities, compared to white families with similar needs (Mir et al., 2001). Consideration of the concept of "independence" is obviously problematic in a multi-ethnic context, given that as previously noted many cultures do not share the Western emphasis on "independence". According to Mir et al. (2001) there is a tendency for service providers to assume that a Western approach is shared and understood by people from all ethnic groups. "An understanding of independence that emphasises individuality may run counter to the values of collectivism and close family relationships that exist in some communities. The role of family and community networks needs to be taken into account when planning services for individuals" (p. 37). Several barriers to independence have also been highlighted for people from ethnic minority communities such as education and employment resulting in limited choices and low expectations (Mir et al., 2001).

The participants involved in this study were originally from a variety of different countries and cultures. Six of the participants were White British and one was White Irish. The other seven participants were Black African, Black Afro-Caribbean, Asian, Middle Eastern or Mediterranean. Despite this there appeared to be little difference in parents' views and levels of independence achieved by their off-spring. Although this study looks at the transition to adulthood by drawing on two very Western concepts, namely "adolescence" and "independence", the highlighted factors seemed to be of importance and relevant to all the parents involved. Four of the parents interviewed said they had left their country of birth, because of the birth of a child with learning disabilities. These parents said that their families had had to make a huge sacrifice in order to get the needs met for the person with learning disabilities. They felt that Britain offered more opportunities to receive better education and they hoped higher levels of independence for their offspring.

This study does not appear to find evidence for the key findings in the literature related to ethnicity. Perhaps this suggests that although the issues highlighted in the literature are very important, service providers should exercise great caution in assuming that they reflect the experiences of all families with a member with learning disabilities. It is possible that being a parent of a child with learning disabilities is already alienating, which results in parents fighting for their rights. Perhaps during these intense struggles with services cultural differences become minimised, as it is apparent that the struggles span all cultural groups. However some of these families may also experience additional racial discrimination.

Marital Status

Although marital status appears to have no effect on independence it possibly has an effect on levels of stress experienced by parents. Three of the parents in this study were single as a result of divorce or being widowed. These parents also had the highest stress scores. Marital status alone does not automatically ensure less stress as the quality of the relationship has also been found to be important. Intimate relationships have been found to be a major source of support in buffering the effects of stress (Flynt et al., 1992). Friedrich (1979) conducted a study of 98 mothers of children with handicaps, of whom about 50% had a learning disability, and found that marital satisfaction was the best overall predictor of coping behaviour. In this study all the parents who were married talked about the responsibility for their child, including the frequent difficult decisions, being shared with their partners. Only the parent who had been very recently widowed talked about missing her husbands input.

Presence of Siblings in the Family

Four of the young adults being discussed had a sibling who was regularly involved in taking them on activities. For example two of the young people had siblings who regularly went bowling with them. One young person regularly went to the pub with a sibling. Another one played sports every weekend with their sibling. Those who had a sibling involved in their care were more likely to access more activities and therefore achieved higher levels of independence. However, having siblings alone does not appear to affect the independence of a young person with learning disabilities- it is the sibling's regular involvement in joint leisure activities that is the deciding factor.

Involvement of Family Members in Learning Disability Services

Many of the families who had a member with a learning disability had become quite heavily involved in the learning disability system. Generally it appeared that the young adults who had a parent or sibling directly involved with services were more likely to have achieved greater levels of independence. Of the young adults who had achieved the highest levels of independence four had a sibling or mother who was a special needs teacher, the mother of another one was a manager of a respite service for people with learning disabilities and for another young person both parents ran clubs and took people with learning disabilities on summer holidays and trips. These families also tended to have accessed the highest numbers of activities at weekends and in the evenings. They had often fought services to have their children's needs met and, not surprisingly, generally seemed better informed about what was available and what they were entitled to. Clearly the families who were closely connected to the services had better information and therefore perhaps better access to resources that enabled their young adults to achieve high levels of independence.

Material Wealth

Both parents' employment details were collected. It was very apparent that more material wealth and spending power had a high impact on achieved levels of independence. Research has suggested that families with a disabled child are more likely to be low wage-earners and to have limited opportunities for overtime and job mobility (Parker, 1990, cited in Malin, 1995). Research has also revealed that families from south Asian communities with a member with a learning disability are living in circumstances of material disadvantage to white families (Beresford, 1995, cited in Hatton et al., 1998). Chamba et al. (1999) also noted that inequalities in income mean that the financial impact of caring may be even greater on minority ethnic families. In this study parents who had good education and employment and lived very comfortably (this was often very apparent as interviews took place in people's homes), were more likely to have offspring who achieved high levels of independence. Again this is perhaps linked to being able to access information. This finding is very important when thinking about how services prioritise resources and highlights the important needs of families who have low incomes and are supporting a person with complex needs. Services need to be more proactive and ensure that resources are allocated fairly on the basis of need, rather than privileging those families who are better informed and better at stating their needs. This is clearly a difficult task and perhaps services need to first record and recognise which families get large amounts of support and how this comes about.

Strengths and Limitations of the Study

This study explored an important, but under-researched area. There is much literature looking at parents of younger children with learning disabilities, but very little looking at those with adolescents. It is also important in light of the recent Government White Paper (Department of Health, 2001b) that highlights the needs of these parents and their offspring. Interviewing both parents would have strengthened the study and this was initially considered. However due to the time limit for the project this was not feasible. The majority of interviewees said their partner's views on the issues discussed would be the same as theirs. However, one mother interviewed said she was quite satisfied with services and her faith in God helped her remain strong. After this interview the researcher had the opportunity to speak to her husband who presented as much more angry and frustrated with services. He said the majority of the fighting and paperwork involved in their appeals against service decisions had been completed by him. For this family in particular interviewing the father as well as the mother would have revealed quite different experiences.

In addition to in-depth interviews, this study used three quantitative measures in an attempt to identify factors, which may mediate parent's views and experiences in this area. Due to the small numbers involved these results have been treated tentatively, but they do point to some useful areas for further research (see later section). 160 parents in total were asked to opt into the study and every effort was made to get a cross section of the population. The sample of parents who eventually participated seemed to recognise the value of research and several of them were involved in the learning disability system, possibly resulting in a biased sample.

Furthermore, in preparing the study the researcher was concerned that in expressing their views about their child's independence, parents might tend to express socially desirable views, or the types of pro-independence views they might expect a psychologist would want to hear. However, the researcher felt that this was not the case- parents appeared very open and honest throughout the interviews and expressed strong views, which were often critical of professionals and services.

Generalisability of the Findings

A major limitation of qualitative studies is the small sample size, which restricts the ability to generalise the findings to a more general population. The parents interviewed in this study raised many areas of concern about the obstacles for their children in developing their independence and the move from child to adult services. Although it is likely that other parents would raise similar issues and concerns, this cannot be assumed. However, it should be noted that interviewees expressed a balance of good and bad experiences with services and there was wide diversity of views about their offspring's independence. Despite this diversity, some concerns were raised by nearly all interviewees, suggesting that these may be common concerns for most parents of adolescents with moderate or severe learning disabilities. These included: the desire to have the opportunity to discuss concerns with professionals; concerns about their child's vulnerability and abuse; shock and anger at adult services; and limited opportunities for leisure and further education.

Despite the fairly small number of participants the sample comprised of both fathers and mothers, in contrast to most studies on children with learning disabilities, which usually only gather mothers' views. Also their offspring comprised of a broad range of diagnoses and a comparative number of daughters and sons. A further strength of this study is that the sample was ethnically diverse, again in contrast to other studies in this area (e.g. Redmond, 1996). The young adults had moderate or severe learning disabilities, except one with mild learning disabilities. Therefore the results are clearly more applicable to the parents of young people with moderate or severe learning disabilities. While the parents of adolescents with mild learning disabilities may share many of the views and concerns expressed by parents in this study, due to their child's less severe disabilities one might expect different hopes for the future and possibly less conflicts with services, due to lower support needs.

Evaluating Qualitative Methodology

Several authors have looked at evaluating qualitative methodology such as Elliott et al. (1999), Smith (1996) and Stiles (1993). Elliott et al. (1999) have developed a set of useful guidelines, which can be used when carrying out qualitative research. These guidelines were developed in an attempt to control the quality of studies using qualitative techniques, and arise from a recognition that the concepts of reliability and validity utilised for all quantitative research are not as easily applied to qualitative research. Elliott et al.'s guidelines will now be used to reflect upon this study.

Owning one's perspective

It is useful to be aware of the author's theoretical and personal experiences, as they are likely to become apparent during the research. When developing an understanding of the participants' experiences and communicating these, it is important to attempt to recognise the author's own "values, interests and assumptions and role that these play in the understanding" (Elliott et al., 1999 p.221). This was done by describing the author's previous experience in the field under investigation (see 'Researcher's Perspective' p.36). It must also be recognised that a researcher's perspective is not a fixed entity and as new data emerges, the perspective will change as this information is incorporated. This process is thought of as 'reflexivity' and considers the impact of the research on the researcher and therefore on the research process. In the very first interview the researcher was struck by the participant saying that nobody had ever spoken to them before about any of the issues, many of which were highly sensitive. Also early on a participant cried when reflecting on issues around adolescence and how they coped. The impact of this was for the researcher to work even harder on establishing rapport and sensitivity and ensuring participants were warned about the possibly difficult content of the interview. At least four hours were set aside for each interview so that interviews did not have to end abruptly. All the interviews were highly emotionally charged for parents and a moving experience for the researcher. When analysing the results the researcher was mindful of this and made every effort to take one step back from the intense emotions present during the interviews, to be able to think about the wider meaning of interviewees' accounts.

Situating the sample

This points to the need to describe research participants in detail to help aid the reader's understanding. In this study extensive descriptive data was provided about the participants' life circumstances (see Table 1, p.46). Quantitative measures were also used to give information about the adolescents' levels of functioning, levels of challenging behaviour and family resources and stress.

Grounding in examples

It is important in qualitative studies to offer specific examples, such as quotes, for each theme. In addition it is useful to provide a summary of themes utilised throughout the report. This enables the author to illustrate the analytic procedures used during the study and the understanding that has emerged from them. Quotes were used throughout the results section to bring life to the themes presented.

Providing credibility checks

Elliott et al. (1999) suggest several methods to check the credibility of categories and themes. It can be very useful to check understandings with the original participants. However, it was felt that parents had already devoted many hours to the project and this method would be too time consuming. Instead two colleagues, with extensive experience of working with people with learning disabilities and their families, looked over the analysis and supporting data. Any corrections or suggestions were incorporated into the final report.

Coherence

It is important that any understanding of a phenomenon is represented in a way that "achieves coherence and integration while preserving nuances in the data" (Elliott et al., 1999, p.222). This study aimed to integrate all the experiences of parents into a coherent summary, while doing justice to the diversity of views and experiences that emerged.

Resonating with the reader

This reflects on the hope that upon reading, the researcher's categories and overall narrative of the experiences of these parents supports the reader's understanding of the area being studied. This means that aspects of the researcher's own experience, such as recognising the shock and anger parents had experienced at times, but also clarifying the general experience has been achieved. Ultimately the author would hope that the reader might think about the themes when engaging in clinical work or service planning, if relevant.

Areas for Future Research

The present study has provided a summary of the views and experiences of parents in relation to their adolescent son's or daughter's moves towards greater independence. It has also highlighted several areas of concern, which merit consideration by services. The findings point to some further areas where it would be useful to increase our understanding through further research. As noted the present study predominantly used an in-depth qualitative methodology to explore an under-researcher area. It would be very useful to follow some of the findings in more large scale research which would allow more generalisations. In particular, in the present study a number of factors were found to have little or no impact on the views of parents and their children's levels of achieved independence, including levels of supervision, diagnosis, ethnicity and marital status. Higher levels of challenging behaviour by the young person appeared associated with higher stress levels in parents, but interestingly seemed to have if anything a reverse impact of levels of achieved independence, in that these youngsters seemed to be more engaged in daytime, leisure and weekend opportunities, due to higher levels of service support. These findings are certainly worth investigating further as they suggest that many young people may not be able to reach the higher levels of independence they and their parents desperately hope for, not least due to inequitable provision of service support.

In this context the suggestion in the present study that families of higher socio-economic status and with direct involvement with learning disability services tend to receive more support, regardless of the apparent needs of the youngster, if not surprising, certainly raises some important concerns for services. At present most services monitor equability of access only in relation to service users' ethnicity- these tentative findings should be investigated further and may well suggest that services should consider factors in addition to ethnicity, particularly socio-economic status, in deciding whether access to services is equitable.

In contrast to previous research which has highlighted the very different experiences of family carers from ethnic minorities (e.g. Hatton et al. 1998) in the current studies no clear differences in relation to cultural background emerged. This is certainly worth investigating further. Hatton et al. (1998), for example, highlighted that many family carers of people with learning disabilities from South Asian communities experience very elevated levels of stress and a general lack of information about their rights and services. In the present study these seemed to be important concerns for most parents, not only those from ethnic minorities. Further research should investigate whether adolescence may present as so challenging and stressful for most young people with learning disabilities and their parents and cultural differences may perhaps be minimised during this period.

Clinical Implications of the Study

Although the Government clearly aims through the recent White Paper to give more choice to consumers and to foster independence, this seems to sit uneasily with their accompanying view that services should aim to maintain the contribution of informal carers and therefore reduce demands for expensive residential care. Perhaps this dilemma also effects the amount of information made available to parents concerning their rights, whether intentionally or inadvertently. Parents with children with learning disabilities appear too often to be ill informed about their rights, which in turn perhaps reflects upon the reality that resources are not adequate to meet the needs of every family. A key theme, which emerged in this study, was that of parents feeling unheard or not even asked about their views or concerns. If honest and open communication does not take place the value of any support given is greatly diminished (Drury et al., 2000). In sharing their hopes and concerns with others, parents need to know that they are being heard and supported. Parents also want to know that they are being believed and that if there is a constructive way forward that professionals will fully include them in finding it. The present study suggests that these processes are rarely in place. It would therefore seem vital that services should identify and implement strategies aimed at ensuring that parents are given more regular and useful opportunities to talk about their concerns. In addition, services should evaluate whether any changes have the desired effect and result in more true "partnership" as part of evaluation of routine clinical practice.

It is also important that professionals are able to respond appropriately to the range of emotions experienced by parents and which, if anything seem to intensify during their children's adolescence. Parents in this study suggested that at times they want an "open ear", not necessarily solutions. One mother, for example, was incensed that after simply raising her thoughts abut the future with a social worker, she received a letter suggesting that she was unable to cope and (wrongly) suggesting that she wanted full time residential care for her child. Parents also wanted to be able to voice their concerns without the fear of being labelled "difficult" or worse. Services perhaps need to create opportunities throughout childhood and adolescence of a person with learning disabilities, for their parents to talk openly about their feelings and concerns. While there is always the possibility of accessing counselling or therapy parents may feel this pathologises their experiences. It may therefore be important to create more opportunities, for example during the already structured transition planning process, to enable parents to make themselves more heard and talk about concerns close to their hearts. This was also highlighted by Ryan (1997) whose qualitative research found that transition planning frequently does not focus on issues parents of adolescents with learning disabilities want to focus on.

The majority of parents in this study expressed anger towards services, usually on the basis of previous negative experiences with services. Reder & Fredman (1996) suggest that both clients and professionals bring to the relationship with each other beliefs about the "helping process" and that these beliefs can significantly influence the outcome of treatment. They suggest therefore that these issues are dealt with at the point of referral. If parents approach services with anger and negative expectations, similar to those of most parents in this study, there is little hope for good partnership. In this context suggestions made by Reder & Fredman in exploring clients' "relationship to help" before embarking on providing services would seem very useful. A recent paper by Donati et al. (2001) presents a useful example how learning disability services can benefit from taking on these ideas.

Practical Suggestions

Several parents raised practical issues that would have helped them cope better with the transition to adult services. Many parents talked about the difficulties they had with endless paperwork and the need for assistance with this. They felt the whole transition process needed to be more transparent and information presented more clearly to parents at an earlier stage. The majority of parents felt that access to one person who could co-ordinate their needs would have been very useful. As noted earlier, parents also talked about the need to discuss concerns with professionals, even if not wanting immediate action

An improved hand-over needs to be in place between child and adult services. Parents felt if the transfer was discussed as a matter of course much earlier this might prevent individuals slipping through the net and being left without services. Services also need to be aware of the huge change in ethos between child and adult services and how shocking this can be for parents. While the need for more integration between child and adult services has been recognised as a priority at national level (Department of Health, 2001a, 2001b), the current findings suggest the reality at local level may be very different. Also, this study suggests that simply creating more integrated services will not necessarily mean that young people with learning disabilities and their families experience the transition process as relatively smooth. The accounts of parents in this study suggest that there are many aspects to the transition, not just support from child development and community learning disability teams, which need closer integration.

On a more specific note, parents raised concerns about the way in which services communicate with them, indicating a lack of sensitivity towards parents' feelings. A few parents expressed their annoyance when different services write to them to say they are "closing the case". Although parents were aware that this is needed on file, they felt the wording needed to be changed as they could never "close the case", as their child's needs would always remain.

Parents were also keen that it should become a legal requirement that staff in adult learning disability services are police checked. They felt their young adults were as vulnerable as children and the lack of police checks caused them much concern. Concerns about the risk of abuse seemed to be a significant barrier in parents' efforts to support their child's moves towards greater independence. It is perhaps too often assumed by services that parents are simply "overprotecting" their children and "acting as barriers" to independence. However, the parents in this study clearly stated their desire for more independence, but concerns for their children's safety seemed often to get in the way, as did a severe lack of resources.

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Research looking at parents' experiences of caring for their adolescent offspring.

My name is Helen Turner and I am a Trainee Clinical Psychologist in my final year at University College London. I have several years' experience of working with people with learning disabilities and have especially enjoyed meeting and working with families.

I am really keen to find out more about parents' experiences of caring for their adolescent offspring with learning disabilities. I am also interested in parents' experiences in dealing with services and professionals during this time. I will use the findings to inform services and professionals how they could possibly improve their contact with parents and what is going well.

I AM LOOKING FOR ANY PARENTS WHO HAVE A SON OR DAUGHTER WITH LEARNING DISABILITIES (WHO MAY OR MAY NOT BE LIVING WITH YOU), BETWEEN THE AGES OF 16 AND 25 YEARS.

If you decide to take part it would involve filling in three short questionnaires concerning your child and for me to come and interview you at home at a time convenient for you. There would be no way of identifying you from the information collected and you would be free to withdraw from the study at any time. The project is separate from any service input you currently receive and your decision to take part, or not will not affect the services you receive now or in the future.

Thank you for your time in reading this and I really look forward to speaking with you.

Please ring me (Helen) on 07799 640019 so that we can arrange a convenient time for me to visit you at home.

5 November 2001

Miss H Turner
51 Hove Avenue
Walthamstow
E17 7NG

Dear Miss Turner

Ethics Submission No 2878: Parents' views of moves towards independence by their adolescent offspring with learning difficulties

The above project was approved by the Research Ethics Committee at its meeting on 5 November 2001. It would be appreciated if, in any future correspondence relating to this project or in any entry made in case-notes about procedures undertaken in the course of this study, you would refer to it as **EC 2654.** ***Please note that, before you can proceed with the study, you will need to obtain formal authorisation from the NHS institution where it is to be undertaken.***

If this was a MREC approved project, consideration was restricted mainly to the suitability of the local researcher; the suitability of the site; the suitability of the subjects; and local aspects of the patient information sheet and consent form.

Set out overleaf is the REC membership list which should, if applicable, be copied to the sponsoring organisation.

General Practitioners should be kept informed of research work affecting their patients, particularly when the patient's involvement continues after discharge from hospital.

All adverse events arising during the course of this study should be notified, but please note that the Committee is only concerned to receive such notifications as they relate to subjects participating in trials . Investigators undertaking trials on behalf of drug companies are asked to refrain from sending other adverse event reports, unless there are very exceptional circumstances.

The Committee operates according to GCP in most important respects.

Yours sincerely

NHS

9 November 2001

Ms Helen Turner
51 Hove Avenue
Walthamstow
London
E17 7NG

Dear Ms Turner

LREC Ref: 01/85
Title: Parents' views of moves towards independence by their adolescent offspring with learning disabilities

I am pleased to note that the Local Research Ethics Committee has recommended to the Trust that there are no ethical reasons why your study should not proceed.

Projects are registered with the North London Community Research Consortium if they utilise patients, staff, records, facilities or other resources of Community Health Services NHS Trust or Mental Health NHS Trust. On the basis of the documentation supplied to us, your study has the support of the clinical service manager/assistant locality director of the service in which it will be based.

This Trust therefore grants permission to undertake the research, as stated in the study protocol. This permission is only valid concurrently with the appropriate ethical consideration for this study. This approval is therefore subject to the conditions set out by Community LREC in their letter of 9 November 2001. Should you fail to adhere to these conditions, then the Trust would consider your approval to undertake research to be invalid.

As part of the implementation of the Department of Health Research Governance Framework for Health and Social Care I am required to bring to your attention your responsibilities under the framework. Appendix A to this letter outlines responsibilities for principal investigators; appendix B for local investigators and other researchers. Principal investigators should bring the responsibilities outlined in appendix B to all those in their research teams.

All researchers undertaking research within the Trusts are also reminded of their duties and responsibilities under the Health and Safety at Work Act 1974. These are also contained in Appendix B to this letter.

Further information on the research governance framework for health and social care can be found on the DH web pages at http://www.nhsetrent.gov.uk/trentrd/resgov/govhome.htm. Staff working within one of the Trusts can also find the information on the Trust Intranet.

This approval is subject to your consent for information to be extracted from your project registration form for inclusion in NHS project registration/management databases and, where appropriate, the National Research Register and the UCL Clinical Research Network register.

Except in the case of commercially funded research projects, the following acknowledgement and disclaimer MUST appear on all publications arising from your work.

"This work was undertaken with the support of Mental Health NHS Trust, who received [insert "funding" or a "proportion of funding"]* from the NHS Executive; the views expressed in this publication are those of the authors and not necessarily those of the NHS Executive".

* "a proportion of funding" where the research is also supported by an external funding body;

* "funding" where no external funding has been obtained

This is a requirement of the contract between the Trust and the NHS Executive in which the Trust receives funding to cover the infrastructure costs associated with performing non-commercial research.

Please make all members of the research team aware of the contents of this approval. I wish you every success with your research.

Yours sincerely,

Parents' views of moves towards independence by their adolescent offspring with learning disabilities

Semi-Structured Interview Schedule

Instructions for interviewer: Replace x with name of adolescent. Also wherever possible incorporate the participant's choice of terminology and modify questions accordingly.

Background information and orientation to interview

- Can you tell me a bit about yourself and your family?

Prompts: Who lives in the house? What jobs do parents have? Ethnicity? Age of Carers and x? Do you have friends and family around you? Any contact with similar families? What is the general daily routine? Does x have any diagnoses?

- When did x start puberty? (i.e. for girls - time of first period, for boys – when started shaving)
- What have things been like since x reached puberty?

Prompts: Have things changed much? For x? For each parent?

- (If other children in family): Was age of start of puberty different or similar to other children?
- How much of the typical teenager do you see in x?

Prompts: what do you think is different about being a teenager for x? Is x very different from others of the same age?

- Is/was parenting x during the teenage years similar to or different from other children?

Prompts: What was it like? How was it different?

- What are the challenges? What are the positives?

UNDER EACH TOPIC AREA ASK ABOUT SUPPORT FROM SERVICES/PROFESSIONALS. WHAT HAS SUPPORT FROM SERVICES BEEN LIKE DURING THIS PERIOD? Clarify from outset the type of services. (e.g. x leaving school/in run up to leaving school? In setting up daytime activities? In setting up evening activities? Do you think your views have been listened to? What happened when your and x's views differed? What happened when yours and the professionals views differed?)

Area 1: Adult Roles (employment, leisure)

1. (If left school): What age did x leave school? What has x done since? What were your hopes and concerns in the lead up to x leaving school? What were your partners hopes and concerns? Have these been borne out?
   (If still at school): What are the hopes and concerns for the future? What are the plans?
2. What does x do during the day? . What are your thoughts about x's daily activities?

Prompts: choice, hopes and concerns about future?

3. Evening activities – What does x do during the evenings? (Enough? Too much? Too little?) If any activities could be accessed what sort of activities would you want?

Prompts: hopes and concerns about future?

4. Does X have any hobbies or particular interests?

Prompts: daytime/evening activities? hopes and concerns about future? Where does x do these things and who with?

5. Is x in paid or supported employment? If yes, what are your thoughts about x working?

Prompts: hopes for future? Opportunities? Level of support needed?

Area 2: Leaving home & the future

1. Where does x live? (If away from home): Where and for how long? What prompted this? How do you feel about x living away? Hopes and concerns before x moved out? Were these borne out? How does x feel about living away? How was it when x came back?
2. (If at home): Has x lived away at any point and if so, for how long? What did everyone involved make of this period away? How was it when x came back?
3. Do you think about the future much for x? What do you want for your son/daughter in the future?

Prompts: Do you have any thoughts concerning x learning more independence skills? Do you feel x is being prepared / has been prepared for life away from the family?

4. Support from services during this time? (e.g. support in run-up to leaving home, in thinking about and planning for future?)
5. Do you feel professionals understand what it is like for you?

Area 3: Relationships (parent-child, peer, sexual)

1. How would you describe your relationship with x? Between x and other family members?

2. Can you tell me a bit about x's friends?

Prompts: people with/without learning disabilities? carers e.g. day service support workers? family members? Who are their closest friends? How many friends right no./too many/ too few?

3. Does x have opportunities to make new friends? Where? *Prompt: how do you feel about this?*

4. Does x have a boyfriend/girlfriend (or ever said that they have one)? If no, has x ever said he/she wants a boy/girl friend? How do you feel about this?

5. To your knowledge has x ever been involved in any sexual activity? How do you feel about this?

6. Do you think you would feel the same about other people with learning disabilities? What makes the difference? (level of disability? diagnosis? age? sex?).

Prompts: Do you hope x will experience a sexual relationship one-day? How would you feel about a partner with similar level of functioning/without learning disabilities?

7. How would you feel if x told you he/she wanted to get married? Have children?

8. Do you have any worries or fears in this area we have not talked about? *Support from services?*

Prompts: Have they wanted help from services i.e. advice, information or practical help? Experiences? What would they like from services? Is this available?

9. Did your relationship with x change when s/he became an adolescent?

Area 4: Role of services

1. During x's adolescence have you had much contact with services for people with learning disabilities? *Prompts: what type of professionals have had contact with the family? Specialist services?*

2. Could you describe your experience of contact with services? *Prompts: Have you felt understood/listened to? Have you received what you wanted? If not, was contact useful anyway?*

3. Who would you turn to if you needed help/support with x over the next few years?

4. If you had three magic wishes what would you want for x's future?

Instructions for interviewer:

Obtain feedback on how they found the interview. Say how interesting it has been to talk to them and thank them for their time.

INSTRUCTIONS

The ABC–Community rating scale is designed to be used with clients living in the community. Please note that the term *client* is used throughout to refer to the person being rated. This may be a child of school age, an adolescent, or an adult.

Please rate this client's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behavior is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging this client's behavior, please keep the following points in mind:

(a) Take relative *frequency* into account for each behavior specified. For example if the client averages more temper outbursts than most other clients you know or most others in his/her class, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.

(b) If you have access to this information, consider the experiences of other care providers with this client. If the client has problems with others but not with you, try to take the whole picture into account.

(c) Try to consider whether a given behavior interferes with his/her *development, functioning*, or *relationships*. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item — your first reaction is usually the right one.

1. Excessively active at home, school, work, or elsewhere	0	1	2	3
2. Injures self on purpose	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other children or adults (verbally or physically)	0	1	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3

11. Stereotyped behavior; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behavior	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression; lacks emotional responsiveness	0	1	2	3

21. Disturbs others	0	1	2	3
22. Repetitive speech	0	1	2	3
23. Does nothing but sit and watch others	0	1	2	3
24. Uncooperative	0	1	2	3
25. Depressed mood	0	1	2	3
26. Resists any form of physical contact	0	1	2	3
27. Moves or rolls head back and forth repetitively	0	1	2	3
28. Does not pay attention to instructions	0	1	2	3
29. Demands must be met immediately	0	1	2	3
30. Isolates himself/herself from other children or adults	0	1	2	3
31. Disrupts group activities	0	1	2	3
32. Sits or stands in one position for a long time	0	1	2	3
33. Talks to self loudly	0	1	2	3
34. Cries over minor annoyances and hurts	0	1	2	3
35. Repetitive hand, body, or head movements	0	1	2	3
36. Mood changes quickly	0	1	2	3
37. Unresponsive to structured activities (does not react)	0	1	2	3
38. Does not stay in seat (e.g., during lesson or training periods, meals, etc.)	0	1	2	3
39. Will not sit still for any length of time	0	1	2	3
40. Is difficult to reach, contact, or get through to	0	1	2	3
41. Cries and screams inappropriately	0	1	2	3
42. Prefers to be alone	0	1	2	3
43. Does not try to communicate by words or gestures	0	1	2	3
44. Easily distractible	0	1	2	3
45. Waves or shakes the extremities repeatedly	0	1	2	3
46. Repeats a word or phrase over and over	0	1	2	3
47. Stamps feet or bangs objects or slams doors	0	1	2	3
48. Constantly runs or jumps around the room	0	1	2	3
49. Rocks body back and forth repeatedly	0	1	2	3
50. Deliberately hurts himself/herself	0	1	2	3
51. Pays no attention when spoken to	0	1	2	3
52. Does physical violence to self	0	1	2	3
53. Inactive, never moves spontaneously	0	1	2	3
54. Tends to be excessively active	0	1	2	3
55. Responds negatively to affection	0	1	2	3
56. Deliberately ignores directions	0	1	2	3
57. Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3
58. Shows few social reactions to others	0	1	2	3

RESOURCES AND STRESS QUESTIONNAIRE

- This questionnaire deals with your feelings about your son/daughter.
- Please give your honest feelings and opinions.
- Please answer all of the questions, even if they do not seem to apply.
- If it is difficult to answer True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time.
- Sometimes the questions refer to problems your family does not have. These questions can still be answered True or False.
- Please answer all of the questions.

THANKYOU VERY MUCH FOR THE TIME YOU HAVE SPENT FILLING THIS IN

PLEASE CIRCLE "T" OR "F" FOR EVERY QUESTION	TRUE	FALSE
1. ______ doesn't communicate with others of his/her age group.	T	F
2. Other members of the family have to do without things because of ______.	T	F
3. Our family agrees on important matters.	T	F
4. I worry what will happen to ______, when I can no longer take care of him/her.	T	F
5. The constant demands for care for ______, limit growth and development of someone else in our family.	T	F
6. ______ is limited in the work that s/he can do.	T	F
7. I have accepted the fact that ______ might have to live out his/her life in some special setting (i.e. group home).	T	F
8. ______ can feed him/herself.	T	F
9. I have given up things I have really wanted to do in order to care for ______.	T	F
10. ______ is able to fit into the family social group.	T	F
11. Sometimes I avoid taking ______ out in public.	T	F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress.	T	F
13. It bothers me that ______ will always be this way.	T	F
14. I feel tense whenever I take ______ out in public.	T	F
15. I can go and visit friends whenever I want.	T	F
16. Taking ______ away on holiday spoils pleasure for the whole family.	T	F

17. _______ knows his/her own address.	T	F
18. The family does as many things together now as we ever did.	T	F
19. _______ is aware who s/he is.	T	F
20. I get upset with the way my life is going.	T	F
21. Sometimes I feel very embarrassed because of _______.	T	F
22. _______ doesn't do as much as s/he should be able to do.	T	F
23. It is difficult to communicate with _______ because s/he has difficulty understanding what is being said to him/her.	T	F
24. There are many places where we can enjoy ourselves as a family when _______ comes along.	T	F
25. _______ is over protected.	T	F
26. _______ is able to take part in games or sports.	T	F
27. _______ has too much time on his/her hands.	T	F
28. I am disappointed that _______ does not lead a normal life.	T	F
29. Time drags for _______, especially free time.	T	F
30. _______ can't pay attention for very long.	T	F
31. It is easy for me to relax.	T	F
32. I worry about what will be done with _______ when s/he gets older.	T	F
33. I get almost too tired to enjoy myself.	T	F
34. One of things I appreciate about _______ is his/her confidence.	T	F

35. There is a lot of resentment in our family.	T	F
36. _______ is able to go to the bathroom alone.	T	F
37. _______ cannot remember what s/he says from one minute to the next.	T	F
38. _______ can ride a bus.	T	F
39. I is easy to communicate with _______.	T	F
40. The constant demands to care for _______ limit my growth and development.	T	F
41. _______ accepts him/herself as a person.	T	F
42. I feel sad when I think of _______.	T	F
43. I often worry about what will happen to _______ when I can no longer take care of him/her.	T	F
44. People can't understand what _______ tries to say.	T	F
45. Caring for _______ puts a strain on me.	T	F
46. Members of our family get to do the same kind of things other families do.	T	F
47. _______ will always be a problem to us.	T	F
48. _______ is able to express his/her feelings to others.	T	F
49. _______ is able to use a toilet.	T	F
50. I rarely feel blue.	T	F
51. I am worried much of the time.	T	F
52. _______ can walk without help.	T	F

CAREGIVER INFORMATION QUESTIONNAIRE

The CIQ asks questions about a disabled child's skills, participation in daily life, problem behaviours and progress.

Answer questions in a way that reflects how things are, rather than how they might be if the situation were different. For instance, if a question asks how well your child feeds himself/herself? and you think that your child does this very poorly, please say very poorly, even if you believe your child could do the behaviour better if he/she wanted to or with more enforcement.

THANKYOU VERY MUCH FOR THE TIME YOU HAVE SPENT FILLING THIS IN

The Child's Traits

For each of the following questions, please state the letter of the best answer.

The answers are: A = Very often
B = Fairly often
C = Not too often
D = Rarely or never

1. How often would you say your child is happy?
2. How often would you say your child is sociable?
3. How often would you say your child is affectionate?
4. How often would you say your child is co-operative?
5. How often would you say your child is soothable and easy to calm down?
6. How often would you say your child is hyperactive?
7. How often would you say your child is angry?
8. How often would you say your child is confused?
9. How often would you say your child is demanding?
10. How often would you say your child is sad?
11. How often would you say your child is withdrawn?
12. How often would you say your child is destructive?
13. How often would you say your child is irritable?
14. How often would you say your child is frustrated?
15. How often would you say your child is aggressive?

How the Child Performs Functional Tasks and Takes Part in Everyday Life

For each of the following questions, please state the letter of the best answer.

The answers are: A = Does very well, needs little help
B = Does fairly well needs some help
C = Does poorly, needs much help
D = Does very poorly. Needs a great deal of help
E = Cannot do this

16. How well does your child feed himself or herself?

17. How well does your child use the toilet?

18. How well does your child wash his or her hands and face?

19. How well does your child put on or take off one piece of clothing, such as pants or jacket?

20. How well does your child dress himself or herself?

21. How well does your child respond when familiar persons greet the child to try to get the child's attention?

22. How well does your child use language to talk about things that are going on?

23. How well does your child use language to talk about what is bothering or hurting him or her?

24. How well does your child use language to communicate what he or she wants?

25. How well does your child imitate things that you or other people show him or her how to do, such as holding or stacking something or throwing a ball?

26. How well does your child play appropriately by himself or herself?

27. How well does your child play appropriately with others?

28. How well does your child go to bed at night?

29. How well does your child put things back where they belong when he or she is finished with them?

30. How well does your child clean up his or her place at the table after eating?

31. How well does your child do simple tasks you ask him or her to do, such as getting something?

For the following questions please circle the letter giving the best answer.

32. How often would you say that your child is skilful in doing everyday tasks?

A = Very Often
B = Fairly Often
C = Not too often
D = Rarely or Never

33. How well does your child make simple food, such as a sandwich or bowl of dry cereal?

A = Does very well, needs little help
B = Does fairly well, needs some help
C = Does poorly, needs much help
D = Does very poorly, needs a great deal of help
E = Really cannot do this

34. How often would you say that your child is interested or involved in activities in the home?

A = Very often
B = Fairly often
C = Not too often
D = Rarely or Never

35. How much interest does your child show in family activities, by paying attention, listening, or going to where the activity is happening?

A = Shows a great deal of interest
B = Shows some interest
C = Shows a little interest
D = Shows very little interest

36. How often does your child take part in everyday activities, such as chores?

A = Almost always takes part
B = Frequently takes part
C = Sometimes takes part
D = Rarely takes part

37. How well does your child take part in activities outside the home (e.g. going shopping, behaving in a restaurant, visiting other people's houses or playing on a playground)?

A = Does very well, needs little help
B = Does fairly well, needs some help
C = Does poorly, needs much help
D = Does very poorly, needs a great deal of help
E = Really cannot do this

38. How well does your child fit in as a regular member of the family?

A = Fits in very well
B = Fits in fairly well
C = Does not fit in very well
D = Does not fit in at all

39. How often does your child try to co-operate with requests (e.g. coming when called, trying to do as you ask)?

A = Almost always tries to co-operate
B = Frequently tries to co-operate
C = Sometimes tries to co-operate
D = Rarely tries to co-operate

Child's Problem Behaviour

For each of the following questions, please state the letter of the best answer.

The answers are: A = Not much of a problem or no problem at all
B = Not a great problem, but is occasionally troubling.
C = A problem and is often troubling
D = Definitely a problem
E = Does not apply (e.g. does not perform this behaviour.

40. How much of a problem do you have with your child biting, kicking or hitting others?

41. How much trouble do you have with your child's bedtime routine?

42. How much of a problem do you have with your child breaking or damaging things?

43. How much of a problem do you have with your child making messes, such as throwing things around?

44. How much of a problem do you have with your child throwing tantrums?

45. How much of a problem do you have with your child's eating habits?

46. How much of a problem is your child's running or wandering away?

47. How much of a problem is your child's yelling or screaming?

48. How much of a problem do you have with your child's self-injurious behaviour, such as biting or hitting himself or herself?

49. How much of a problem is your child's whining?

50. How much of a problem do you have with your child doing strange things, behaviour, such as rocking or flapping hands?

51. How much of a problem is your child's inappropriate toileting, such as messy bowel and bladder habits?

How Much Supervision the Child Needs

For each of the following questions, please state the letter of the best answer.

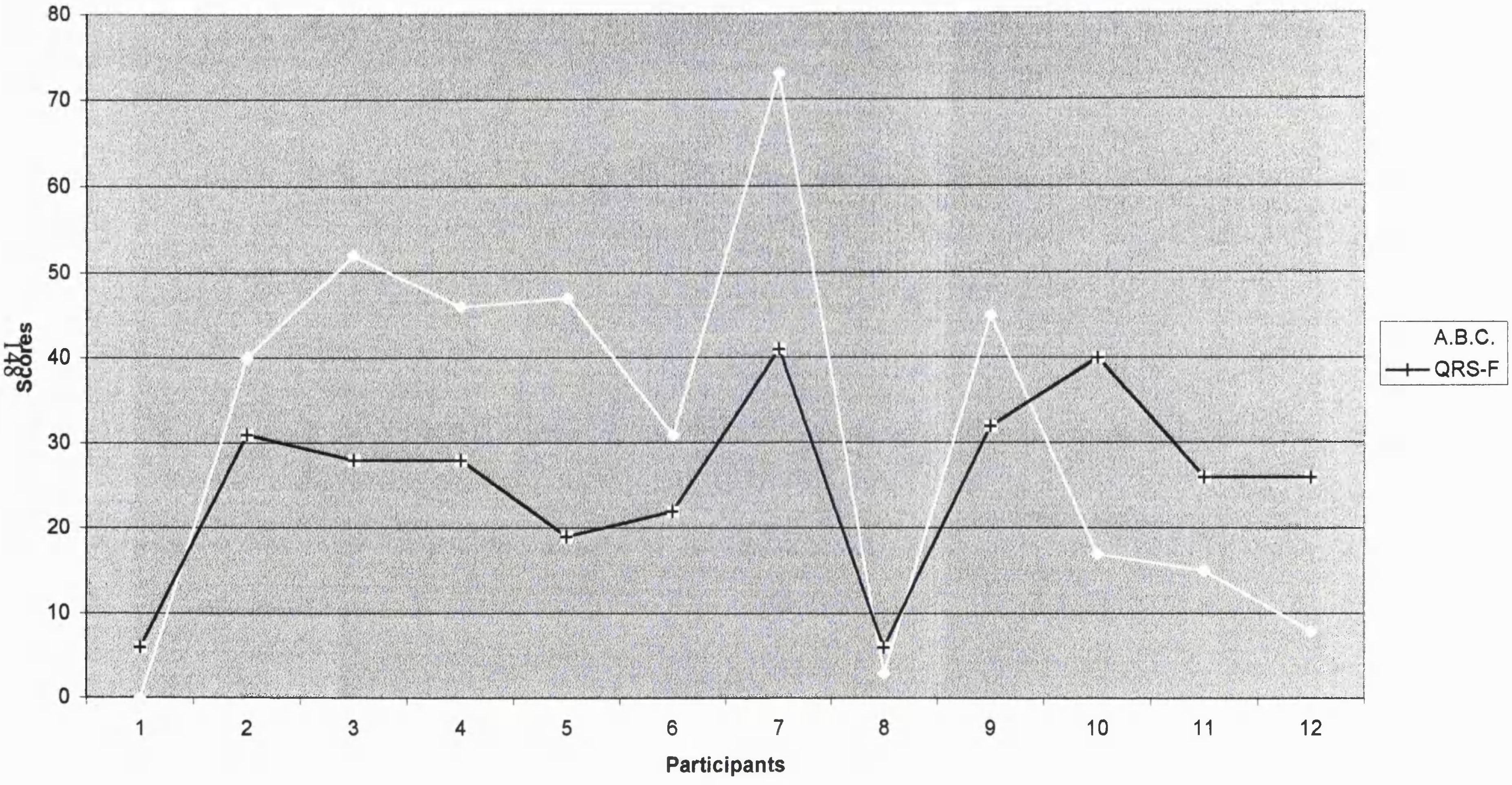
The answers are: A = Almost constantly
B = Most of the time
C = Some of the time
D = Very little

52. How often does your child need supervision from 6.00a.m. to 5.00p.m.?

53. How often does your child need supervision from 5.00p.m. to 10.00p.m.?

54. How often does your child need supervision from 10.00p.m. to 6.00a.m.?

Line Graph of scores on Aberrant Behaviour Checklist (ABC) and Questionnaire on Resources and Stress (QRS-F).



Example of a Transcript of Interview for MO5

P: Participant
I: Interviewer

P: The day we got her diagnosed, life became so much clearer I couldn't understand before. She won't let you walk behind her, going up the stairs, and you can't walk behind her coming down the stairs. And we had battles getting her up the stairs there were tears, there were fights, there was shouting and screaming on both sides, because I couldn't understand what the problem was, but once we realised and knew then it's no problem. I go up the stairs before her, such a simple thing, it's heartbreaking, it really is. I look back on it and I could cry for all the times I think she must have been so frustrated, you know because we didn't know about the autism.

I: It sounds like you have been fighting for her for all these years.

P: I've had to fight for her all the time, because life is one big struggle for her. We have fought for her rights from the minute we had her and particularly since we adopted her, before that we were having an uphill struggle, because she was in the care of X, but at least they were getting things done, now it's even worse.

I: Where is she currently?

P: She is at a day centre unit for young people with autism, which is a good unit. They wanted to send her to a different day centre and I said over my dead body. She's not going to any basement underground car park or anything else and I went there and wasn't impressed. It's a horrible place.

I: You said that where she goes is good?

P: Yes, it's very caring, she has her respite there so she's very secure and it's a safe environment for her. She enjoys being there.

I: How often does she go to respite?

P: She went yesterday at 3pm. and then she stays in respite day centre and then she comes home at a regular time. She's there every Sunday and one long weekend in 6. And she had 2 split weeks in the summer as I don't like to put her in there for two long. So she had one week in August and another week in October and in between that we took her away for a week so she wouldn't get too stale. Because it must be very difficult being there all day and then being there for respite, because you've got no change of environment at all. And your whole life is centred around the day centre and she doesn't seem to mind too much as she seems to like the routine.

I: So she's been diagnosed since she was 18.

P: It was so simple and so quick and it was the psychiatrist Dr. X who diagnosed it and she said well "of course, it's so obvious". I always thought she was autistic, but of course never realising, but it was so obvious. And then when I found out I know so many other parents who would say to me "do you have this problem, do you have that problem" before the diagnosis, and I'd say well yes I do, but my daughter's not autistic and they'd say "but she must be". I cried the day I found out and I rang the National Autistic Society Headquarters and they said if it's any consolation this happens a lot and there are lots of people now being diagnosed in their 30's. Oh my poor little girl. It was a big sigh of relief and I hate labels but we had a diagnosis as it helps so much and parents say Oh, I don't want a diagnosis. Well I think my god they should think themselves lucky if they do get it, early diagnosis, because early intervention is so important. But of course we are doing our best now and learning a lot more and she couldn't be in a better place and day centre.

I: You mentioned you'd got a psychology degree when I came in.

P: Yes I did a Child Psychology degree and lots on the early years. I used to use a lot of child psychology on my kids, it didn't work as I was too emotionally involved, but I certainly applied it when I was running the Mencap Club and it worked on those. I had those kids in the palm of my hand. My own daughter screaming and giving me the biggest hassle and I couldn't understand why this young woman was screaming and didn't like crowds and nobody said that does not go with cerebral palsy. And she didn't like certain head-banging music like heavy metal and stuff like that and of course now I look back on it and I think Oh. No I was torturing her. I used to take her on a Saturday with all those people in the hall, all rushing at her and that's another thing she couldn't cope with. So obviously she couldn't cope with it.

I: Are you still involved now with Mencap?

P: I did it for seven years and I had to give it up because of my daughter. You see I saw loads and loads of autism, bizarre behaviours and suddenly realised that she seemed to have the majority of those bizarre behaviours in every child. I was picking out a behaviour and I could apply it to Carol, but still didn't make the connection. My daughter and my son were saying is she autistic mum, it's incredible I missed it.

I: You did your very best and it's much easier to look at other people's children.

P: It's not up to me to come up with a diagnosis, they just kept trying to make out this child is useless and has a mental age of 15 months if that. I would not except that statement and I would not to this day accept that statement. I made such a fuss. This was done when she was 14 and she was at school, it should have been blown up.

I: Why was that?

P: I hated it from the minute I saw it, but I had no choice as she was in the care of the borough. I never liked the school the school, I didn't agree with their behaviour modification, because you can't apply behaviour modification to every single child. It's impossible, each child should have its own programme. You cannot do it, it was impossible, nothing worked. They made her worse if anything and she certainly benefited nothing from being at that school.

I: How long was she at school for?

P: She was there until she was bloody 19, but the only time I ever enjoyed her being there was in her last year because she had her.

I: Who was that?

P: because she had x (The teacher), she was the most fantastic teacher she was fantastic, she was the one who phoned me up and said "hello I'd like to know why your daughter has not been diagnosed as autistic", she'd only been there a day as well. She said my specialist area is autistic children, that's who I work with and she said I've actually named 3 children in my class who are autistic and your daughter has very, very severe autism. What I need you to do is go and get it confirmed. This was a teacher who had been in the classroom for one day with my daughter and comes up with this diagnosis. Well I was straight on to Dr. x (Psychiatrist). We went to the hospital and saw her and she was only with her for 15 minutes and asked me a few questions and now it's all so obvious (laughed). I came home and said to my husband she's autistic somewhere on the Spectrum disorder, but pretty severe, they even asked me about things she used to do as a baby. She used to bite her mother all the time, that was quite difficult and apparently to do with autism. You could never initiate a cuddle with her, she'd go stiff and she screamed and I couldn't understand that. And I'd say to her "I love you". She'd then come up to me and say I love my mummy, I love my mummy and give me the biggest loves so I could hardly breathe...

...I: When did she first start puberty?

P: I reckon she started it when she was about 11, but she actually had periods starting when she was 14, usual time, quite normal. But she hit puberty, god, with avengence.

I: Can you tell me a bit more about that?

P: She was a right cow when she, oh what a bitch, you know just like my eldest one. No different, no different to any other woman, all the same old problems. Typical teenagers! It was no different to her sister except worse. (laughing).