

VOLUME I

**MENTAL HEALTH PROBLEMS IN YOUNG PEOPLE WITH
LEARNING DISABILITIES:
THE PERSPECTIVES & EXPERIENCES OF PARENTS**

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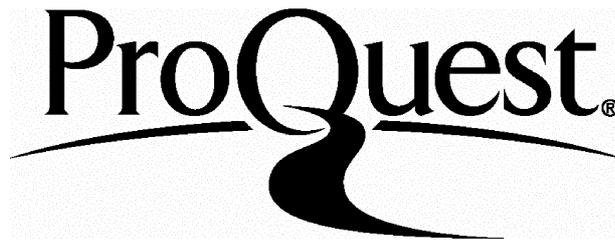
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ABSTRACT

Adolescence can be an exciting yet also difficult time for young people. It has long been recognised that the multiple internal and external changes and stresses associated with this life stage result in some young people developing mental health problems. While young people with learning disabilities have long been overlooked, there now appears to be evidence that they are at risk of elevated rates of mental health problems, with rates of psychopathology in this group being estimated as up to seven times higher than their non-disabled peers (Emerson, 2003). Despite evidence of increased vulnerability, little is known about how such additional problems affect the lives of these young people, their parents and wider family members.

The present study aimed to expand the existing, mostly epidemiological, literature by investigating the experiences of parents who have an adolescent son or daughter with learning disabilities and additional mental health problems. Eleven semi-structured interviews were conducted with a total of fourteen parents from an inner city area. Areas of exploration included: the process of initially recognising a change in the young person; parents' understanding of the mental health problem; the impact of the mental health problem on the young person, the parents and the rest of the family; how the family attempted to manage; and parents' experiences of professional help.

The interviews yielded rich qualitative data, which was analysed using the principles of Interpretative Phenomenological Analysis. Four themes were identified from the analysis: (1) The Struggle to Understand, relating to the difficulties parents had with respect to understanding and making sense of the changes in their child's behaviour and emotional state; (2) Changing Us, relating to the impact of the additional problems; (3) Managing the Best We Can, relating to parents' experiences of managing the situation; and (4) The Battle for Help, relating to parents' experiences of professional help. Confusion, loss and hardship were at the core of all themes. Cultural and religious differences mediated parents' perspectives and experiences. The results are discussed in terms of the existing literature. The methodology of this study and the research and clinical implications are also discussed.

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CHAPTER 1 ~ INTRODUCTION

Overview

For many young people, adolescence and the move from childhood to adulthood can be a period of significant emotional upheaval. For some, internal and external stresses can become so overwhelming that they develop emotional or behavioural problems. This also applies to young people with learning disabilities. In fact, there is now convincing evidence that young people with learning disabilities are at risk of highly elevated rates of mental health problems, with rates of psychopathology in this group being estimated as up to seven times higher than their non-disabled peers (Emerson, 2003).

While some in the field remain cautious regarding the magnitude of these rates (e.g. Moss, 2003), not least because of the possibility of further stigmatisation for an already stigmatised group, such figures obviously point to the need to understand more about the actual impact of additional mental health problems on the lives of these young people and their families. We do not know what it is like to be parents to a son or daughter with both learning disabilities and mental health problems: for example, what sense parents make of the problems experienced by their offspring, what impact these additional problems have on the young person, the parents and the rest of the family, and what experience parents have of services regarding these additional problems. It is important to ask parents about these issues: their responses could give us important clues as to how to improve help for these families, and shed light on how complex presentations are perceived and therefore reacted to by parents. The neglect of such lines of research would seem unexpected in the light of the increased vulnerability to mental health problems in learning-disabled young people compared with their non-disabled peers, and given that service providers are struggling to help young people and their families with such problems (Scior & Grierson, awaiting publication).

This chapter begins by summarising the key literature regarding mental health problems in adults with learning disabilities. This will set the scene for considering adolescence and learning disability, and what is known about the increased risk of mental health problems in young people with learning disabilities, outlining prevalence rates, clinical presentations and factors associated with increased risk. A review of service provision for young people with learning disabilities and mental health problems will be presented, followed by a synopsis of the literature examining the impact of such additional difficulties on the young person and the family. This limited literature will be expanded by incorporating what is known in the general learning disabilities literature about the consequences of having a learning-disabled child in the family, and considering what implications this literature has for understanding how additional mental health problems might affect family experience. This will then lead to the rationale for the current study, and the research questions under consideration.

Mental Health Problems in Adults with Learning Disabilities

Background

Historically, mental health problems in people with learning disabilities have been largely left unattended. One widely held assumption was that individuals with learning disabilities are incapable of, or somehow immune to, developing mental health problems (Borthwick-Duffy, 1994). This is encapsulated by Fletcher (1988), as cited in Nezu (1994): “The mildly retarded have been characterised as worry-free and mentally healthy. The severely retarded have been considered to express no feelings and therefore do not experience emotional stress” (p.255). Another common assumption was that people with learning disabilities are vulnerable to developing mental disorders, but that the problems are usually biological in origin (Szymanski & Grossman, 1984).

In recent years, research has shown these assumptions not only to be invalid, but importantly, that people with learning disabilities appear to experience higher levels of psychopathology compared to the normal population (e.g. Nezu, Nezu & Gill-Weiss 1992). There is now a growing recognition of the need to respond more adequately to mental health problems in this population, so as to improve their quality of life (Moss, Bouras & Holt, 2000).

However, there are still a number of issues that present as obstacles to the identification, recognition and treatment of mental health problems in people with learning disabilities.

These include:

- For people with learning disabilities suspected of having a psychiatric disorder, problems of identification are confounded by the characteristics of each condition. For example, communication deficits in people with learning disabilities affect capacity to give information about their mental state, making accurate diagnosis more complex (e.g. Campbell & Malone, 1991) and psychiatric disorder may exacerbate difficulties in intellectual, adaptive and social functioning, resulting in an individual appearing more impaired than is actually the case (Costello, 1982, as cited in Borthwick-Duffy, 1994).
- The people who are usually first to notice significant signs and symptoms (the immediate carer) are often least qualified to undertake the task, resulting in a failure to meet needs simply because the problem is never recognised (Moss & Patel, 1993).
- Caine and Hatton (1998) note that the paucity of social roles assigned to people with learning disabilities also inhibits diagnosis, given that a breakdown in such a role (e.g. competence at work) is often a telling sign of mental health problems in the general population.
- Diagnosis is often further complicated by the presence of multiple clinical problems simultaneously, for example the co-occurrence of learning disabilities and an additional

diagnosis e.g. Down's syndrome or autism, often resulting in a 'triple diagnosis' if a mental health problem is also concurrent (Barlow & Turk, 2001).

- With respect to recognising psychopathology, Reiss, Levin and Szyszko (1982) coin the term 'diagnostic overshadowing', where symptoms of a mental health problem are misattributed to the learning disability by carers and professionals. Individuals with learning disabilities were less likely to receive a psychiatric diagnosis than those without learning disabilities, although identical behavioural symptoms were displayed. Sovner (1986) similarly describes 'psychosocial masking' - impoverished social skills and life experiences that may mask the importance of psychiatric symptoms.
- The differential diagnosis between mental illness and challenging behaviour results in uncertainty as to when a challenging behaviour should be considered indicative of mental illness, given that mental health problems may express themselves differently in people with learning disabilities (Moss, 1995, as cited in Caine & Hatton, 1998). Conversely, some behaviours shown by people with learning disabilities can be misinterpreted as signs of mental illness (Moss et al., 2000).
- Service structure also contributes to confusion, given the traditional separation of learning disability and mental health services, which has resulted in segregated, non-integrated systems, training for professionals, assessment and treatment (Nezu, 1994).

Prevalence and Epidemiology

In addition to the above identification and diagnostic complexities, there are also methodological factors that confound the epidemiological literature. For example, the selection of the target population to be studied, and the characteristics of the sample, impact greatly on prevalence and epidemiological findings from study to study (e.g. Reiss et al., 1982). The majority of studies have been based on samples of individuals referred to clinics for psychiatric assessment, or who reside in in-patient settings (Borthwick-Duffy,

1994). These referred samples tend to result in over-inflated estimates of dual diagnosis. In addition, the diversity of definitions of what constitutes mental health problems in this group, some inclusive of challenging behaviour whereas others excluding such symptoms, has consequently resulted in wide ranging prevalence rates (Borthwick-Duffy, 1994). The literature on prevalence rates is therefore large, so only a flavour of the results will be reported here.

In a review of twenty-one studies examining prevalence rates for dual diagnosis, Borthwick-Duffy (1994) found a rate ranging from 10-71%, depending on method of sample selection and assessment, and the characteristics of the people who participated. Higher rates were reported for studies including behavioural disturbance within the definition of psychiatric disorder (e.g. Reiss, 1990) or if the sample were referred for psychiatric evaluation (e.g. Pary, 1993). Prevalence rates were lower for studies using case file information (e.g. Borthwick-Duffy & Eyman, 1990). However, Borthwick-Duffy (1994) concluded that there is now general consensus that people with learning disabilities are at an increased risk of developing mental health problems compared to the general population. Nezu et al. (1992) estimate that most prevalence rates cluster around 20-35%.

Young People with Learning Disabilities: At Increased Risk of Developing Mental Health Problems?

Adolescence is a highly complex stage of development and a time of major change. Individuals experience enormous changes in their physical, emotional and behavioural characteristics, and within their whole social structure, such as living and working situations, social expectations, responsibility and independence (Coleman & Hendry, 1999). Core tasks that must be successfully negotiated in order to move into adulthood include physical maturation, development of sexuality, emotional autonomy from parents, identity development and development of rational thought (Erikson, 1968). These changes are affected by the systems that the adolescent exists within, including family and peers.

Possible consequences of failure to negotiate these tasks encompass a wide range of mental health problems, including psychosis, anxiety disorders, eating disorders, depressive disorders, conduct disorders and self-destructive behaviours.

The concept of adolescence has been highly neglected, and some have argued “denied” (Baker, 1991), in the learning-disabled population both in terms of research and service provision. This is perhaps because adolescence brings with it challenges such as independence and sexuality, that pose specific difficulties for those with learning disabilities and those in their systems. However there is a current line of thinking that adolescence, or the tasks that define adolescence as a developmental stage, may span a longer time period and take a different (even incomplete) course for young people with learning disabilities compared to the non-disabled population.

Kymissis and Leven (1994) argue that the “identity crises” associated with adolescence occur later in life for mildly and moderately learning-disabled young people. Marshak et al. (1999), as cited in Blacher (2001), agree, arguing that the developmental tasks of adolescence may be an ongoing struggle throughout the transition to adulthood for young people with learning disabilities. It has also been asserted that young people with more severe learning disabilities may never achieve some or all of these developmental tasks. This is illustrated by McKinlay, Fergusen and Jolly (1996), who found that females with severe or profound learning disabilities reach menarche later than their non-disabled peers, or in some cases, not at all.

This altered course, and potential non-achievement, of the adolescent tasks may therefore have implications for these youngsters’ mental health. As already noted, adults with learning disabilities have a significantly higher risk of developing mental health problems than their non-disabled peers. This then begs the question, are young people with learning disabilities at increased risk?

Approaching adulthood, youngsters with learning disabilities, like their non-disabled peers, encounter difficulties in dealing with issues such as developing sexuality, emotional development and role adjustment, social relationships and activities, and family problems (Dossetor & Nicol, 1989). These areas of development are thought crucial for adolescents to master in order to achieve a successful transition to adult life, as noted earlier. These issues can be overwhelming even without cognitive and social disadvantage. Peterson and Leffert (1997) note that children who enter adolescence already vulnerable psychologically or socially are likely to experience a more difficult adolescence under more challenging social circumstances. Indeed McIntyre, Blacher and Baker (2002) assert that in order to understand learning disabilities in adolescence and young adulthood, this time must be recognised as a 'developmental hot spot' for the initiation or exacerbation of mental health problems.

Several authors have provided evidence that illustrates adolescence as a time of increased difficulties for young learning-disabled people. Dossetor and Nicol (1989) describe adolescence as a time of crisis for this population, citing figures showing a peak in referrals to inpatient and outpatient mental health care during adolescence. Zetlin and Turner (1985) provide comparable evidence. They completed detailed life history interviews in order to examine how mildly learning-disabled young adults and their parents viewed adolescence in retrospect, and compared it to the learning-disabled adult's current life circumstances. Findings suggested that both parties viewed the adolescent experience as more problematic than childhood, with over 75% of the sample experiencing serious disturbances (emotional and behavioural) in adolescence that were either non-existent or of less magnitude before that time. Of course, it could be argued that these findings may equally apply to young people without learning disabilities, given that this period is known to be associated with multiple tasks and changes which, if poorly negotiated, can result in various mental health problems. However, in this study, the emotional or behavioural problems were exacerbated by a limited or unclear set of normative parental expectations as well as factors such as absence of peer support, attributed to their learning-disabled status.

Prevalence Rates and Associated Factors

The literature reporting prevalence rates for mental health problems in young people with learning disabilities is small in comparison to the adult literature. Epidemiological studies are difficult to compare for the kind of reasons as previously outlined with respect to the adult literature, namely differences in characteristics of the sample, selection of the sample, and issues of conceptualisation and measurement of mental health problems. However, there is now convincing evidence spanning over thirty years of epidemiological research, to suggest that young people with learning disabilities are at significantly increased risk of developing mental health problems compared to their non-disabled peers (Cormack, Brown & Hastings, 2000; Einfeld & Tonge, 1996a,b; Emerson, 2003; Gillberg, Persson, Grufman & Themner, 1986; Linna, Piha, Kumpulainen, Tamminen & Almqvist, 1999; Rutter, Graham & Yule, 1970).

Few studies have focused specifically on adolescents with learning disabilities. Therefore what will follow is a review of studies relating to children and adolescents (normally in the age range of 4-18 years) with learning disabilities and mental health problems.

In their landmark study of epidemiology of childhood psychiatric disorders on the Isle of Wight, Rutter et al. (1970) found emotional disturbances in 7-10% of typically developing children. In comparison, 30-40% of children with learning disabilities demonstrated psychiatric disorders. The prevalence of psychiatric disorders was higher for those with lower IQ levels. This groundbreaking study is, however, restricted with respect to geography, age and gender, in that only boys of a limited age range (7-11 year olds) from the Isle of Wight were investigated.

In a Swedish study Gillberg et al., (1986) examined 83 mildly and 66 severely learning disabled children aged 13-17 years using psychiatric interviews with parents and observations of the children. 64% of the severely learning-disabled (IQ of less than 50) and 57% of the mildly learning-disabled (IQ of 50-70) children were found to have one or more

psychiatric conditions. Some correlates of psychiatric disorder were also investigated. In the severe learning disabilities group, a diagnosis of epilepsy was associated with higher rates of psychopathology, and in the mild learning disabilities group gender was a risk factor in that boys were at increased risk of psychiatric disorder.

Einfeld and Tonge (1996a,b) conducted a study of the association of psychopathology, age and sex with severity of learning disabilities in a population-based sample of 454 4-18 year-old Australian children. They used the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1995) to assess psychopathology, a measure developed specifically for use with children with learning disabilities. Results showed that 40.7% of the children could be classified as having emotional or behavioural disorders or other psychopathology. In contrast to the Rutter et al. (1970) study, children with profound learning disabilities had lower levels of disturbance than did those with mild, moderate and severe learning disabilities. Age and sex did not affect prevalence of psychopathology. Importantly, they also found that fewer than 10% of the children received specialist assistance.

In Finland, Linna et al. (1999) examined a sample of almost 6000 8-year old children, of whom 1.5% attended special schools. The prevalence rate of children identified as possibly suffering from psychiatric disturbance in the learning-disabled sample was about 34%, with 11% displaying depressive disturbance. These rates were significantly higher than rates obtained for non-disabled peers.

In England, Cormack et al. (2000) completed the DBC with the parents of 123 children between the ages of 4-18 years old, attending schools for children with severe learning disabilities, in order to identify children with clinically significant behavioural and emotional problems. In addition, they explored some potential correlates of behavioural and emotional disturbance. Some 50.4% of the children obtained results indicating presence of psychiatric disorder. The child's physical disability was related most strongly to parental ratings of behavioural and emotional disorder.

In a population-based study, Emerson (2003) performed a secondary analysis of the Office of National Statistics survey (1999) of the Mental Health of Children and Adolescents in Great Britain. In this random sample of 10438 British children between the ages of 5 and 15 years old, children and adolescents with learning disabilities were found to be seven times more likely to have a diagnosed psychiatric disorder than their non learning-disabled peers. Factors associated with increased risk of psychopathology included age (which was associated with specific types of psychopathology), gender (males more prone to developing mental health problems), social deprivation, stressful life events, the mental health of the child's caregiver, family functioning and child management practices.

In summary, prevalence rates for mental health problems generally cluster around 40% for children and adolescents with learning disabilities. This is in comparison to a figure of around 8% for their non-disabled peers, indicating that youngsters with learning disabilities are at significantly increased risk of developing mental health problems. The literature points to a link between male gender and psychiatric disorder in young people with learning disabilities. Age is also associated with different presentations of mental health problems. No clear association has been found between severity of learning disability and psychiatric disorder. A number of associations have also been reported between social disadvantage, parenting practices, parental mental health and psychiatric disorder. These are risk factors applicable to the general population, but more significant for this population, given that families of young people with learning disabilities are at greater risk of material and social disadvantage (e.g. Beresford, 1995, as cited in Emerson 2003).

Clinical Presentation

Cormack et al. (2000) note that very little research has addressed the nature of mental health problems in young people with learning disabilities. Only a handful of studies have empirically investigated differences in clinical presentation, with some authors reporting findings based on clinical experience. As a result, very little is known about the natural history, long-term course and treatment of psychiatric disorder in this population.

However, there is now some evidence that in addition to prevalence rates differing for these young people, the types of problems that they present with also differ. For example, Emerson (2003) reports that the incidence of conduct disorders, anxiety disorders, ADHD and pervasive developmental disorders appears significantly increased in this group, whereas there were no statistically significant differences between learning-disabled and non learning-disabled children with regard to the prevalence of depressive disorders, eating disorders or psychosis. Harden and Sahl (1997) studied 233 children and adolescents with learning disabilities who were clinically referred, and found that the most common psychiatric diagnoses were oppositional defiant disorder and attention deficit hyperactivity disorder. In addition, they found the diagnoses to be associated with level of intellectual functioning: autistic disorders were more frequent in children with lower IQ levels, and depressive disorders and post-traumatic stress disorder more common in higher functioning children.

Mental health problems in youngsters with learning disabilities also seem to present in different, altered, or masked ways compared to their non-disabled peers (Barlow & Turk, 2001). Masi, Pfanner and Marcheschi (1998) investigated depression in adolescents with learning disabilities aged 14-19 years, as to whether psychopathological phenomena in these young people corresponded to similar phenomena in non learning-disabled adolescents. They found that some depressive symptoms are more frequent than others in depressed learning-disabled adolescents, specifically low mood, psychomotor agitation or retardation, and loss of energy or interest. Cognitive symptoms (depressive ideation) and functional symptoms (disturbed sleep, appetite etc.) were less frequent than emotional symptoms and psychomotor symptoms. Turk (1996) notes (on the basis of clinical experience) that young people with learning disabilities often present with unusual presentations of psychopathology, which may be confusing to professionals and carers. For example, adjustment problems may be mistaken for increased dependency, anxiety for clinginess, and sadness for withdrawal and irritability. He also notes that verbal expressions of sadness may be concrete and expressed in the context of relationships, for example 'I'm depressed' may become 'my mum doesn't love me'.

Barlow and Turk (2001) also report that there is a risk of schizophrenia and other psychotic disorders being over-diagnosed in people with learning disabilities: maladaptive behaviours being mislabelled as psychotic features rather than affective symptoms. Masi (1998) reports that when it does occur, the onset of schizophrenia occurs more in late adolescence, is less reversible, and prognosis is considerably worse than amongst adolescents with more average intellectual functioning. This highlights the atypical nature and age presentation of psychiatric disorder in adolescents with learning disabilities, but also the risk of misdiagnosis.

There are still large areas of under-researched territory with regard to the presentation of mental health problems in this population, for example, suicidal behaviour. Harden and Sahl (1999) set out to test the common assumption that learning disabilities act as a 'buffer' against suicidal behaviour in children and adolescents. They found that 20% of individuals in a clinically referred sample, assessed over a 1-year period, exhibited suicidality and concluded that suicidal ideation and behaviours are frequently encountered in this population. These findings are in line with Walters, Barrett, Knapp and Bordena (1995), who reported a suicidality rate of 21% in a clinically referred population of young people with learning disabilities. Suicidality was more often encountered in individuals diagnosed with oppositional defiant disorder, depressive disorders, and post-traumatic stress disorder, and less often in autistic and the severe / profoundly learning-disabled groups. They therefore concluded that the assumption that limited cognitive abilities are a protective factor against suicidal ideation and behaviour is inaccurate for young people with mild or moderate learning disabilities who do indeed exhibit the full range of suicidality.

Factors Associated with Increased Risk of Mental Health Problems

So what makes young people with learning disabilities more prone to developing mental health problems? As already discussed, an altered adolescent course may contribute. In addition, an obvious answer may be that young people with learning disabilities have fewer

problem-solving skills to cope with the demands of everyday life, leading to distress or difficult behaviour. For example, Masi (1998) describes how the intellectual impairment experienced by youngsters with learning disabilities can reduce a young person's ability to integrate bodily and psychic transformations, so increasing the risk of psychopathology.

However Dykens (2000) asserts that these explanations mask a complex aetiological picture and that a number of factors make young people with learning disabilities more vulnerable to mental health problems. Consistent with this, in a report into meeting the mental health needs of young people with learning disabilities, the Foundation for People with Learning Disabilities (2002) indicate that young people with learning disabilities are disproportionately vulnerable to a whole range of risk factors for mental illness, such as economic disadvantage, abuse, bullying, low self-esteem, physical ill-health and, for those from ethnic minorities, racism. Multiple factors, both internal and external, appear to be implicated in the mediation of the expression of psychopathology in this group, including biological, psychological, familial, social, environmental and cultural factors. These factors will now be explored in turn.

Biological Factors

Children and adolescents with learning disabilities are more vulnerable to seizure disorders, self-injurious behaviours, sensory impairments and some specific genetic conditions, which have all been linked to the development of behavioural and emotional disorders.

The incidence of seizures increases as IQ level decreases, so that as many as 30-50% of the severe to profound learning-disabled population experience seizures (Dykens, 2000). Epilepsy has been associated with many psychiatric conditions in children with learning disabilities, especially psychosis (Gillberg et al., 1986). Self-injurious behaviour (observed in 4-16% of the learning-disabled population) has been linked to both behavioural factors

(e.g. trying to exert some control over their environment) and to biological factors (abnormalities in the endogenous opioid and serotonin systems) (Dykens 2000).

Self-injurious behaviour and other psychopathology are also associated with specific syndromes, including Lesch-Nyhan disease, Fragile X syndrome, Williams syndrome, Prader-Willi syndrome and Cornelia de Lange syndrome, thought to be a result of genetic and biochemical anomalies. Finally, as many as 17% of children with learning disabilities are hearing impaired; hearing impaired children are three times as likely to show psychiatric disturbance than their peers, especially anxiety and conduct disorders (Hindley, 1997). Furthermore, it is known that children with both learning disabilities and multiple sensory impairments are particularly vulnerable to emotional and behavioural problems (Hodapp, Fidler & Smith, 1998).

Psychological Factors

Dykens (2000) reports that psychopathology in young people with learning disabilities may be associated with aspects of self-image. She notes that in contrast to their typically developing peers, these young people show less idealised views of themselves, more poorly formed self-concepts and lower self-esteem. These views may result in more negative self-appraisal over time that are exacerbated by repeated exposure to experiences of failure, which dominate the learning experiences of these young people, due to cognitive and adaptive delays. Such failure is then associated with a learned-helpless state, which has been linked to depression and other psychopathology. Lindsey (1997) adds to the argument regarding the importance of self-esteem in protecting against psychopathology in children and adolescents, noting that being disabled, stigmatised and / or disadvantaged will predispose children to emotional problems.

Several authors have examined self-concepts with regard to adolescents with learning disabilities. Raviv and Stone (1991) compared the self-image of adolescents of average or below average functioning using a self-image questionnaire. They found that the

adolescents with lower IQs scored significantly lower on 4/10 subscales: body and self-image; mastery of external world; psychopathology; and superior adjustment. The latter three of these subscales constituted a domain that represented the adolescent's self-perceived emotional strength to cope with his or her internal and external world. Prout, Marcal and Marcal (1992) carried out a meta-analysis comparing self-reports by 6-20 year old children and adolescents with learning disabilities to their non-disabled peers. They found that there was a generalised tendency for youngsters with learning disabilities to score more poorly on self-esteem, have higher anxiety levels, and a more externally focused locus of control. It should be noted that both these studies used definitions of learning disabilities that included individuals with IQ scores above 70 in their samples. It is therefore questionable whether their findings are applicable to youngsters with more severe cognitive limitations.

The attachment literature is also implicated when considering the mental health of children and adolescents with learning disabilities. Cognitive skills are central to the development of childhood attachment relationships, which are the foundation stone for emotional adjustment in adolescence (Ainsworth, 1973). Dossetor and Nicol (1989) suggest that delay in cognitive development may affect the development of a secure attachment, which in turn may hinder exploration and learning. Others have noted that having a child with a disability may affect early attachment, through the sense of loss and trauma experienced by parents and through possible lengthy separations if the child is hospitalised in infancy. Such attachment disorders may then affect the learning-disabled adolescent's capacity for trust and the awareness of one's actions on others. Related to this, Dykens (2000) notes how certain personality styles of young people with learning disabilities may be linked with psychopathology, for example, aberrant social styles such as being either too wary or disinhibited with others. Possible outcomes of such personality styles include low self-esteem, sadness, depression, dependency, withdrawal, helplessness and impulsivity.

In addition, Levitas and Gilson (1994) describe the psychosocial development of young people with mild learning disabilities. They suggest that issues of separation and

individuation are more complex for adolescents with learning disabilities than their peers, due to 'carer domination', the active parental intrusion observed in some families that reduces opportunities for the young person to practice autonomy. They describe how inability of the young person to break away from the family may lead to psychopathology such as depression and anger.

Family Factors

Lindsey (1997) notes that there is little doubt that most families with a child with learning disabilities face many stresses that test their ability to cope and adapt. The family's capacity to deal with these stresses and meet the needs of the child is crucial with respect to the development of the child. Children with learning disabilities are at greater risk of dysfunctional family responses that may predict psychopathology, especially if there are additional family, marital, financial or other stresses (Lindsey, 1997), all of which may be increased for families in which a child has a disability. Indeed, Emerson (2003) found associations between socio-economic deprivation, punitive child management practices, carer mental distress and increased psychiatric disorders in children and adolescents with learning disabilities, consistent with the existing literature on the mental health of children and adolescents in general (e.g. Meltzer, Gatwood, Goodman & Ford, 2000), but made all the more salient given the increased risk of deprivation and stress for these families (Emerson, 2002) which will be described more fully in a later section.

Turk (1996) argues that emotional or behavioural disturbance may be an understandable reaction to family tensions and high levels of expressed emotion. He describes persisting familial grief or chronic sorrow regarding the learning-disabled child (Wikler, Wasow & Hatfield, 1981), parental anxieties regarding the past, present or future of their child, or intra-familial conflict or inconsistency as possible factors that the young person may react to, resulting in emotional or behavioural disturbance. Furthermore, Dossetor, Nicol, Stretch and Rajkhowa (1994) found that high expressed emotion in parental primary carers was

associated with psychological ill health, poor quality marriage and poor social support of the carer, and psychiatric disorder in adolescents with learning disabilities.

Although family stress has long been implicated in the poor adjustment of children and adolescents with learning disabilities, such work has assumed that such families were inherently pathological (Dykens 2000). More recent studies suggest that how families fare (positively or negatively) is mediated by a wide range of both child and family factors, for example, the severity of the learning disability, the amount of support available to the family, and parental coping style. Both family and child factors are implicated in the development of psychopathology, and causal direction is often unclear. Child behaviour problems emerge as the best predictor of parental pessimism and higher stress levels in families of children with Prader-Willi syndrome, Smith-Magenis syndrome, and 5p-syndrome (Hodnapp et al., 1998). However Lindsey (1997) and Dykens (2000) note the difficulties in trying to disentangle cause and effect. For example, some children's predisposition to developing psychopathology may set in motion a series of parental responses that may ameliorate or worsen psychopathology. In some families a spiralling of stress and behaviour problems may lead to rejection of the child, which may result in child psychopathology.

These issues are closely related to the question of what the impact of having a child with learning disabilities is on the family generally, which will be more fully explored in a later section.

Social Factors

Social factors can also play an important role in the development of psychopathology. In a society where achievement and independence are highly valued, negative evaluations of people with learning disabilities are very common. Many authors have noted that people with this label are often aware of these negative evaluations, and may share them (e.g. Edgerton, 1967; Sinason, 1992; Szivos & Griffiths, 1990).

How one is perceived by one's peers is of great importance to most adolescents. Barlow and Turk (2001) argue that adolescence is a time when young people with learning disabilities become increasingly aware of their disabilities and increasingly frustrated by them. Adolescence is also the time when the inability to satisfy the age-related expectations of society is likely to become particularly poignant. Edgerton and Gaston (1991) (cited in Dykens 2000) found a negative effect of such social stigma on self-esteem, depression and adjustment. Furthermore, many people with learning disabilities have limited 'social intelligence' (Greenspan & Granfield, 1992), i.e. are not as able to 'read' social situations or cues, which may also contribute to feelings of isolation or loneliness and stigmatisation

Young people with learning disabilities are at risk of a number of adverse life experiences and losses (Lindsey, 1997). They often experience peer rejection or ostracism. Freeman and Kasari (1998) report that peer relations are partly mediated by the ability of these young people to negotiate peer conflict, and by how 'different' they are perceived as by their peers. Even when they do negotiate friendships, these often show abnormal friendship patterns, typically lacking in shared play, decision-making, laughter and equal role allocation (Siperstein, Leffert & Wenz-Gross, 1997). As adolescents, they are frequently excluded by their non learning-disabled peers resulting in poor self-esteem and self-image. Kymissis and Leven (1994) argue that learning-disabled adolescents take on only a peripheral role in social groups and tend to be exploited within these groups. As adolescents they are more likely to be aware of such exclusion, which leaves them feeling more stigmatised than in middle childhood.

Social exclusion is also an important factor when considering opportunities for sexual development in young people with learning disabilities. Barlow and Turk (2001) note that during adolescence sexual curiosity and interest increase, but that the scope for sexually oriented relationships is usually severely limited. Levitas and Gilson (1994) expand on this theme of social inequality and exclusion, arguing that the onset of puberty finds adolescents with learning disabilities with scant experience of private time and few true

peer contacts. They also suggest that restricted opportunities in adolescent “rites of passage” such as driving, drinking, owning possessions, sexual experimentation are seldom open to adolescents with learning disabilities, which may result in frustration and, potentially, emotional and behavioural difficulties.

The Department of Health’s National Service Framework for Mental Health (1999) stresses the bi-directional nature of social exclusion, namely it can both cause and come from mental health problems. A young person with learning disabilities who is experiencing mental health problems may be at risk of social exclusion, as a result of the behavioural manifestations of underlying emotional or psychiatric difficulties (Foundation for People with Learning Disabilities, 2002). This could then be further compounded by the various difficulties in diagnosis outlined earlier, which prevent mental health problems being effectively and efficiently identified and treated, leading to further exclusion. Thus these young people then become vulnerable to segregation, leading to further stigmatisation and a failure to provide opportunities for modelling on, or learning from, a peer group (Lindsey, 1997).

Turk (1996) discusses the impact of educational factors on the development of psychopathology. Educational programmes pitched at either too high or too low a level may contribute to emotional and behavioural disturbances, triggered by boredom or frustration. Furthermore, the educational placement itself may be implicated. Learning with a disabled peer group may expose children with learning disabilities to inappropriate or maladaptive behaviours. Conversely, learning with a more able peer group can highlight just how disabled the child is, and may leave them vulnerable to teasing, bullying and social isolation. That the Foundation for People with Learning Disabilities (2002) report that schools and colleges are only just beginning to understand mental health issues for young people with learning disabilities makes the issue of difficulties at school even more pertinent.

The issue of change and transition is also relevant when considering mental health problems in young people with learning disabilities. This is perhaps especially important when a diagnosis of autistic spectrum disorder is concurrent, given the difficulties that change presents to people with such disorders. Due to a severe lack of research it is difficult to estimate the impact of changes from school to post-school or child to adult lifestyles on learning-disabled young people's mental health. One study conducted by Hepper and Garraida (2001) investigated how leaving school impacts on psychiatric adjustment in adolescents with learning disabilities. They theorised that the life changes associated with leaving school may precipitate psychopathology, due to having reduced abilities to problem solve and adjust to change (Bicknell, 1983). They then hypothesised that the process of leaving school may therefore constitute a developmental period in which adolescents with learning disabilities are particularly vulnerable to psychiatric disorder, compounded by the withdrawal of education-based psychological services and links to child health services. Although there was a high frequency of emotional and behavioural problems prior to the transition period, there was no significant change in psychiatric morbidity for the group as a whole after leaving school. The authors put forward a number of factors that may be reflected in the insignificant outcome namely: the presence of a number of protective factors such as stable home environments, comprehensive transition planning, good level of social functioning and clear plans for future college or vocational placements; a small sample of 15 young people; and uncertainty regarding the reliability of the pre-transition measure of morbidity (as to whether this was actually anticipatory anxiety). In the light of improving transition planning for such young people, it would seem important to carry out further research regarding school transitions and mental health.

Environmental Factors

Environmental factors, such as inappropriate or poor quality services have also been associated with poor mental health. Lindsey (1997) describes how environmental deprivation and institutionalisation are well known factors in the predisposition of young

people to emotional and behavioural problems. People with learning disabilities are also at heightened risk of exploitation, physical or sexual abuse (Ammerman, Hersen, Van Hasselt, Lubetsky & Sieck, 1994). Although prevalence of abuse in children and adolescents with learning disabilities is unknown, there is little doubt that it occurs and that such young people are at greater risk (Tharinger, Horton & Milea, 1990). Obviously, such maltreatment may initiate or exacerbate emotional or behavioural difficulties.

Environmental stresses and poverty have a powerful effect on mental health. Poverty is a mental health risk for all young people. It is estimated that children in the poorest households are three times more likely to have mental health problems than children in well-off households (Department of Health, 1999). Families with a disabled child are more likely to experience poverty (Department of Health, 2001b), thus increasing their risk to developing mental health problems. Indeed, it is estimated that about 43% of children with learning disabilities, and 55% of children with learning disabilities and mental health problems live in poverty (Emerson, 2002).

Cultural Factors

Ethnic minorities represent a significant part of the population in the UK, especially in some inner city areas. They face substantial inequalities, discrimination and disadvantage, are more likely to live in inner city areas, in substandard housing and to suffer discrimination in employment, education, health and social services (Acheson, 1998). Increased material deprivation in itself may therefore put young people with learning disabilities from ethnic minorities at even greater risk of developing mental health problems.

However, young people with learning disabilities (and to some extent their families) are also vulnerable to 'double discrimination' (Baxter, Poonia, Ward & Nadirshaw, 1990). They experience both the stigma associated with having learning disabilities, and the racism associated with being a member of an ethnic minority, which may also impact on mental health. The prevalence of learning disabilities for young people from South Asian

communities between the ages of 5 and 32 is up to three times higher than in other communities (e.g. Emerson, Azmi, Hatton, Caine & Parrott, Wolstenholme, 1997), and it is estimated that from 1991 to 2021 the number of people with learning disabilities from “minority” ethnic communities will increase by 70% compared to a 3% increase in white people (Emerson & Hatton, 1999). It is important, therefore, to understand how such extra stresses impact on these young people.

Azmi, Hatton, Emerson and Caine (1997) explored the views of South Asian adolescents and young adults with mild or moderate learning disabilities. While these young people reported positive ethnic and racial identity and were generally satisfied with their home and family circumstances, they also reported pressure on them from pervasive racism, stigma and conflicting cultural demands. Double discrimination did indeed seem to be a painful reality for these young people, which surely then has implications for development of mental health problems.

There is also evidence that young South Asian women (without learning disabilities) are at three times higher risk of suicide than their white peers (e.g. Bhugra, Desai & Baldwin, 1996), and that cultural conflict accounts for a significant proportion of suicide or parasuicide (Handy, Chithiramohan, Ballrad & Silveira, 1991). While it is unknown whether this applies to young people with learning disabilities, the conflicting cultural demands and racism reported by Azmi et al. (1997) imply that it is at least a possibility.

Services for Young People with Learning Disabilities and Mental Health Problems

Child and Adult Mental Health Services have traditionally been poor in meeting the needs of adolescents, whether or not learning-disabled. This has led to the development of an increasing number of services across the UK designed to address the mental health needs of adolescents. However, young people with learning disabilities, particularly if their disabilities are anything but mild, are frequently excluded from these services. In turn,

within specialist learning disabilities services, treatments that are deemed particularly suitable for adolescents, such as family therapy and group therapy (e.g. Kymissis & Leven, 1994), are frequently not available. Where services for these young people do exist, they have been variously described as “poor” (McCarthy & Boyd, 2002), “insufficiently developed” (Royal College of Psychiatrists, 1998) and “fragmented and lacking co-ordination” (Audit Commission, 1999).

One of the difficulties for young people with learning disabilities is that they span two very different service frameworks, child and adult, rather than fitting neatly into one or the other. The lack of co-ordination between child and adult learning disability services has long been recognised, complicated by the fact that child and adult services tend to be organised in different ways and have different cultures. This can result in disjointed and fragmented experience of services for both the young people and their families. 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). Therefore in many areas ‘transition to adulthood teams’ were set up to try to address these needs. However, the focus for these teams is mostly on educational and social needs, tending to have no or very limited capacity to address mental health needs.

Cass, Regan and Rhodes (1996) go so far as describing a ‘white hole’ in services for young people with learning disabilities and mental health problems, to reflect the fact that these young people are attended to neither by adult nor child services and therefore are at risk of falling through the gap. This is supported by McCarthy and Boyd (2002), who conducted a retrospective study to determine the extent of specialist health service use during adolescence by a group of individuals with learning disabilities and mental health problems. They found that the majority (64%) of participants with persistent challenging behaviour from childhood to adult life and those with an established childhood psychiatric disorder received no specialist mental health professional input during the transition period to adult services.

The significant gap in understanding and addressing the particular mental health needs of young people with learning disabilities has been explored by a one-year UK wide committee of inquiry set up by the Foundation for People with Learning Disabilities in recognition of poor provision and lack of knowledge. In the inquiry report, Carpenter (2002) goes as far as saying that “the lack of appropriate services is a scandal” (p. 4). The report recommended development in a wide range of areas, including extending the limited evidence base by carrying out further research.

In investigating service providers’ perspectives of mental health problems in young people with learning disabilities, Scior and Grierson (awaiting publication) identified a gulf between current policy and the reality for this group of young people, not least in terms of all agencies working in partnership. While service providers appeared sensitive to the needs of families, all described instances when young people in this group fall through gaps between services. The authors note that very little is known about factors that promote good (or indeed poor) outcomes for these young people and their families and point out an urgent need to identify essential factors for good service provision by understanding the actual experience of the young people and their families.

In summary, what is clear is that young people with mental health problems and learning disabilities fall between a number of service providers, including child and adolescent mental health services, specialist learning disability services, paediatricians, transition to adulthood social services teams, and education. It is perhaps not surprising that services for young people with learning disabilities and additional mental health problems have been identified as in need of considerable improvement (Department of Health, 2001a; Foundation for People with Learning Disabilities, 2002). Further research investigating the actual experiences of young people and their parents is therefore required, in order to further the understanding of what promotes good and poor outcomes for these young people and their families.

Additional Mental Health Problems: The Experience of Young People with Learning Disabilities and their Families.

There is a paucity of research investigating what it is like to experience mental health problems in addition to learning disabilities, both with respect to the young person and the experience of their families, which is perhaps surprising given what is known about increased risk and poor service provision as already outlined. Dykens (2000) notes that in the main, work over the last few decades has focused primarily on measuring the mental health problems, and asserts that the time has come for researchers to build in other directions. Blacher (2001) also reports that research on mental health problems in young people with learning disabilities has so far been primarily epidemiological, with scant attention to effects of psychiatric disorder on the individual's life.

The dearth of literature is also surprising given what is known about how mental health problems in non learning-disabled young people affect their families. In a recent review, Berg, Turid, Vikan and Dahl (2002) concluded that child psychopathology is a major stressor for families and substantially impacts on parenting abilities, increasing parental negativity and various forms of ineffective disciplining practice. Turcotte (1990) examined parents' experiences of dealing with difficult adolescents and found that unsuccessful efforts at managing the difficulties had led them to develop feelings of incompetence and isolation. This is in line with Farmer, Burns, Angold and Costello (1997), who found that children's emotional and behavioural problems impacted specifically in terms of parental well-being (e.g. depression and worries) and parents' sense of competence to handle their child's problems. It seems that even in the absence of learning disabilities, mental health problems have a significant effect on parents. The coexistence of the two conditions together may point to an even more complex picture. Surely additional mental health problems have implications with respect to the young person's, and also their families', experience and quality of life?

Einfeld and Tonge (1996a,b) argue that behavioural and emotional problems are a major source of additional suffering for the young person and their families, while the Foundation for People with Learning Disabilities (2002) also suggest that experiencing significant levels of emotional distress or behaving in ways others find difficult to accept or understand can have a devastating impact on the life experiences of the young people and their families, with respect to their relationships, education and ability to negotiate the transition into adulthood. However, while such deductions about the impact of additional mental health problems and therefore quality of life are rife, these deductions are so far not backed up by an adequate empirical research base.

As far as the researcher is aware, to date, no study has investigated how additional mental health problems affect young people with learning disabilities, and only one questionnaire-based study has specifically investigated the impact of these mental health problems on their families. This was conducted by McIntyre et al. (2002) who found that the mothers' perceived negative impact of a young person (aged 16-25 years) with learning disabilities on the family is exacerbated by maladaptive behaviour and/or mental health problems, increasing family stress and decisions concerning out of home placements. They concluded that service providers need to be highly attuned to the presence of mental health problems during this high-risk period in order to provide the necessary help for families. They further stressed that management of these problems should be a high priority for services given the potential benefit not only to the individual but also to the family with respect to quality of life and sustaining in-home placements.

The link between the young person's mental health and family well-being has been conceptualised by Blacher (2001), who proposes a model of learning disabilities and family well-being during the transition years from adolescence into young adulthood. Her model implicates the role of: individual characteristics (cognitive level, adaptive functioning and psychiatric status); environment and culture (social supports, socio-economic status, service supports, religion and cohesiveness); and family involvement (or detachment) with the young person, on transition success and therefore family well-being (defined by levels

of negative and positive impact, depression, caregiving burden, health and life satisfaction). In this model, additional mental health problems are clearly implicated as impacting on transition success and therefore family well-being, mediated by environmental and cultural factors. However, this is purely a conceptual model and no research investigating these proposed links has been conducted to date.

Given the limited research base regarding the experience of being a parent to a son or daughter with learning disabilities and mental health problems, individual accounts have been called upon to inform about the experience of these families. Relating to service provision, Power (2002) describes her family's experience of her learning-disabled son being hospitalised for psychosis. She highlights key areas where the experience could have been improved: parents should be given more information about mental health around transition from child to adult services; there should be a proper handover at transition; mental health jargon should be avoided; services should listen to parents; alternative and holistic treatments, rather than just medication should be considered; specialist units for young people with dual diagnosis should exist; rehabilitation should include on-going support, with a named co-ordinator in order to stop numerous readmissions.

While Power (2002) provides a user perspective on service provision, we still lack a more all-round understanding of parents' experiences, including how parenting a young person with learning disabilities and mental health problems impacts on parents, the family, and the young person themselves. Due to the lack of research evidence in this area, in the following section, literature focusing on what is known about being a parent to a young person solely with learning disabilities will be reviewed. It is hoped that this will help us begin to understand what the effect of additional mental health problems may be. The implications of being a family from an ethnic minority with a learning-disabled offspring will also be examined, in the light of an appreciation of some significant differences in circumstances and needs for these families.

Families of Learning-Disabled Offspring

Early research regarding families of children with learning disabilities was largely focussed on pathology, tending to assume negative outcomes in families as a consequence of their child's learning disability. More recent research has revealed variations in parental caregiving experiences, with both positive and negative outcomes (Blacher & Hatton, 2001). What is clear is that the amount of stress any family member experiences will change over time and seems to be associated with a number of child, parent and family factors (Bromley, 1998). Child factors that seem to increase stress include severe levels of disabilities, extreme levels of activity, the existence of behavioural problems, poor physical health and poor sleep patterns. Parent and family factors include social isolation, economic difficulties, marital problems, lack of family closeness and passive coping strategies (Bromley, 1998). A recent study by Olsson and Hwang (2001) illustrates the influence of both child and parent factors: they found that mothers of children with learning disabilities were at increased risk of suffering from psychological distress and depression; an additional diagnosis of autism and being a single parent seemed to significantly increase parental distress further.

The diagnosis of a learning-disabled child brings with it a series of complex reactions. When a family comes to learn that their child has learning disabilities, it is commonly recognised that they will go through a series of psychological stages reflecting their grief at the loss of the anticipated idealised child (Bicknell, 1983). Denial of reality is common and varies from temporary inability to understand the news ('shock') to long-term denial of the child's needs and abilities. Subsequent protest and anger is common, both outwardly at professionals (although this depends on how the diagnosis is given) and inwardly in the form of guilt or depression, with respect to finding someone or something to blame. Searching behaviour can be both internal (soul-searching) and external, with respect to shopping around for multiple professional opinions. These phases are usually replaced by the slow gaining of a new individual and family identity ('adaptation').

In addition to the initial bereavement reaction, the phenomenon of 'chronic sorrow' has been recognised, whereby repeated reminders of the disabled family member's problems and differences from others rekindle grief feelings and some of the processes outlined above (Wikler et al., 1981). This chronic, but periodic (rather than time-bound) course of grief seems to characterise the experiences of parents of young people with learning disabilities (e.g. Turk, 1996). Periodic recurrences of grief feelings (termed 'recapitulated grief' by Goldberg, Magrill, Hale, Damaskinidou, Paul & Tham, 1995) usually coincide with times that emphasise the young person's differences from their peers, especially around key life events and changes, such as those seen in adolescence.

Vetere (1993) draws on family life cycle theory (Carter & McGoldrick, 1989) to illustrate potential crisis periods for families of offspring with learning disabilities and to understand likely sources of stress within family life. The seven stages delineated by Carter and McGoldrick (1989) are courtship and marriage; starting school; adolescence and sexual maturity; ending school; death of grandparents/parents; the empty nest; marriage of children. For the family with a learning-disabled member, there are commonly different expectations of family life, different decisions to be made, different tasks to be negotiated at each life cycle stage and during each transitional period. For example, the arrival of adolescence and puberty can bring an increase in social isolation for the young person and a growing awareness of the extent of their disabilities, often predicated upon some failure of normal developmental phases. Leaving school then sees a major change in service provision and personnel with the need to make decisions about where to live and work. These life changes frequently happen in the absence of the usual markers of adulthood, such as independence from parents and development of intimate relationships. Expectations for the future may then need to be adapted for family members.

Kymissis and Leven (1994) illustrate this point in writing about families of young people with learning disabilities experiencing complex problems during adolescence, which may in turn affect experiences of parenting. They suggest that parental hopes about the condition improving decrease as the child reaches adolescence, and that burgeoning sexual

curiosity causes anxiety within families. The authors also describe how as the young person's struggle to establish their identity and autonomy is frustrated, and they realise that their goal to completely break away from their families is unattainable, they may become depressed or act out aggressively. Families are then caught in a dilemma: between wanting to assist in achieving greater independence and wanting to remain supportive and nurturing.

Cheseldine and Jeffree, (1981) found that while it is the case that adolescence and young adulthood is a time of increased carer stress and demand, respite and service support may be more difficult to locate than in earlier childhood. Indeed Suelzle and Keenan (1981) investigated changes in available family support networks over the life cycle of people with learning disabilities and found that parents of older adolescents, ages 19-21, were less supported, more isolated and more in need of expanded services than parents of younger children. Given that these studies took place over twenty years ago, it could be argued that much has changed in service provision since that time. However, other more recent research (e.g. Foundation for People with Learning Disabilities, 2002; Morris, 1999; Turner, 2002) would indicate that the experiences of parents of learning-disabled adolescents are not so different now, and that these same issues continue to be salient even with significant changes to service planning.

So what are the implications of this literature when considering the experience of families of young learning-disabled people with additional mental health problems? As outlined, family stress is not static, but changes with time and is affected by child, family and environmental factors. Adolescence and young adulthood is clearly a life-stage that can be a potential crisis period for families of learning-disabled offspring. The concurrent experience of additional mental health problems during this time may act as a significant 'child' factor in relation to family experience, and exacerbate rekindled chronic grief feelings as the young person's difference is even further delineated. Poor service provision (an environmental mediating factor) at a time of high (but often unmet) need may also impact on the family's experience, as might other various environmental or family factors.

Ethnic Minority Families with Learning-Disabled Offspring

Research has highlighted that the circumstances and needs of families from ethnic minorities with a child with learning disabilities are quite different than those of the ethnic majority (Mir, Nocon, Ahmad & Jones, 2001). While it is clear that most families have a great deal of resources and coping ability (as for the majority ethnic group), it seems to be the case that an ethnic minority family with a learning-disabled offspring has additional hurdles to overcome. Given the increased prevalence rates of learning disabilities in some minority ethnic groups (specifically the South Asian population) as already described, and in view of the findings suggesting a significant increase in the number of young people with learning disabilities from ethnic minorities in the near future, it seems important to consider these differences in preparation for considering how additional mental health problems in their young learning-disabled offspring might then impact on ethnic minority families

Some aspects of the initial stage of being given a diagnosis of learning disabilities seem to be different for people from ethnic minority communities. It has been found that South Asian parents receive the diagnosis of learning disabilities later than white parents (Mir et al, 2001). Possible reasons for later diagnosis include parents' concerns about not being taken seriously by professionals involved (Mir et al., 2001), difficulties in communication and differences in conceptual understanding (Reading, 1999). For families with English as a second language, there seem to be considerable difficulties in understanding the information given to them at diagnosis (e.g. Fatimilehin & Nadirshaw, 1994); furthermore differences in attitudes to child development and mistrust in professionals might also impact on understanding.

Research in the UK has found South Asian parents reporting greater religiosity and a different set of attitudes and beliefs regarding learning disabilities compared to their white counterparts (e.g. Faimelshin & Nadirshaw, 1994). They are more likely to contact a holy person (Fatimilehin & Nadirshaw, 1994) or traditional healer (Chamba, Ahmad, Hirst, Lawton & Beresford 1999) with respect to their learning-disabled child, and believe that

doctors and religion can bring about a cure (Fatimilehin & Nadirshaw, 1994). These differences also have implications for family coping, and for the understanding of the concepts surrounding learning disabilities. However, it is also the case that a lack of information, as well as cultural and religious differences, account for differences in parental attitudes (Baxter et al., 1990).

There is also evidence that Black and South Asian families with a child with learning disabilities generally receive both less formal and informal support. With respect to formal support, South Asian families with a member with learning disabilities tend to find services inadequate and inappropriate to their needs (Hatton, Azmi, Caine & Emerson, 1998). While there is an over-representation of children from black and South Asian groups in special education (e.g. Emerson et al., 1997), there is an under-representation of people with learning disabilities from ethnic minorities in residential care, thought to be due to a greater reluctance by these parents to place offspring outside family and concern that cultural needs may not be met, for example, regarding mixed sex houses and staff (Reading, 1999). Short-term breaks for carers and family support groups are also underused by ethnic minority parents (Chamba et al., 1999). This is assumed to arise from a lack of awareness of services (associated with proficiency in English language), and a failure by services to identify carers' needs and work flexibly and within an appropriate cultural framework (Mir et al., 2001).

Ethnic minority families also appear to receive less informal support from extended family networks than white families (Chamba et al., 1999; Hatton et al., 1998), largely due to family members being geographically distant. Research has found that carers from ethnic minority communities do not report support from neighbours in caring responsibilities, unlike at least some white carers (Butt & Mirza, 1996). This is in direct contrast to the widely held stereotype of Asian and black families as typically large supportive extended families, who neither need nor want service support. There is however a higher incidence of young women and girls within the immediate family adopting the caring role (Mir et al., 2001), although it is not specified for which communities this holds true, illustrating a

limitation in some of the literature regarding cultural difference, in that group differences are not differentiated.

What seems clear is that many ethnic minority families are caring for offspring at home with relatively little informal or formal support. While the resilience of some families is evident, such isolation can result in negative consequences for all family members (Turnbull, Patterson, Behr, Murphy, Marquis & Blue-Banning, 1993, as cited in Hatton, 2002). This has perhaps been illustrated by the very high rates of emotional distress indicative of psychiatric disorder (78-80%) that have been reported in South Asian parents of children or young adults with learning disabilities (Hatton et al., 1998). In addition, Mir et al. (2000) found high levels of hospital attendance for carers as inpatients and outpatients. Hatton (2002) comments that this is likely to be associated with the same factors that increase risk of psychiatric diagnosis in white parents such as poor health and financial hardship, but exacerbated by increased disadvantage and deprivation in light of their ethnic minority status.

So what might be the implications of this literature for ethnic minority families caring for a young learning-disabled person with additional mental health problems? Differences in beliefs and attitudes to learning disabilities, mediated by religion and culture, is something that may well extend to the presence of additional mental health problems. Certainly this poses some important questions, including how these problems are conceptualised by parents from ethnic minorities and how this in turn affects their parenting experiences and coping. Drawing on the wider psychological literature, religious and cultural group differences do indeed appear to impact on beliefs about mental illness, and subsequent coping strategies and therefore service utilisation. For example, Cinnirella & Loewenthal (1999) found that community stigma (in Pakistani Muslim, Indian Hindu, Afro-Caribbean, and Orthodox Jewish groups) associated with mental illness resulted in a preference for private coping strategies, and a fear of being misunderstood by outgroup health professionals. In addition, beliefs about religion being both a cause (in terms of lack of faith and failure to pray regularly) and a treatment (in terms of prayer) for mental illness were

common. Religious and cultural variations in conceptualisation and coping with mental health problems may similarly apply to ethnic minority parents of young people with learning disabilities and mental health problems, with implications for their parenting experience.

In the same way that a lack of information about learning disabilities impacts on parents' attitudes and beliefs about learning disabilities, a lack of information about mental health problems might affect parent's understanding of the problems experienced by their offspring. The lack of both formal and informal support systems in ethnic minority families with learning disabled offspring also has implications with respect to the experience of ethnic minority families of young people with learning disabilities and additional mental health problems. Young people with learning disabilities from black and ethnic minority communities may also be at even greater risk of not having their needs met when they experience mental health problems. There are suggestions that South Asian adults with learning disabilities are under-represented in psychiatric services (Chaplin, Thorp, Ismail, Collacott & Bhaumik, 1996), which then begs the question as to whether this equally applies to adolescents with learning disabilities, and what the consequent effects are for the young person themselves and for their family members. In addition, it would seem important to consider whether the high levels of psychological distress noted in ethnic minority carers of learning-disabled offspring may be exacerbated by additional mental health problems.

Rationale for Current Study

The previous review of the literature highlights that young people with learning disabilities appear to be at risk of highly elevated rates of mental health problems compared to their non-disabled peers (e.g. Emerson, 2003). However, little is known about the actual experience and impact of additional mental health problems on the lives of these young people and their families (e.g. Blacher, 2001). The review of the literature relating to

families and children with learning disabilities demonstrates that the diagnosis of learning disabilities can have a great impact on the family, which changes with time and at different life stages and is mediated by various child, familial, cultural and religious factors. It is also known that mental health problems in young people in the absence of learning disabilities impact significantly on parents (e.g. Berg et al. 2002).

Given these findings, it seems likely that the presence of mental health problems in addition to learning disabilities during the adolescent life stage will prove challenging to families of such young people. In order to begin to understand this, the current study aimed to investigate the experiences of parents who have an adolescent son or daughter with learning disabilities and additional mental health problems.

A 'discovery-oriented', phenomenological approach was taken because such a focus is upon an individual's experience of their world, and the diversity and variability of individual experiences (Willig, 2001). In accordance with this, the study aimed to obtain an in-depth understanding of these parents' experiences of their adolescent offspring's difficulties.

It was decided to focus on the parents' experiences and views for a number of reasons. First, given what is known about how learning disabilities impact on families, it seems important to investigate how families manage the additional occurrence of mental health problems on top of the learning disabilities, especially at such an important stage in the life cycle. Second, given the difficulties associated with recognition and diagnosis of mental health problems in people with learning disabilities, and evidence of poor service provision, families are crucial in identifying, caring for and seeking help for these young people. Third, the majority of young people with learning disabilities live at home with their parents, who are therefore likely to have extensive views about their child's experience and quality of life. Fourth, the bi-directional relationship between the family's and young person's well-being is evident and deserves further exploration. Fifth, families supporting a young person through the transition from child to adult services have been highlighted as a group of carers who have priority needs and require particular attention (Department of Health,

2001b). Sixth, parents often can feel excluded and lacking a voice with respect to adult services (Department of Health, 2001b; Turner, 2002).

It is hoped that the findings will contribute to our understanding of what it is like for these families and young people with learning disabilities and additional mental health problems with respect to initially recognising, making sense of, coping with, and accessing services for these additional problems. In turn this might inform future service planning for young people with learning disabilities and their families.

Research Questions

Given the relative infancy of this area of research, this exploratory study has one main research question, supplemented by sub-questions.

Main Research Question

- What are the experiences of parents of young people with learning disabilities who have additional mental health problems?

Sub-Questions

- What were parents' experiences of recognising and making sense of the mental health problems?
- What impact do the mental health problems have on the young person, parents and other family members, and how is this managed?
- What is the role of culture and religion in mediating parents' experience?
- What are the parents' experiences of trying to access help and what are their perceptions of the actual help provided?

CHAPTER 2 ~ METHOD

Overview

Eleven semi-structured interviews were conducted with parents of young people with learning disabilities and mental health problems. The principles of Interpretative Phenomenological Analysis (IPA) were used to analyse the data. This chapter has five main sections. The first will describe the participants and procedure, the second, ethical considerations, the third, the researcher's perspective, the fourth, the measures used and the fifth, analysis of the qualitative data.

Participants

Inclusion Criteria

This study included parents of a young person with learning disabilities and experience of mental health problems. In order for parents to be invited to participate, their son or daughter needed to satisfy the following criteria:

- Aged 14-25 years
- Presence of a learning disability
- Current or past experience of mental health problems defined as:
 - Marked fluctuation in young person's moods or
 - Behaviour changes for the worse without any obvious reason or
 - Development appears to be impeded for no medical or predicted reasons or
 - A key relationship/s becomes significantly problematic, having not been so previously and
 - Change in the young person has persisted for several months

As noted in the previous chapter, the issue of defining mental health problems in people with learning disabilities is complex. The definition used in this study was adapted from that used by

The Foundation for People with Learning Disabilities to guide its year long inquiry into meeting the mental health needs of young people with learning disabilities (Foundation for People with Learning Disabilities, 2002), which took place at the same time as this study. The main criterion of the definition is that there has been a change in the individual that is impacting negatively on the life of the young person. This definition recognises that there are intense difficulties diagnosing mental health problems in people with learning disabilities, and that psychological or psychiatric problems may have a range of outward signs and symptoms, for example individuals with very limited communication skills may have few means of showing distress other than through disturbed behaviour.

It is now widely recognised that for young people with learning disabilities, the move from childhood to adulthood typically takes longer than for their non-disabled peers, with some taking considerably longer to move towards greater independence, while a minority may never acquire a significant level of independence. The age span used in this study, namely 14-25 years, reflects an age span representative of when transition to adulthood issues are likely to be of greatest importance. This age range is also in line with other research under way regarding young people with learning disabilities and mental health problems (see Foundation for People with Learning Disabilities, 2002).

Parents of young people with all levels of learning disabilities were included, as were those with additional diagnoses, for example of autism, in order to portray a varied and typical sample of the learning-disabled population. Parents were included regardless of whether their son or daughter was still living with them, in order not to exclude those whose offspring were in hospital or living in a group home, and again, achieve as varied a sample as possible.

Participants from ethnic minority groups were included in this study in order to obtain a demographic sample representative of the inner city borough where recruitment took place, obtain as rich and diverse picture of the experience as possible, and based on a concern to

avoid adding to a research base that tends to exclude ethnic minorities. This was thought particularly important given that the study took place in a geographical area where minority ethnic groups comprise 60.6% of the population (Office of National Statistics, 2001) and that at least 45% of the service users of the Community Health Team for People with Learning Disabilities are from non-white backgrounds. All participants were given the option of being interviewed with an interpreter, who would be accessed from the local interpreting services used by local service providers. As it transpired, none of the participants recruited wanted an interpreter present at interview, preferring to be interviewed in English even if this was their second language.

If parents asked to be interviewed with another son or daughter present, this choice was also respected. This was thought especially important in minority ethnic families, where siblings often play a major part in care-taking, and, at times, take a 'parenting' role for learning-disabled siblings (Mir et al., 2001). By disregarding the views of these siblings, it was felt that the study would lose out on important wide-ranging effects of dual diagnosis on other family members.

In order to gain an in-depth understanding of a phenomenon, qualitative research investigates a small number of cases. This study followed the recommendations of Hill, Thompson and Nut Williams (1997) that qualitative studies should draw on a sample of about 8 to 15 participants.

Recruitment Process and Procedure

Participants were recruited from one healthcare trust in London. Contact was made with all professional team members of the Community Health Team for People with Learning Disabilities, the Transition to Adulthood Team (Social Services) and Educational and Voluntary Sector Carers Associations. Information regarding the aims of the study, the inclusion criteria, and what would be involved in participating was circulated. Professionals in these agencies suggested to the researcher any young person known to them (either currently or in the past) who met the inclusion criteria and whose parents (or parent) might be willing to participate.

Discussions about suitability then followed, in order to ensure definitional consistency, but information regarding presenting problems, diagnoses and family situation was kept to the minimum. This was firstly to ensure that strict rules of confidentiality were adhered to, and secondly in order not to influence or bias the researcher's thinking in any way, so as to enter into recruitment and interviewing procedures with limited preconceptions and avoid becoming side-tracked by potentially irrelevant information.

When potential participants had been identified, information sheets were sent to the parents along with a covering letter detailing who had identified them as a possible participant. Parents were asked to complete a detachable reply slip indicating whether they were a) happy to discuss the project further b) did not want to be contacted about the project, and whether they would need an interpreter for an initial meeting and subsequent interviews. A stamped addressed envelope was enclosed. If the reply slip was not returned, a follow-up telephone call was made to ascertain interest in the project. If interest was shown (either by reply slip or follow-up telephone call), the researcher made a time to visit the parents at their home to discuss the study (including issues of confidentiality, voluntary participation and consent). If they wanted to proceed, a convenient interview time was arranged.

With respect to recruitment source of those who agreed to take part, several participants were, not surprisingly, identified by different services, reflecting the fact that at least some of these young people tend to be in contact with numerous services. Ten of the eleven participants were identified by the Community Health Team for People with Learning Disabilities; two by the Transition to Adulthood Team (Social Services); two by the Carers' Association; and one by Education Services. As can be seen, identification was not exclusive to one professional or service.

Characteristics of the Sample

Twenty-eight letters of invitation to participate in the study were sent out to parents. Thirteen sets of parents expressed interest in the study, either through completing the reply slip or as a result of the follow-up phone call. However, one expressed interest but withdrew due to increased work commitments and another decided against participating following the preliminary meeting to discuss the research, because she was uncomfortable with the audio taping aspect of participation. In the end, eleven sets of parents of young people with learning disabilities and mental health problems agreed to participate in the study.

A total of fourteen parents and one female sibling were interviewed in the eleven interviews. In seven of the interviews, only one parent was present at interview. Three of these seven were single parents, all mothers. The remaining four of these parents, all mothers, while given the choice to be interviewed with their partner present, chose to be interviewed alone. In three interviews both father and mother were present. In one interview, the mother (a widow) chose to be interviewed with her eldest daughter present, given the crucial parenting role that she viewed her daughter as having for her son. Of the fourteen parents, twelve were unemployed or retired, and two were in skilled or manual employment. None of the parents were, or had been, in professions.

Six sets of parents were of South Asian origin (two from Punjab, one from Gujarat, one from Bangladesh, two from Pakistan) (54.5%), three were of White British origin (27.3%), one was of Black African origin (Ghanese) (9.1%), and one was of Turkish Cypriot origin (9.1%). This results in a total of 72.7% of the sample being of ethnic minority status. Five sets of parents identified themselves as Muslim (54.5%), two as Sikh (18.2%), two as Christian (18.2%), and two specified no particular religious beliefs (18.2%).

The age of the young people ranged from 17-24 years old, with a mean age of 19.9 years. Seven of the young people were male, and four were female. Although not all young people

had been formally tested, it was indicated by the professionals involved in their care that nine of the young people had mild or moderate learning disabilities, one had borderline learning disabilities and one had severe learning disabilities. Two of the young people had an additional diagnosis of autism, one of Down's Syndrome and epilepsy, one of Klinefelter Syndrome, and one of brittle asthma. Eight of the young people were living at home, two were in hospital, and one now lived in residential care. Four young people attended day services on a regular basis, two were at school or college, one young person had a part-time job, and four young people had no daytime occupation (one because of frequent and disruptive admissions to hospital).

Ethical Considerations

Ethical approval for this study was obtained from the NHS Healthcare Trust Research Ethics Committee (see Appendix 1). A joint application was made because at the time the service where the research was taking place was seeking funding to carry out a larger body of related work, which they did not eventually obtain.

An information sheet and a letter of invitation were sent out to parents, which gave an outline of the study and what it entailed (see Appendix 2). The information sheet stated that the study was independent of any current service input and that the decision to participate or not would not affect any of the services they were receiving or might receive in the future. Time was spent with the parents ensuring that they understood that participation was voluntary and that they were free to withdraw at any time. Confidentiality was also emphasised. Before the interview all participants signed a consent form (see Appendix 2). Following interview, if the participant expressed interest, the researcher left a sheet with relevant contact numbers such as for the local Carers Association, in order to provide them with perhaps unknown local resources that may be sources of help for them or their child.

Researcher's Perspective

It is good practice in qualitative research for the researcher to state their personal biases that might have an influence on the research (Elliot, Fischer & Rennie, 1999). The idea for this research was influenced by aspects of my clinical work in adult mental health, and then in learning disabilities. As an Assistant Psychologist on a psychiatric intensive care ward, I was struck by the inadequacies of such a unit for those who had learning disabilities as well as an acute mental health problem. Even for those without learning disabilities, the experience of the ward seemed to be one of confusion and bewilderment, but for those with dual diagnosis, the effect appeared to be multiplied due to cognitive, communication and social difficulties. Many of these inpatients were young adults, mostly under the age of 25. Then, whilst completing my placement in learning disabilities, I became aware of some of the challenges that are faced by parents of young people with learning disabilities and mental health problems. I witnessed this both on an individual level, through working with parents of young people, and on a service level, through work with the Transition to Adulthood Social Service team. In trying to understand the experiences of these young people and their families, I was struck by the dearth of research. Systemic models of working, including social constructionist thinking, have been influential in shaping my approach to this work.

Measures

Procedure

All interviews took place at the participants' homes. The interviews lasted between 1 and 3 hours. At the beginning of the interview participants were reassured of the confidentiality of the interviews and of their anonymity, and that they could stop the interview and have a break at any time. All interviews were audio tape-recorded with participants' consent.

The two standardised measures were completed with participants after, rather than before, the semi-structured interview, in order not to influence any personal concepts or constructions that the participants held prior to interview (e.g. impose medical terminology from the measure of mental health status). Participants were informed that in due course a summary of the results of the study would be sent to them, if they wished to receive it (see Appendix 2).

Semi-Structured Interview

A semi-structured interview schedule was designed for this study (see Appendix 3). In designing the interview schedule the researcher was informed by findings reported in the literature regarding adolescence, learning disabilities and mental health problems, as well as incorporating areas that have been largely unresearched, such as constructions of mental health and the process of identifying mental health problems in young people with learning disabilities.

The interview schedule served as a guide, which allowed exploration of new areas that emerged during the course of the interview. The style of the interview was one of 'directed conversation' (Pidgeon & Henwood, 1996). Thus the format was to pose open questions designed to facilitate disclosure and thought and did not request specific answers. It was hoped in this way interviewees' own conceptualisations of their experiences of learning disabilities and mental health problems could be elicited. However, the desire not to limit and constrain participants' responses was also balanced with the need for the interview to remain focused, and therefore follow-up questions and prompts were used. Prompts were also used in order to reframe questions if this was required. Care was taken to follow the participants' lines of thinking, and only to return to topics on the interview schedule if they had not been covered towards the end of the interview.

The interview schedule contained seven sections that were covered in a flexible order and varying degrees of detail in each interview.

1. Getting to Know the Family. The main purpose of this section was to establish a rapport with the participant and elicit demographic information about the young person in question and their family.
2. Process of Identifying Mental Health Problems. The aim of this section was to explore when, how and who first noticed changes in the young person, and how these changes manifested themselves.
3. Understanding of Mental Health Problems. This explored what sense the parents made of the difficulties experienced, taking into account cultural, religious and professional constructions where applicable.
4. Impact of Mental Health Problems. This part considered how the difficulties experienced by the young person influenced different aspects of their lives (occupational, social and familial domains) and the lives of their parents and other family members.
5. Informal Coping Strategies. This section explored in what ways the family and young person tried to manage the difficulties, and what was perceived to have been more or less successful.
6. Experience of Professional Help. This section asked about experiences of accessing help and the actual help provided by services.
7. Closing the Interview. This was an opportunity for participants to clarify any points raised during the interview, ask any questions, and for the researcher to thank the participants for their participation.

Standardised Questionnaires

Two self-report measures were administered and used for descriptive purposes, to give an indication of the young person's level of functioning and the nature of emotional and behavioural problems experienced.

Degree of Dependency Scale (Evans, Caddell & Woods, 1981)

The Degree of Dependency Scale is composed of four short sub-scales, measuring continence, mobility, problem behaviours and self-help ability. Versions of this measure have been used in a number of recent studies (e.g. Grant & McGrath, 1990; McGrath & Grant, 1993; Walden, Pistrang & Joyce, 2000). The version used in this study was composed of three additive scales: continence (four items), mobility (two items), and self-care (two items). Problem behaviour was omitted as this was measured by a separate scale. Each item within each scale has three response categories scored one, two or three. The more able the person with learning disabilities, the higher the score. For example one item within the self-care scale is 'Washes him/herself'. The response categories are (1) Not at all; (2) With help; (3) Without help. An overall level of physical dependence is determined by adding the scale totals. Scores can range from eight to twenty-four, with higher scores indicating a higher level of ability.

The Degree of Dependency Scale is derived from the Wessex Mental Handicap Register (Kushlick, Blunden & Cox, 1978), and was administered to participants to ascertain the level of physical dependency of their son or daughter. Although all young people identified had a diagnosis of learning disabilities, the referrals came from a number of different sources who may well have different understandings of different levels of learning disabilities. It was therefore considered important to gain a specific measure of dependency for this study. A measure of physical dependency was used in the absence of being able to assess learning disabilities, which requires a very detailed assessment. Although no direct assumptions about level of learning disabilities can be made from this scale, it gives a description of parental input and level of care required. This scale was also chosen for its simplicity and brevity, given that participants had already completed a lengthy interview.

With respect to reliability, the Wessex Mental Handicap Register has been demonstrated to have an inter-rater reliability of 0.68 (May, Hallet & Crowhurst, 1982). Humphreys, Lowe and Blunden (1983) report that interviewing staff or parents as opposed to letting them complete

the scale unsupervised increases the reliability of the scale to above 0.70, as was done in this study.

Aberrant Behaviour Checklist-Community (ABC: Aman & Singh, 1986)

The ABC is an empirically derived psychometric instrument to rate the maladaptive behaviours of people with learning disabilities. The scale was designed for use with people with mild, moderate, severe and profound learning disabilities. It is an informant rater tool and can be filled in by parents with no special training required before.

For each item, participants were asked about their son or daughter's behaviour at the time when their mental health problems were at their very worst (an adaptation to the original which asked about the previous four weeks' behaviour). The checklist has 58 items that are divided into five subscales: I. Irritability, Agitation, Crying (15 items); II. Lethargy, Social Withdrawal (16 items); III. Stereotypic Behaviour (7 items); IV. Hyperactivity, Non-compliance (16 items); and V. Inappropriate Speech (4 items). For each item participants rate whether the behaviour specified is a problem and respond on a four-point scale (0 = not at all a problems; 1 = behaviour is a problem but slight in degree; 2 = the problem is moderately serious; 3 = the problem is severe in degree). The rating scale is scored by summing the obtained ratings (0 to 3) for the relevant items to obtain totals for each subscale. The authors suggest that special note be taken when a person's subscale score exceeds the 85th percentile for his / her normative group.

The Aberrant Behaviour Checklist (ABC) was administered to participants to ascertain the type of problems that their son or daughter was experiencing. Again, although all young people were identified as having mental health problems as defined in the inclusion criteria section, it was thought useful to clarify exactly what behaviours were experienced.

In terms of reliability, Aman, Singh, Stewart and Field (1985) found high internal consistency of the subscales (alpha coefficients of mean 0.91). Test-retest reliability of the checklist was also found to be good, suggesting that the subscales are stable over time. They advised that clarification of terminology and instructions by the researcher to the rater prior to completion of the checklist increased already adequate inter-rater reliability, which was done in this study. In terms of validity, Aman et al. (1985) report high convergent validity with the corresponding domains on the Adaptive Behaviour Scale (ABS; Nihira, Foster, Shellhaas & Leland, 1974) and direct observation of inappropriate and maladaptive behaviour, and also good discriminant validity.

Analysis of Qualitative Data

All interviews were audio recorded and transcribed verbatim, and any details that might identify the participants or professionals involved were excluded to ensure confidentiality (see Appendix 4 for an excerpt of an interview transcript). Transcripts were then analysed following the principles of Interpretative Phenomenological Analysis (IPA; Smith, Jarman & Osborn, 1999).

Rationale for Using IPA

IPA was specifically designed as a psychological research method. It is a phenomenological approach and is therefore interested in the subjective experiences of individuals within particular contexts and at particular times, as opposed to being interested in discovering objective 'truths' (Smith et al. 1999). IPA is not attempting to develop comprehensive theories about the phenomena under investigation from participants' accounts of their experiences, unlike Grounded Theory. Instead it is concerned with gaining insight into the nature of individual experiences. It is participants' accounts that become the phenomenon with which the researcher engages.

IPA is a dual approach, being both phenomenological and interpretative. Smith (1995) describes this as being represented by an attempt to understand participants' internal worlds from the examination of their overt communication, as well as the researcher's own interpretations of the text to clarify less 'transparent' meanings. Thus IPA explicitly recognises that the researcher's conceptions and beliefs influence the process of making sense of the data, and it therefore states that the themes derived are a reflection made by both the participants and the researcher.

Data Analysis

Several stages are involved in the process of 'looking for themes' in the data (Smith et al., 1999). In the initial stage of the process, the transcripts were read in turn in order to become familiar with the data. The first transcript was then focused on in more detail. This involved a cyclical process of reading and re-reading the transcript several times, noting down initial thoughts and summaries. At this stage, comments closely reflected the data. An example of this initial stage is illustrated below:

Quote	Preliminary Notes
<i>"I feel guilty about his emotional problems, I feel like I should have been able to protect him from all his troubles. I've failed him really. Mothers should be there to protect their children."</i>	Guilty Should have been able to protect him Failed him Mothers should protect children

After this stage the transcript and initial notes were read again, with the aim of identifying emerging themes, capturing the essence of what was being said. An example of this stage of the process is illustrated with the same quote below:

Quote	Initial Theme
<i>"I feel guilty about his emotional problems, I feel like I should have been able to protect him from all his troubles. I've failed him really. Mothers should be there to protect their children."</i>	Failed Protector

A list of these initial themes was noted. These initial themes were then further refined with reference to the original transcript, and quotations illustrating each initial theme were noted.

Once this had been done for one transcript, the theme titles were used to analyse further transcripts, in conjunction with the same noting and summarising process already described. These initial themes were refined and added to as more data emerged from each further transcript. This process was cyclical, in that a continual process of checking back to the original transcripts in relation to the emerging themes was employed. This process continued until a final list of themes and sub-themes had been created, which was facilitated by the use of coloured post-it notes to represent initial themes, grouping them together into the final sub-themes and overall theme titles.

For the above example, the initial theme of 'Failed Protector' was grouped under the sub-theme heading of 'Living with Blame', within the overall theme title of 'Changing Us', as illustrated below:

Theme	Sub Theme	Initial Theme
<i>Changing Us</i>	<i>Living with Blame</i>	<i>Failed Protector</i>

See Appendix 5 for the full set of quotes relating to the initial themes of the above sub-theme, 'Living with Blame', and Appendix 6 for the full list of initial themes grouped into sub-themes and themes.

Credibility Checks

A variety of credibility checks of the themes were made throughout the analysis process. These procedures were used to ensure that the themes reflected the essence of the parents' experience and help increase the validity of the final themes. A second researcher experienced in IPA crosschecked the initial emerging themes of the first few transcripts. Two further researchers then cross-checked the emerging themes of the next four transcripts, and their feedback was used to modify emerging themes. Following the development of a tentative organisation of the themes into a hierarchical order, this was discussed with the second researcher. This organisation was then modified and examined through discussions with this and the other researchers, whereby a final set of themes and sub-themes was agreed upon.

CHAPTER 3 ~ RESULTS

Overview

This chapter has two sections. The first presents the questionnaire data in relation to related descriptive data, and together with demographic data presented in the previous chapter sets the context for the second section. The second section presents parents' perspectives and experiences of having a son or daughter with learning disabilities and additional mental health problems.

Questionnaire Data

Degree of Dependency Scale & Level of Learning Disabilities

These scores ranged from 17 to 24 (where the maximum score is 24), with a median score of 24 (no norms available). As would be expected, there appears to be an association between scores obtained on the Degree of Dependency Scale and the severity of learning disabilities of the young person. In general, lower scores seemed to be associated with more severe learning disabilities, while higher scores seemed to be associated with less severe learning disabilities. Further, lower scores appear to be associated with additional diagnoses such as autism and Down's syndrome.

Six young people were rated by their carer as completely physically independent. These six young people were described as having borderline to mild or mild learning disabilities. Two young people received a score of between 20 and 24 by their carer; these young people were described as having mild or mild to moderate learning disabilities. Three young people received scores of less than 20, and all of these young people were described as having moderate or severe learning disabilities. These three young people also had additional diagnoses of either autism or Down's Syndrome.

Aberrant Behaviour Checklist – Community

An overall score was obtained for this scale (maximum 174), as well as scores for each of the five subscales. Overall scores ranged from 53 to 116, with a median score of 91. There are no norms for the overall scores therefore norms were examined for the subscale scores. No set of sub-scale norms perfectly matched this sample, therefore the nearest matched norms (18-30 year old adults in group homes) were used, as agreed in discussion with one of the authors (Aman, personal communication). These scores are presented in Table 1, with other relevant data.

All young people exceeded the 85% percentile for their normative age group on at least one subscale. The subscale that young people were rated most commonly above the 85% percentile was subscale I, Irritability, Agitation and Crying. The next most common was subscale V, Inappropriate Speech, then subscales II and IV, Lethargy and Social Withdrawal, and Hyperactivity respectively. The least common subscale that young people were rated above the 85% percentile was subscale III, Stereotypic Behaviour. Three young people exceeded the 85% percentile on one subscale, four on three subscales, two on four subscales and two on all five subscales. In general, the presence of a specific psychiatric diagnosis seemed to be associated with higher scores and more 'extreme' subscale scores. Both young people who exceeded the 85% percentile on all five subscales required regular hospital admissions and had specific psychiatric diagnoses, namely bipolar affective disorder and delusional disorder. Additional diagnoses such as autism did not appear to be associated with higher scores.

Table 1: Parental Ratings on the Aberrant Behaviour Checklist, displayed with relevant descriptive data.

Participant *	Additional Diagnoses	Level of Learning Disabilities **	Diagnosis / Mental Health Problem ***	Aberrant Behaviour Checklist Score ****
1 (M)	Autism	Severe	Psychosis	53 (V)
2 (F)	–	Mild-Moderate	Anger & Aggression	81 (I,IV,V)
3 (F)	Downs & Epilepsy	Moderate	Depression	68 (II)
4 (M))	–	Mild	Hallucinations Delusions ?Psychotic	98 (I,III,IV,V)
5 (M)	Klinefelter Syndrome	Mild	Aggression ?Paranoid Personality Disorder	90 (I,II,V)
6 (M)	Autism	Moderate	Aggression Low mood	116 (I,II,IV)
7 (M)	Brittle Asthma	Borderline-Mild	Low mood Aggression	58 (I)
8 (M)	–	Mild-Moderate	Delusional Disorder	102 (I,II,III,IV,V)
9 (M)	–	Mild	Chronic Dysthymic Disorder Self-Harm	108 (I,II,IV,V)
10 (F)	–	Mild	Depression	91 (I,II,V)
11 (F)	–	Mild-Moderate	Bipolar Affective Disorder	116 (I,II,III,IV,V)

Key

- * Gender of young person
- ** Information gathered from files or professionals: not formally assessed for all participants
- *** Information gathered from professional who identified young person for research and file, ? denotes a possible but uncertain diagnosis
- **** Maximum score of 174, higher score indicative of more aberrant behaviours, bracketed figures represent subscales where the score exceeded 85% percentile for age (i.e. extreme behaviour), where I= Irritability, Agitation, Crying, II= Lethargy, Social Withdrawal, III= Stereotypic Behaviour, IV= Hyperactivity, Non-Compliance, V=Inappropriate Speech

Parents' Accounts

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 to a young person who has both learning disabilities and additional mental health problems. Analysis of the transcripts of parents' accounts yielded a number of themes and sub-themes, illustrated in Table 2 below. These themes are not mutually exclusive: inevitably there is some degree of overlap, with confusion, loss and hardship running through all themes.

Table 2: Overview of Themes and Sub-Themes

Themes	Sub-Themes
1. Struggle to Understand	<ul style="list-style-type: none"> • Struggling in the Dark • Playing Detective • Searching for a Cause • Needing to Know
2. Changing Us	<ul style="list-style-type: none"> • Fresh Wound • Extra Care and Pressure • Suffering and Loss • Living with Fear • Living with Blame
3. Managing the Best We Can	<ul style="list-style-type: none"> • Existing not Coping • Isolation
4. Battle for Help	<ul style="list-style-type: none"> • Not Listening to Us • Waiting for Us to Break • Inadequate Provision

Excerpts from the transcripts that are used in this section have in some instances been edited to capture the most important information. Where editing has occurred, this is represented by three dots "...". Where dialogue is presented, "I" refers to Interviewer, "Mo" to Mother, "Fa" to Father. Where the young person is spoken about, "X" denotes this. The source of each quotation is indicated by the participant number.

THE STRUGGLE TO UNDERSTAND

This theme captures the essence of these parents' struggle to understand what is going on for their child, as they try to make sense of changes in their child's behaviour and emotional state. The theme describes parents' sense of utter confusion when their child began to display different behavioural or emotional responses. This confusion was compounded by having to understand these changes within the context of learning disabilities: their task of understanding seemed to be made harder by having to 'play detective' with respect to their child's well-being and by their child's struggle to understand through reduced cognitive abilities. Parents tried to make sense of the behaviour by searching for causes, which were numerous and wide-ranging, but in the main related to their child's puberty and associated changes, and learning-disabled status. While parents expressed a strong need for a diagnosis, and relief when one was given, their understanding of the diagnosis was in the main confused. The theme has four sub-themes, 'Struggling in the Dark', 'Playing Detective', 'Searching for a Cause', and 'Needing to Know'. These sub-themes will be outlined in more detail below, with extracts from interviews to illustrate each one.

Struggling in the Dark

All parents described a strange and puzzling time when their child's behaviour changed. For some, whose child had not had any significant challenging or difficult pre-existing behaviour, these changes were abrupt, and left them with a sense of utter confusion and puzzlement.

"He started adopting this, you know, acting like a cat, climbing across people's gardens and fences, jumping up on their roofs and getting little fixations with the neighbours. He would be convinced that they were all staring at him, and later on it transpired that he used to make signs at them, swear at them...but when you looked out you couldn't see anybody, it was in his mind. But he thought it was there...I just couldn't understand it at all. I didn't know what was going on with him. I thought, what's this weirdo doing? Is he being deliberately weird? Is he putting it on? Is he just trying to piss me off? Honestly, I didn't know what to think." (8)

For other parents, whose children had always displayed some degree of difficult or challenging behaviour, the change in behaviour was not quite so abrupt. Where the initial

changes were less abrupt, parents tended to put the difficulties down to the pre-existing learning disabilities, an extension of their learning-disabled behavioural repertoire. However, as these behaviours became more distinct from the pre-existing behaviour, parents then tried to make sense of these 'different' behaviours and emotional responses that they were not used to seeing in their child. This task was equally confusing, having to distinguish 'abnormal' behaviour from behaviour already defined as 'abnormal' or 'challenging'.

"We've always been used to X displaying certain types of behaviour which other children, or normal children don't display. So we're quite accustomed to that...but what my mum noticed was that the behaviour was actually looking more and more disturbed, like we hadn't seen before." (1)

Where parents had no alternative explanation for the changes, for many there was a feeling that perhaps the new behaviours and emotional states were a result of their child simply misbehaving, being "bad" or "awkward".

"At the time I continually thought he was acting. And that sounds ludicrous now I say it. How could I have thought that? But we really didn't know what to do. We had no idea what was happening, what help we could get. I just thought he was bad, I didn't know what to think." (8)

For many parents a strong sense of bewilderment and confusion was apparent regarding the signs and symptoms of their child's mental health problems.

"He talks to himself a lot, he's just talking talking talking. And I say hey! What you doing? Stop that talking! But he just carries on. I just don't understand him." (9)

Often, parents experienced these changes as very dramatic and a complete change to their child who had once 'just' had learning disabilities. All parents reported feeling totally perplexed and 'at sea' by the inexplicable changes in their child.

"I remember it was so confusing, like my little boy had just changed into a monster...I felt lost...it felt like we were struggling on in the dark, blind if you like." (5)

Playing Detective

It was apparent that parents' thorough confusion was exacerbated, or sometimes caused, by the difficulties of having to understand the mental health problems in the context of pre-existing difficulties, namely their child's learning disability.

Parents expressed the need to play "detective" for their child in respect to detecting signs of the mental health problem, and intuit what might be happening for their child, in a way that parents of children without learning disabilities perhaps would not have to. Parents felt this was mainly due to their child's limited communication abilities, which impacted on their ability to communicate to their parents that something was wrong, and so necessitated careful, methodical observation.

"Because of his autism he's always had very limited language, so he isn't able to signal to us that this is what's happening. We have to try and work it out ourselves. So my mum tends to observe him really really carefully, so she will look at things like is he sleeping properly, is he eating properly, how does his face look and so on." (1)

This necessary "detective" work was also seen as a function of their child's reduced cognitive abilities, which parents felt limited their child's ability to perceive and understand their symptoms, and to take responsibility for their own health status. The young person's limited abilities to reflect on, discuss or understand the problems that they were encountering were also perceived as a further barrier to parents understanding their child's problems.

"It's a bit like being a detective with X, [laughs] like Inspector Morse if you like, I have to be constantly on the look out for her illness, the signs of the illness, that's my job as it were. I'm constantly on the look out. I think if she were a bit more with it, like actually 19 and not mentally 8, then perhaps she may be able to do that a bit more herself, but I think her illness is so much more confusing for her than if she were, you know, normal. She may be able to take it on a bit more, for herself. Or maybe not. I don't know, but it's like a constant detective job." (11)

"I know people who suffer from depression who don't have any sort of learning difficulty whatsoever. I can think of one person who is academically quite accomplished and they are able to reflect on their experiences and I think that with X being autistic he is not able to do this clearly or express it to us." (1)

There was also a feeling for many parents that additional mental health problems in the presence of pre-existing learning disabilities put a huge strain on their child's own state, resulting in their own confusion. There was a perception that having mental health problems in the absence of learning disabilities would be difficult enough for a young person to understand, but having them in already disadvantaged young people made it even harder.

"...she ain't just got one thing to cope with, but two. And I suppose their mind must get scrambled, because like they said, she's only like an 8 year old, and that's a lot to take in." (11)

"Having a learning disability and getting ill, it's a lot for someone to take in. I mean I don't think I'd be able to cope, and I don't have no learning disability." (6)

A few parents felt that this confusion relating to what they were experiencing was likely to be a source of further distress and frustration for the young people.

"I think it gets too much for him, he can't digest it, and that is when he gets aggressive. It's the frustration coming out of him. Like people who have it all up there [points to head], like me, sometimes I can't get my brain round feeling depressed, so for X, it's harder because he hasn't got like the brain power I suppose." (7)

Searching for a Cause

Amongst this confusion, parents seemed to be trying to make sense of the mental health problems by searching for a cause, a trigger, or factors that contributed to the onset of the mental health problems. Most parents cited a wide range of factors, both internal and external to the young person. These factors seemed to be closely related to the teenage years and changes associated with this period in the life cycle, and for the majority, were tied up with their child's learning disabilities.

There was a strong sense that because of their child's pre-existing learning disabilities, parents struggled to understand the meaning of this new behaviour, and had considered a range of possible causes. Most parents had considered whether the learning disability

itself was at the root of the change in their child. A parent whose child experiences delusional episodes commented:

"He'll ask you a thousand times in a visit, are my arms alright are my legs alright. Ridiculous questions. It drives me absolutely potty... he's not the sharpest tool, and sometimes I've even wondered if it is that that makes him ask these questions, maybe that's it." (8)

The majority of parents also implicated the role of adolescence in the change. Parents were unsure whether the changes they were witnessing might be typical teenage behaviour, or were in fact caused by something entirely different.

"It was so hard to say. Is it her learning disability? Is it adolescence? Or something else? What is causing what part of her problems? I don't know that's for sure." (11)

Bar none, parents felt that bullying, or other forms of abusive treatment had caused their child's additional difficulties, or at least strongly contributed. The abuse or bullying was usually connected to the learning-disabled status.

"The worst part was when he was involved in a fight with bullies when he was 12. He went totally, I don't know, psychologically down...he was getting bullied, kids calling him stupid and thick." (7)

"Sometimes he is banging his head like this [demonstrates head banging on wall]. Last week he damaged his head you know, from the wall, hitting his head on wall, hurt himself bad yes. Another time he took the razor, he shaved his whole head, and it was all cut, bleeding. I said what happened? Bleeding all over. He said I'm harming myself...He thinks his body is all bad. He is ugly man, nobody likes him, he is not a tall man, he is fat man, horrible looking, that is what he says, what he thinks, because of what they say to him at school." (9)

Parents' felt that others' responses to their child's learning disabilities had a central role in causing the mental health problems. They talked about their child feeling different, excluded from, or left behind their peers and siblings, which resulted in strong negative reactions.

"She is miserable about herself. Nothing in there, nothing good about herself, she doesn't think so, because of her learning problems. She thinks she can't do nothing. I don't like talking about this but sometimes she cuts herself, on her wrists, because she is so depressed about the learning." (10)

The young person's increasing awareness of their lesser abilities at this age was also cited as contributory. Many parents felt that their adolescent child was struggling to come to terms with their learning-disabled identity and that this contributed to the development of mental health problems.

"He goes day centre, in the van. But even that makes him upset, it makes the upset and silly talk worse. Because he looks normal, and all in the van they look, you know, very bad, disability. So he thinks why am I in that van with those people like that? He feels shame. He says he don't want to go there in the van. He doesn't like to be seen with them. He thinks he is different from them...He feels shame of his learning problem. That makes his mental problems worse you know, he no accept it." (9)

This struggle to come to terms with the learning-disabled status, and associated negative consequences for mental health, was not limited to the young people themselves. One mother, whose child's learning-disabled status had not been fully understood or diagnosed until she was 16-years old, discussed how her and her husband's own difficulties in coming to terms with her daughter's learning disabilities probably contributed to the development of her daughter's mental health problems.

"He [Father] can't accept that she can't do nothing, he thinks that she don't want to, that she wants to be a lazy devil and just sit on her backside. And that makes her more upset and depressed, like he don't believe her, that it is her fault she is slow." (10)

Puberty was a common theme that emerged in parents' search for a cause, specifically around their children having to deal with pubertal changes with limited cognitive abilities, and the confusion and upset that results. Delayed, or sometimes absent signs of puberty, were also viewed as causing distress for their child.

"I think with kids like X, if their hormones are playing up because they are getting into teenagers, they don't really know what's going on, so that's probably a bit confusing for them. I don't know if they do understand what's going on, I don't know, but it must be different because their bodies are changing inside and their hormones are changing and they don't understand why it's changing. Then it must be very confusing for her." (2)

"You know what was really hurting him? In his physical appearance he was very delayed, you know, going into teenage years. Delayed puberty, I think that caused him to be aggressive too." (7)

A struggle for increased independence was also a key theme experienced by parents as contributing to their child's mental health problems. For many, parents recognised that fears concerning their child's increased vulnerability, due to their learning-disabled status, resulted in them being very protective of the young person and imposing quite strict restrictions with respect to independence. Such restrictions were acknowledged as conflicting with the young person's wish for increased independence and freedom as a teenager, which often resulted in frustration, anger and upset.

"She has no life really if you think about it, not compared to a normal teenager, but she has all them same urges, you know hormones, wanted to party, go out with her friends, but it's hard to let her go because of what could happen to her. And I'm sure that makes her angry and frustrated you know, she must feel like, restricted." (11)

Parents also cited a wide range of factors associated with education as contributing to the development of the difficulties. Changes in educational placements, specifically the change from special school to mainstream institutions, or from primary school to secondary school were cited as contributory. Some parents also perceived the mental health problems as at least partially resulting from their child's learning disabilities not being recognised early enough, not getting adequate help in the classroom, or not being placed in an appropriate educational setting. Both inclusion in mainstream classrooms (through bullying and through feeling inadequate in relation to their peers) and segregation into 'special' educational settings (through copying maladaptive behaviours) were seen as contributing to the problems.

"The change came when she went to college, she was 18, her teens, so the changeover there, being a big school, from private school, I mean the special school, to a big school brought a lot of change of atmosphere and everything, the teachers the pupils and everything." (3)

"Providing the right support in the first place, recognising learning difficulties very early, that is very important. Early, so that the child doesn't feel that he is different and so that the peers don't pick on him. Before the peers pick on him, pick it up, because the bullying can be awful, like it was for X. If it had been picked up earlier he would be confident, he would not be so down in himself." (7)

Other contributory factors cited by parents included a paucity of friends, a lack of meaningful daytime activities or opportunities for employment, bereavement, and

possession by evil spirits. Lastly, for a minority of parents (all fathers), there was a tendency to see the changes in behaviour and emotional state as within the young person's control, resulting in a blaming attitude. One young person tried to tell his father that he was hearing voices, and received the following response: *"My husband said 'I don't believe this, you are lying, you are just a horrible person'."*(5). Another father attributed his son's crying and withdrawn behaviour to *"habit and so lazy"* (4).

Needing to Know

For most parents, their sense of confusion and struggling to understand was experienced as being made worse by not knowing what was wrong with their child, by not having a diagnosis. This not-knowing state evoked a strong sense of helplessness in parents, with respect to how they might help their child.

"If we knew maybe it would make it easier us to help him, how to be with him, what to do." (4)

While parents were trying to make sense of the behaviour and emotional response (as illustrated in the preceding sub-theme), they were generally of the opinion that receiving a diagnosis would be beneficial to their understanding and ability to help their child. The following excerpt, from a parent whose child received a diagnosis of bipolar affective disorder or 'manic depression', illustrates this:

"I needed to know. It was important so I could understand her, how to help, what it all meant. You know, to go from angel to a tyrant so quick, it just didn't make sense and I needed to know why. To put the pieces together." (11)

Amongst the minority who had received a diagnosis of a mental health problem most spoke with great relief about knowing what was wrong. Being given a diagnosis removed the tendency to see the mental health problems as deliberate or wilful on the young person's part.

"It has been so important for us to understand what is happening to X, understanding his condition, and just simply knowing that he has a diagnosis as opposed to this is what he has become, like because that was the most difficult thing in the beginning, we didn't know what was going on...And just the fact that we were able to name the condition, and that this is something that is recognised and possibly treatable to a certain extent, that was really

really reassuring, so I think for me and my mum, that has been the most important thing.” (1)

“... if we'd have known that [mental health problem] was it all those years we struggled with him, it would have made everyone's life easier. But we didn't know he was ill, just thought he was being bad and weird.” (8)

However, even when parents had received some form of diagnosis, most were still confused about what it actually meant, feeling that no-one had explained the complexities adequately, or that professional explanations had not made sense.

“He's got a range of, you know, this dual diagnosis they keep talking about, which really only implies to me that they don't know what is wrong with X, I've always thought that. They have never sat down and explained it, just dual diagnosis, well that means nothing to me.” (8)

“No-one didn't tell me much about the manic depression, I just picked it up. No-one has ever told me, I don't really understand it to be honest...I mean I didn't think it would go on this long. I knew she had manic depression, but I thought it would get better after about a year, I didn't really understand what it meant. That could have been explained better I think. I had no idea actually what it meant for X. So 2 years, 3, the next time it is 5 years.” (11)

Struggling to understand the mental health problems was made more difficult for a significant proportion of parents for whom the concept of learning disabilities was still mystifying. For some parents, even those whose children had been in contact with services for many years and had received both diagnoses of learning disabilities and a specific psychiatric disorder, the term learning disabilities was understood with respect to difficulties in learning only, with less or no appreciation of the more wide ranging implications of the concept.

“When someone says learning difficulties I think to myself well they've got problems learning. It don't have nothing to do with the way they behave and act. It's to do with learning.” (2)

Where misunderstanding and confusion concerning learning disabilities occurred, having to get to grips with and integrate the meaning of a further diagnosis of mental health problems seemed then to be all the more difficult. A few parents were clear that they needed more input from services regarding explanation of the various diagnoses, in order to help them in this struggle to understand.

"It needs to be explained more to people like me. I'm not the most educated of people I know, but if they take the time to explain it more, I'm sure I would get a better grip on it and I think that would help. She had all these things, and it's hard to keep in my mind, me and X. They don't realise how much there is to cope with and understand." (11)

CHANGING US

This theme encapsulates the ways in which the mental health problems affect the young person, parents, and wider family. It describes the implications of having a child with learning disabilities and additional mental health problems, both emotionally and practically. There was a general consensus that all parents' lives were made significantly more difficult as a result of having to cope with these additional problems:

"Since he changed everything has become harder, now we have to cope not just with a slow son, but also he has this terrible anger and voices. It's too much." (5).

This theme consists of five sub-themes: 'Fresh Wound', 'Extra Pressure and Care', 'Suffering and Loss', 'Living with Fear' and 'Living with Blame'. The first sub-theme describes how the additional mental health problems are perceived emotionally by parents. The second sub-theme describes the extra stress, care-burden and responsibilities that the additional mental health problems put the parents under; there was also a sense that at times, these parents were in need of escape, but there were no means by which this could be achieved. These two sub-themes are closely related to the next, which describes the suffering, hardship and losses encountered as a result of the additional mental health problems. The final two sub-themes detail the sense of fear and blame that parents live with in relation to the additional mental health problems.

Fresh Wound

This sub-theme encapsulates the emotional impact of the additional mental health problems on the parents. The problems seemed to provoke new and additional pain in these parents: *"Anything fresh is a fresh wound so you feel the pain. The pain was there."* (3). The mental health problems appeared to be perceived by parents as yet another blow

to an already disadvantaged young person, which frequently exacerbated and accentuated the young person's sense of being different from their peers.

The majority of parents talked about feelings of pain regarding the additional mental health problems. They expressed hurt and anger that their child had yet another problem, in addition to the pre-existing learning disabilities. This pain was seen as additional to the pain they had experienced when discovering that their child had learning disabilities. There was however a sense that these new problems in some way re-triggered the shock, grief and pain that they had felt for their child when the diagnosis of learning disabilities had been made. It seemed then that a cumulative effect resulted, with the pain and grief of the learning disabilities resurfacing, adding to the pain and grief felt regarding the mental health problems. The following excerpts illustrate these points:

"It hurts us, another problem, another hurt for us. Is it not enough he slow? He has to have these problems also?" (9)

"It is painful, painful all over again, again! You know, when we first realised he slow it was hard, now this, with his terrible anger and the voices, is like more pain, all over again, again." (5)

"Not only did she have the learning disability, but now also the manic depression. And each one piles up on the other you know, like it was such a shock when they said about the mental age like, but then when they told me about the manic depression, it hit me again. Again! It was like, whoa, too much." (11)

"Every little difference, his phobias, his development, is like another pierce through my heart, my husband as well." (7)

This additional pain was exacerbated by parents' recognition that the mental health problems served to accentuate their child's difference from peers and siblings. This resulted in parents feeling further hurt, a sense of unfairness and injustice, and anger.

"I look at my other children and friends children and they are so normal, X is different in all these ways. And I think, it's just not fair, why does he have all these different things wrong with him and their children are completely normal?" (5)

The additional mental health problems also impacted on how parents viewed their child's safety in the world. There was consensus that having both learning disabilities and mental health problems significantly increased, or perhaps even doubled, their child's vulnerability.

“And other people, well I think it gives people more ground for being nasty, to take the micky out of her. Because both of the things X has got, people take the mick out of around here, so having them both is like even more ammunition for them...I think having both makes it worse, you cop it left right and centre to be honest. It’s double hard.” (11)

Extra Pressure and Care

The additional mental health problems resulted in extra care responsibilities for all parents. Parents described increased pressure as a result of their child’s additional care needs. This increased pressure appeared to result from a number of factors. Some parents described their child losing independence and self-care skills as a result of the mental health problems, therefore increasing the carer burden.

“Before he turned 16, a year or so before his first break down, X was very independent. He would brush his teeth well himself, he could shower himself, he could clean himself after going to the loo, he was very very independent in terms of the basic everyday activities, he could do basically all of that really well. And things at that point actually looked quite positive, we thought that maybe he might even be able to travel by himself, use public transport by himself and so, he was very very good like that. After his breakdown he’s actually lost a lot of those skills or he is not using them or is no longer able to use them...it does put us under extra pressure as we are having to now do things that we didn’t have to before.” (1)

Many parents described how the symptoms or manifestations of their child’s mental health problems created extra stress or pressure in different ways, as illustrated by these following quotes:

“It was the all night vigils he used to keep. We didn’t sleep properly for years. Years. And we had to go to work, earn a living. We were only in the next room. We couldn’t sleep.” (8)

“She did talk about ending it once to [friend], that is why we don’t like leaving her alone by herself. We don’t like leaving her on her own, because I think it could get worse if she was left. She would start in her mind, why can’t I do this and that, I’m thick, I’m stupid. She doesn’t think very much of herself, because she can’t read. So we have to be with her all the time really, well someone does, because we worry, so that’s quite stressful you know, its like 24/7 on our guard with her since the depression started.” (10)

“There are so many things he does now. He won’t come down to eat with us now. Then he comes downstairs and eats everything and anything from the fridge. He is throwing everything, it is costing me so much. We can’t keep anything around in the house. The bathroom he ripped apart for no reason. We don’t have any soap there for our hands, no toothpaste, nothing, we have to carry these things around with us like we were on holiday. Because everything gets broken, flushed, squashed.” (6)

This additional pressure and responsibilities resulted in a number of consequences for parents, and subsequently the young people. There was a sense that parents struggled with juggling family and work roles in the face of these increased responsibilities, especially in the light of decreased sleep and time for their own self-care needs. The extra pressure caused by the mental health problems also meant that some parents felt that their caring abilities were compromised. Further, the mental health problems also resulted in many parents feeling a greater sense of responsibility for their child.

"She is my priority. She always has been, but even more now, since she got ill. My life revolves around her and her illness. I can't help it." (11)

As a result of this sense of extra pressure and responsibilities, a common theme that emerged for these parents was one of needing escape. A few parents described feeling envious of their son's or daughter's siblings' ability to avoid or leave the family home when the situation became too much. Many parents described similar feelings of needing to escape, physically and emotionally, simply needing to get away from their son or daughter. While parents spoke of this need to escape, it was also apparent that they did not feel supported by services in this respect, and thus their escape was not achieved. There was a consensus that because of the additional pressure resulting from their child's difficulties, respite or support was even more required, but less available than if their child 'only' had learning disabilities. All parents commented on the need for services to provide more respite opportunities; parents discussed the function of such respite in terms of providing them with a break from their caring responsibilities, in terms of giving their child varied opportunities, and in terms of being able to give their other children some 'quality' time.

Suffering and Loss

All parents described numerous instances of loss and ways in which their lives, the young person's lives and sibling's lives had suffered. For most parents, the recognition of extra responsibilities as a result of loss of skills or independence in the young person brought with it loss of hope for the future with respect to the young person ever being independent

from them. This loss of hope extended to the young person's ability to take part in 'normal' aspects of adult life, such as getting a job, forming intimate relationships and getting married.

"At one point we all thought that if he develops into an adult able to look after himself, then it would be possible for him even to get married and live like maybe not a particularly fulfilling relationship, but able to hold down a job, manage to cope on his own, be in a relationship, then we were hoping he could get married. But at the moment we really believe that this is impossible it just won't happen, because of him developing psychosis." (1)

For a few parents, where the young people were first born males in South Asian families, the additional mental health problems appeared to result in losses with respect to culturally shaped parental expectations. For these parents, there seemed to be intense disappointment and a sense of loss when their child could not live up to their cultural expectations of traditional male roles. As a result, some of these parents appeared willing to go to extremes to ensure that their child fulfils at least some of these expectations, even if the outcome is likely to be very unsatisfactory. This is illustrated by the following excerpt, which describes one parent's struggle in trying to arrange a marriage for his son:

"I can't find a girl here, but in Pakistan there are many girls over there, poor girls you know, who if we explained he has problems they would marry him. There are a lot of poor people over there who want to come here. Maybe we will find a girl, a good girl, normal girl, who would marry him and look after him. This may be solution. No girls here, they would not want him here with his problems, the silly talking. If it was just the learning problems I would have no trouble to find a wife, but the silly talk, the crying, the punishing himself, well that is different, a much harder thing." (9)

As well as loss of skills, independence and hope for the future, other losses were numerous and wide-ranging, relating to the young person, the parents, siblings and family life in general. With respect to the young person, parents described multiple losses including loss of friends, quality of life, interests, self-pride and schooling. For some parents, additional mental health problems were perceived as quite catastrophic for the young person, a major blight to their life.

"His life is ruined, ruined by these problems that he is having. That's all. Ruined child he is." (4)

With respect to losses for siblings, parents tended to feel that their other children had suffered, regarding 'normal' home life (when the young person 'just' had learning disabilities), their school work, and quality of sibling-parental relationships. In some cases, siblings had to take on significant new responsibilities and roles within the family as a result of the mental health problems, either directly, through helping with the care of the young person, or indirectly, through parents needing additional help in other areas due to their own increased care burden. These extra responsibilities resulted in further losses for siblings and parents.

"After the changes, they would not bring friends into the house because they were scared of how X would be. And their school work went bad." (5)

I never had any time for them [other siblings]. Because I was so worried about X, he took up all my time. It definitely affected my relationships with them. Definitely...I think they feel I neglected them." (7)

Parents felt they had also suffered significant losses as a result of the mental health problems. This included losses with respect to personal space and time, the quality of their relationship with the young person, the quality of the parental relationship, the quality of their everyday lives and contact with friends and family. There was also a feeling of great loss for these parents with respect to family life, many yearning for the life they knew when the young person had 'just' had learning disabilities. The following excerpts illustrate some of these points:

"We didn't have people round. We just couldn't handle the hassle and embarrassment. He took this place over, he ruled the roost. We couldn't have a bit of privacy at any point. We never had any space. We could never just sit together and relax, always worried about what he'd do next...it put all of us under incredible pressure, you know, constantly on the go with him, worrying about him, what he was doing, so we stopped doing the normal things in life, seeing friends, family and that." (8)

"It wasn't all roses [prior to depression] but then she was happy, so we were all happy. We know that she was handicapped but we could be happy, although she was a handful. Like she'd wash up and mess up the kitchen or go to toilet and you see faeces all over the place or whatever. But we were getting on alright even so." (3)

"He had learning problems early age you know, but never like this. He used to be happy, we have lost that now, he was happy and so were we, even though he was slow, we were OK." (9)

All parents described significant suffering and hardship (for them and their other children) as a result of their child's mental health problems. These included deterioration in their mental and physical health, including feelings of depression, sadness, anxiety, increased physical illnesses, poor sleep, anger, and a general consensus that the experience had 'changed' them in a negative manner. The following quotes illustrate the breadth of suffering identified by the parents.

"When I go to bed at night I just can't relax and just calm down and go to sleep, there's just too much going on inside my head." (2)

"You know, to look at, everybody says oh you are fine you are ok, but inside you are not, you know, you are really broken inside." (5)

"I started getting ill, with stomach pains and indigestion when my X was acting so strange and I didn't know what to do, I think it was my body's way of showing how stressed I was about her, her change." (11)

"I cry a lot you know. I sit in now and cry a lot." (10)

Only two parents described any positive outcomes of the additional problems. One parent described how she felt closer to her son as a result of the additional problems; another described the parental relationship becoming closer.

"I am closest to him, because he is the oldest and he has been through so much, and we have together. I mean I do get angry with him a lot but I think it has made us close as well." (5)

"I suppose it has bonded us even closer really...That hasn't driven us apart, if anything closer, we had to. Perhaps other couples wouldn't, perhaps they'd have gone the other way, but for us it was us against the rest of them, because we didn't have any help." (8)

Living with Fear

Fear was common to most parents' experiences in relation to their child's mental health problems. These fears were wide-ranging. The majority of parents described feeling frightened in response to their child's behaviour and emotional state. There was a feeling for most parents that they bore the brunt of their child's internal distress or unhappiness, often in the form of verbal or physical aggression. The majority of parents described feeling

completely terrorised by and scared of their child as a result of the mental health problems at some time. The following excerpts illustrate these points:

“He takes all his anger out on us, verbally and sometimes physically, I’m fucking sick of this world he says. He has been dealt a bad hand of cards in life that is for sure. He’s fed up of it, feeling different all the time, not keeping up with people his age, not developing, being scared of going out. He takes it out on us. It’s frightening.” (7)

“He was wild, eyes so frightening, I was so scared he might kill himself...he said if you don’t listen to me I will kill you in this car. My legs and hands were shaking, I thought I was going to die.” (5)

Mo *“The last experience I had, it is lucky I’m even here I reckon.”*

I *“What do you mean by that?”*

Mo *“Well I nearly went through that glass door. She lost her temper and she pushed me. She smashed it all, and pushed me into the doorway. I was so frightened, I was bleeding.” (11)*

This fear was not exclusive to the parents. The majority cited numerous examples of siblings being scared of the young person, often the target of the young person’s aggression. This experience of fear and victimisation was perceived by parents as having wide-ranging negative effects on the siblings’ general and emotional functioning. However, whilst parents recognised the impact the young person had on their siblings, there was a sense of helplessness about what they could do to make it better. Parents seemed to find themselves in a dilemma: wanting to protect and defend their other children from the young person, whilst caring for and not excluding the young person themselves. A few parents described being so scared of what their child may do to their other children that they avoided ever leaving them alone together, for fear of what might happen.

“You know X, he has beaten up my younger son many times you know...once my younger son needed stitches on the head you know. So he is very scared of X.” (9)

“I used to sleep with my daughter and my son because they were so scared when all these things happened they wouldn’t sleep on their own. I used to have to sleep in the middle with my daughter and my son on each side, three or four years like this...my daughter, she would make sure there were no knives around, they were scared as well that he would come night time and try to hurt us or hurt himself.” (5)

Parents also expressed fears concerning their child’s well-being during the peak of the behavioural or emotional responses, and regarding how long the episode might last. Often

these fears related to worries concerning their own or the young person's safety and well-being.

"Sometimes we are scared and worried about how long it will last, whether X will be OK, because there have been times when he's punched his fists into the walls and had bruises on his fists because he's been so anxious...two years ago we had a very very unpleasant and frightening experience where X was very very ill and he was throwing things around and breaking things in the house and we were all very worried." (1)

Some parents described fears relating to their other children's futures, due to concerns that the mental health problems experienced by their child might have a genetic component. There was consensus that it would be catastrophic if their other children had to go through the same experiences that they had.

Mo *"I really hope that it is not some kind of hereditary gene, the learning disability and the mental illness, I really hope it is not something that the girls have to go through."*
Fa *"I can't face them going through this." (8)*

Lastly, a minority of parents of South Asian origin at some point in their experience had fears that their child's behaviour could be indicative of possession by evil spirits, in line with suggestions from their cultural and religious communities, or their own cultural or religious beliefs.

"To be honest we did have a lot of initial 'maybe he's been possessed and something's happened and let's get the priests and so on involved'. To be honest we did have a little bit of that from a couple of people... I mean to be honest we were really really frightened, I was terrified, so was my mum, and I was hoping that it wasn't that." (1)

Living with Blame

The majority of parents experienced a strong sense of blame in relation to their child's difficulties. Parents experienced both self-blame, and blame from others. With respect to the former, many parents felt as if they had somehow failed their child, that somehow they should have been able to prevent the mental health problems or protect their already vulnerable child from negative experiences. A general sense that they didn't do enough left many parents with powerful feelings of guilt and failure.

"To tell the truth I feel guilty about his emotional problems, I feel like I should have been able to protect him from all his troubles. I've failed him really. Mothers should be there to protect their children. And I feel guilty that he is so low, so down, it breaks me you know, I feel his pain as well." (7)

There was a strong sense of inadequacy amongst the majority of parents, that their best efforts were just not good enough to help their child. Again, this resulted in self-blame and associated emotions. There was also a feeling for some that it was something they had done, or not done, that had resulted in these additional mental health problems.

"We couldn't make him better, and that made me feel so inadequate you know, I wasn't good enough." (8)

"I'm her mum, I should be looking after her. I suppose it felt like I'd failed with her, every time she got ill, I felt I should be able to manage, because mum's should be able to manage." (11)

"We were blaming ourselves you know, thinking maybe it is something we have done to make him like this. So that made family life really hard, we felt like we were failures." (7)

Most parents also experienced blame from a variety of external sources. When behavioural or emotional manifestations of the mental health problems were exhibited in public, most parents felt judged, criticised and blamed by observers.

"She attacked me in a shoe shop just up the road, she just went for me, she got this idea in her head that everyone was taking the mickey out of her in the shop...all those people who was standing around, staring at us, gawping, straining their heads to have a look in the window. I don't get embarrassed easy you know, but I felt mortified then, because it was in public, my daughter attacking me. She was swearing, calling me f-ing b and c-u-n-t and everything. It was awful. I said stop swearing, everybody is looking at us, then I've said the wrong thing, because then she is going for the people in the street. Them people were laughing at us. Standing and watching and laughing. Like they are thinking, it's your fault as a mother." (11)

For a few parents, this experience of external blame was compounded by the fact that their child 'looked normal', having only mild learning disabilities. The sense was that if visually the young person looked disabled or ill, others would be more sympathetic and less blaming and judgemental of their child.

"You'd see people looking at me, like on the plane when he'd start up, and they'd look at me like saying why doesn't she whack him, why can't she stop him. But because he looks so normal people don't realise that he's not well. Like if he was in a wheelchair you'd get the reaction like, poor boy, poor parents, but they don't know he's not well. It was so humiliating." (8)

A few parents also talked about feeling blamed by professionals regarding their child's additional difficulties, perceiving that some professionals regarded the parents as being responsible for their child's additional difficulties.

"The GP he would laugh, he just thought it was me I think, probably blamed me as well, stupid mother can't control her son." (5)

For one parent, the blame from others was from her family in relation to religious beliefs. Her son's additional difficulties were conceptualised by her father as a punishment from Allah for her own failings as a person, which seemed to compound her sense of being a failure or responsible for the problems.

"My dad used to say to me that I'd had X, been given X, because I was such a rebellious child myself. You know, that it was because of what I had done, that is why he had learning disability and the illness. To teach me. See you was bad, so Allah has repaid you." (7)

MANAGING THE BEST WE CAN

This theme encapsulates parents' attempts at coping with the additional mental health problems. As the title portrays, for the great majority of parents, there was a sense that they were simply getting by or muddling through as best they could. Two sub-themes make up this theme. 'Existing Not Coping' describes most parents' sense that their existence was one of survival; in the main, these parents felt helpless in the face of these difficulties, but had developed strategies to survive. This leads into the second sub-theme, 'Isolation', which reflects the lonely and unsupported state parents found themselves in. This sense of isolation was exacerbated, for the majority of parents, by feeling unable to tell others about the additional mental health problems, for fear of stigmatisation, misunderstanding, or even out-casting. The isolation was further exacerbated, with respect to services, by not having the knowledge of where to turn for, or how to access, help.

Existing Not Coping

Most parents described a powerful sense of helplessness in the face of the mental health problems. They were unsure of how to help their child, which resulted in further feelings of inadequacy, distress and frustration. As a result, most parents described their experiences in terms of getting by, existing or surviving.

“She would start to weep for not reason at all, she start to weep. We found that she’d go to the toilet and sit on the toilet and weep so long, and I’d be looking for her and I’d say X and no answer and I’d go and find her in the toilet weeping or maybe in her bed weeping and all that. I felt so helpless.” (3)

“We didn’t cope we existed. We couldn’t cope, couldn’t cope.” (8)

The majority of parents strove to find strategies that helped their son or daughter calm down, to avoid escalation of anger, violence or other difficult behaviour. Often these strategies were employed simply as a result of not knowing how else to diffuse a difficult and potentially violent situation, and because of the extreme levels of fear they experienced in relation to their child’s behaviour. That parents (and siblings) often felt threatened by the young person seemed to elicit such calming strategies. However, these strategies often left parents feeling powerless or trapped, as their and other family members’ needs and rights were over-ridden or subsumed in order to prevent escalation, which had the effect of making parents feel even more helpless.

“Only if you let him have complete control, that would calm him down. So he took over the house, watching cartoons on video, listening to music full blast, and so we became prisoners if you like because that was the only way to calm him, to let him do everything his own way.” (8)

“I have to move away, because when he gets like that we don’t get anywhere, it’s like going round in circles, so I’ve developed a strategy so when he is like that I move away from him, because otherwise I get hit.” (7)

“I have to agree with him or else I don’t know what he do to me. To calm him.” (5)

While the overwhelming sense conveyed by parents was one of ‘existing not coping’, there were a few isolated but notable exceptions. A few parents talked about their efforts to reassure their son or daughter, to hone their strengths in order to try to develop positive

self-image, or at least to distract them from the negative or difficult experiences that they were having.

"I tried to get her to learn to knit, to get good at something she could do, to make her feel good about herself and give her something to do. It made her a bit happier, trying to think she had done something positive. It was such an achievement her actually doing something, but she wouldn't do it most of the time. To get her mind off her learning, why am I like this, I'm thick, I'm stupid, why didn't the teachers help me, all that, when she is in depression." (10)

"I tried to talk to her, ask her what was wrong, get her to talk to me. I tried to reassure her that she was ok, that I loved her." (11)

Where the few parents were less 'existence' and more 'coping' focused, religion seemed to play a significant role. These parents, all from ethnic minority groups, described how their religious beliefs and practices had helped them with their child's problems. These strategies ranged from using prayer and one's belief in Allah or God in order to cope or feel better, to employing religious rituals or taking their child to a religious person in order to make them better. The latter strategy tended to depend on the parents' beliefs about what was causing or contributing to their child's mental health problems, for example, where possession by evil spirits was seen as causal, the young person was taken to the priest in the hope of being 'cured' or made better, by using direct (by the priest conducting prayers and rituals with the young person themselves) or indirect (by the parents being given prayers and rituals to carry out for their child's recovery) strategies.

"Religion is a great healer. It is the main thing that supports. My religion has given me strength. I asked Allah for that strength and he has given it. I think because of that strength I am standing here, doing all this. Without Allah's help I couldn't have done that." (6)

"Whatever the priest told me I did...someone in the Punjabi community told me to take him to this religious person in Birmingham, when he was 16 or 17 and things were bad, and I used to take him to the religious temple there, where he would be seen by the priest... I had a light I had to burn for so many days, and I believe in that, I think it made him a lot better, because he was going through very bad time." (5)

Religion, or religious constructions of their child's difficulties, was also used as a motivating factor to carry on, to keep going, in the face of the extra responsibilities, pressure or hardship that the additional problems presented them.

“As a mother she feels that this is my child, this is how God has created X, she actually sees it as a test. As a Muslim she sees it as a test from God to see how well she bears it...I see it as my responsibility as a Muslim, the fact that he is my brother, I have responsibilities towards him.” (1)

Isolation

The great majority of parents felt completely alone and isolated in coping with and managing their son or daughter’s mental health problems. For some, isolation was apparent even when their child was linked in to special education resources; there was a feeling that staff in education did not have the expertise to help parents with the complexities of a child presenting with mental health problems. This sense of isolation seemed to be exacerbated by parents simply not knowing where to turn for help. Even when parents did know of a service to turn to, that service often did not refer them on to the appropriate help. Many spoke about such difficulties of inaccessible or unknown service provision being a significant obstacle to getting help; a few elaborated on this with respect to how service accessibility could be improved, for example, by delineating clearer paths to accessing help and increasing public information regarding what help is available. Some parents also felt that a support group for parents in similar situations could have helped alleviate their sense of isolation, through sharing their experiences with parents in similar situations. The following excerpts illustrate some of these points:

“It felt ever so lonely you know, isolating like. I felt 100% alone, not knowing where to turn, what to do, how to help him, what to think of him. It was the most confusing time of my life.” (8)

“For all those years we were without nothing, no help, alone. Nothing. We didn’t know where to go. All I did was bloody cry at home.” (5)

Mo *“I didn’t know where to turn to. I went to Social Services, and they more or less knocked me back, they said they couldn’t do nothing for me. I said but my daughter has just tried to commit suicide by jumping out the window...”*

I *“Did they advise you to go and see someone about X’s behaviour?”*

Mo *“No, they didn’t say a dicky bird, not a thing, I tried to get help but no-one wanted to know...it was murder trying to get help.” (11)*

“We need to know where to go. Somehow, there needs to be information out there that is easy to get to, so people like me know where to turn to. I mean, I don’t know how these systems work, even now after 5 years.” (11)

Many parents talked about their family offering help. However, they also described feeling these offers to be unrealistic due to the extent of the young person's difficult behaviour, or insincere and made just to make them feel better.

"I couldn't leave them with him, I know they wouldn't be able to cope. I can't cope with him, how could they? You know, since the change they are frightened of him, basically that is what it is." (6)

"They will say to me it will be alright don't worry, I'm there for you, and then my daughter always says to me I'm there for you mum, any problems phone me. And she'll get up and go home. And I says to her, but nobody is here. I'm the one, I have to cope with it." (2)

Some parents of South Asian origin spoke specifically about having to battle professionals regarding the popular myth (that they felt was rife within the service culture) of ethnic minority families having big extended families who are available to help out and take on responsibility.

- Mo* *"...I was so angry with the GP because he used to say oh you have this extended family, this wonderful family who are there for us beck and call. But the reality is that they are not. They are more of a hindrance."*
- I* *"So your GP felt you were getting support?"*
- Mo* *"He assumed. He never asked me. He never asked me once what is your family support network like? Then maybe I would have felt able to tell him." (7)*

A few parents described how this myth of extended family and community was in stark contrast to their own experiences. For one parent, it was felt that this was mainly due to the nature of the additional difficulties, namely that they were mental health problems.

- I* *"So in the Pakistani community, what's it like to have these mental problems?"*
- Fa* *"Difficult, very difficult, but not only Pakistani; Indian, Asians all same problems. They think people with those problems is mad. And you know, you may think that we all help each other you know. But nobody wants to know you, not with them outside there, not with these problems. It is bad to have these mental problems, embarrassing, shame, so we don't tell people." (9)*

All parents' sense of isolation, regardless of their ethnic status, was exacerbated by fear of stigmatisation, shame or further blame from their community. This prevented them from being open and telling other people about their son or daughter's additional difficulties, and thus inhibited increased social support systems. For some, disclosure of the mental health

problems was unthinkable, because of fears about how these problems would be understood and acted on in their communities. This resulted in keeping the mental health problems from the community, and therefore further isolation.

- Fa* "We never go talk to those people in the religion no. We keep everything in the family, and [Consultant Psychiatrist], that's it, not even to Social Services, nobody."
- I* "Why is that, why don't you talk to them?"
- Fa* "They would blame it on us you know, the parents, having a strange son...In a Sikh community there is nowhere we can talk about these things, we can't say anything in the temple. So we keep it to us only." (4)
- Mo* "You know, there is so much bad attached to having a mental illness."
- Fa* "Absolutely, absolutely, stigma, especially in an area like this. You know, at the time, we didn't really want to explain X's problems to anybody, because we were embarrassed. You know I'm from a male family, where if we break our leg we smile and carry on at work, laugh it off. This type of problem, well they just don't understand it." (8)

However, this is in direct contrast to one parent's view, who had disclosed the mental health problems to their community, and felt that their son's pre-existing learning disabilities somehow reduced the impact of the stigma, because the community were used to seeing him as 'different'.

"I do feel there is a bit of stigma attached to it, but in X's case it's not been too bad because he's always had autism, he's always been recognised as a child with very special needs...so I think we've been quite lucky in that respect, nobody has tried to outcast him." (1)

There was a consensus however that having mental health problems was much worse for a female in both the Bangladeshi and Pakistani communities. Reasons given were that women do not have an equal entitlement to utilising parental time and resources, that sons are entitled to more parental time, energy, attention and resources because of being "*more culturally responsible*" (1); that women are expected to be more independent of their families than men; and that such problems in women are perceived as hysterical rather than true problems and thus elicit a negative reaction. The gender of their child therefore seemed to impact on some parents' decisions about whether or not to disclose these problems to their communities.

"It is a gender thing as well. It's much worse for women. I mean thank God X is male, because as hard as it is to have that label in the community as a man, it is hundred times worse for a woman." (6)

THE BATTLE FOR HELP

This final theme captures the essence of parents' experience of services. The start of this battle has already been described in the previous theme, in terms of not knowing where to turn for help, information about services being inaccessible to these parents. However, there was a general sense that parents not only had to fight with services to get help, but that they also continued to fight throughout their contact with services: *"I've had to fight there, here, every bloody way" (7)*. This theme consists of three sub-themes: 'Not Listening to Us', 'Waiting for us to Break', and 'Inadequate Provision'. The first sub-theme describes parents' experiences of their pleas for help falling on deaf ears and not being taken seriously. The second sub-theme is closely related, describing parents' experiences of having to reach a crisis or breaking point before services will respond to their needs. The third sub-theme describes parents' experiences of inadequate service provision, with respect to services provided and service organisation.

Not Listening to Us

The great majority of parents felt that services had not listened to their call for help. These parents felt that their concerns about their child had not been taken seriously, usually by professionals who are the 'gatekeepers' to other services, such as staff at school, GPs, and Social Workers. This left them feeling let down, badly treated, belittled, labelled as neurotic parents, and in some cases, abandoned by services. Parents often felt that their child was scapegoated by services because of their learning-disabled status, and that the additional difficulties were not taken seriously as a consequence.

"I used to tell him [GP] about X, because he knew all the family, my husband's family, his brother and his wife, my brother-in-law's shop, his surgery was next door. He used to say to me 'oh don't worry all families have some bad temper'. I used to say, 'please Dr. I am going through this, this is not how X should be'...I used to cry in front of him, didn't know where else to go. Every time I tried to talk seriously with him he would always laugh at it, at

me...I used to beg, 'Dr. we are going through a very bad time, please what should I do? He is smashing, scaring me and the other children', but he never did nothing, he let us down." (5)

"The teachers call me say 'your boy is a fighting trouble-maker boy'. They don't understand he had problems. Nobody cared, nobody cared. School people didn't bother. And then we went to Social Services here, but even then, the first social worker said X was alright. I said 'no, he has problems', she said 'no this boy has no problems'. I said 'no, I am not lying about it, this boy has problems'... You know, when I tried to get help from the school, from social services, I couldn't believe it they don't believe me... They should listen when the parent says something is wrong." (9)

Alarming, even when parents were very explicit about their sense of desperation, to the extent of openly discussing their fears about what they might do to their child (often involving threats of physical violence), these concerns still seemed to fall on deaf ears.

"To be honest I'm scared I'm going to hit her and I'm going to hurt her. Because I'm getting to a point where I can't control myself anymore. (Cries). And I say to social services 'I'm going to kill her one day', and they go 'oh you shouldn't say that to us because we are there for her' and I say 'well if you are there for her get up and do something because I'm telling you I can't handle it anymore'. And they just don't listen, they just don't listen." (2)

There was a sense that services simply 'paid lip service' to parents' pleas, pretending to take their concerns on board in order to placate parents instead of offering the kind of active listening that leads to constructive outcomes.

"I am sobbing on the phone because I don't know what to do, where to go for help, and they [Social Services] say 'yeah we understand how you feel, we understand what you are going through', but then I will put the phone down and that will be it till I phone up next time." (2)

Most parents felt that they had to shout in order to be heard, that the only way to get help or for their concerns or wishes to be heard was to be assertive, or even aggressive and threatening with services. Without such an approach, there was a consensus that parental views were either not heard and so no help was offered, or that views were over-ridden, resulting in help that was perhaps not wanted or required by parents. This sense of not being listened to was also apparent with regards to the transfer from child to adult services, bringing with it a change of ethos and attitudes towards parents and their role. This appeared especially salient for the parents whose son or daughter was a psychiatric

inpatient for an extended period, where they felt changes to care were made without even letting them know, given their offspring's new adult status.

"At the hospital they are always like, well it's like I am a nuisance to them, especially since X is now legally an adult you know. The decisions just go over my head, I get pushed out. But what about how I feel about all this?" (11)

A few parents described feeling that they were not listened to, or taken seriously, because of their ethnic minority status. These parents frequently perceived themselves as victims of racism, which they experienced as rife within services.

"Being Asian affects the treatment you get from services. If we were white we would have got better treatment for X. At school, social service, everywhere, 100%. Very different treatment. Services put white people first. If X had all those problems and he was white, they would all have paid attention to me, to him." (9)

Parents were very explicit that being listened to and taken seriously are crucial components to feeling valued and attended to. Where they highlighted aspects of their experiences with services that were helpful, nearly all were in relation to being listened to.

"They [Voluntary Service] will actually be there for you, they'll help you, they'll talk to you about what it is like for you, and they say to you if you've got any problems come back and we'll speak to you, they listen. They have, they've been there for me." (2)

"By [Consultant Psychiatrist] listening, that made me a bit stronger person." (5)

Some parents also commented on their experience of participating in the present study to illustrate what they considered to be gaps in service provision. Where they did, there was consensus that the experience had been a valuable encounter, in that it provided a space to discuss their experiences, gave them an opportunity to tell their story, and most importantly, to be listened to. There was a feeling that in general, this experience was different from their experiences of professional help, and would be a valuable addition.

"At least you have listened to my story. For the first time someone sat me down and asked me actually what it has been like you know. That is a change. A good one. Made me feel a bit more valued you know, a bit better." (7)

"I mean to be honest this is so good to talk to someone and let this out. Because I've never had no counselling nothing. No-one has ever sat down and asked me what I think. Maybe that is what I need. Maybe I need to talk to someone about it. You are actually listening to me. I've never had this before." (11)

Waiting for Us to Break

There was general agreement that a breaking point had to be reached before services would intervene and offer the appropriate help parents needed. Many parents described this experience of being pushed to breaking point, for some reaching a stage of such desperation that some sort of crisis occurred (frequently involving violence towards their son or daughter). Where this hadn't yet occurred, some parents described feeling that services were actually waiting for them to break before getting involved.

"It wasn't till I nearly killed him that anyone paid us a blindest bit of attention....although [Consultant Psychiatrist] did eventually get us help, but only because she knew that it was a crisis and I think she was worried then. She should have done something sooner. Perhaps she didn't realise how serious it was. Then I think she was shocked." (8)

"Things got worse and worse you know, and we just kept going. Then when that happened, the crisis, he got the section, and then we got to meet [Consultant Psychiatrist], but that was about 4 years after it all started...it took the police and the section to get a specialist. Nothing before, just me at home crying." (5)

"I'll be totally honest with you, you don't do nothing till actually really something bad will happen. And then they will do something and help you out. It has to get to a point where either I'll punch her in the face, I'll break her legs or whatever... But they are they are waiting for something horrible to happen, till the parents actually can't take no more, before social services does anything." (2)

There was a sense that such crisis situations could be avoided by services actively listening to parents; by being open and honest with parents about the additional mental health problems; and by actively offering resources and help when it is needed.

"It's about information, about rights, resources, the diagnosis, giving positive information rather than letting people find out from their own stumblings, which is what we had to do, to avoid the crisis." (8)

Inadequate Provision

Overall, parents felt that there was inadequate service provision for young people with learning disabilities and mental health problems. This was seen as a significant problem not least because of the limited opportunities available for such young people in the community at large.

“Opportunities for them are very very limited. Like for example, me and my family might find it difficult to take X to certain places because facilities just aren’t adapted for people like him. Like we know X likes swimming and sometimes it is difficult to take X swimming if there are people who want to do laps and suddenly X becomes very noisy, it makes it uncomfortable for other people. And therefore I think we do need to have more services available that are adapted for people like X and I sometimes think we don’t have enough of that.” (1)

As a result of limited service provision, parents felt that the services offered to their child were often inappropriate, for various reasons. One such reason noted by parents was their perception that all young people with learning disabilities are lumped into one homogeneous category by services, regardless of the severity of their disabilities. Another reason was that parents perceived that young people with learning disabilities are infantilised by services, which instead should offer them more age appropriate activities that appeal to young people.

“They seem to send me to places for like kids who are more sicker than her, and she doesn’t want to go. You know, they’ll be kids in wheelchairs, really ill, or kids that can’t talk very well, not like learning difficulty like her...when she goes to [name of resource] there are kids that are really ill, they are, dribbling and need looking after, they need one to one. And when she does go there she comes back upset, she doesn’t like to go, she doesn’t want to go.” (2)

“It’s more older things they need to be doing, like taking them bowling or taking them to the pictures, things like that you know activity things. That’s what she wants to do, not sitting in their club doing finger painting or listening to music or building puzzles. She’s not stupid, she’s not a baby.” (10)

This theme of services somehow providing inappropriate resources also applied to when these young people required a psychiatric inpatient treatment. All parents whose son or daughter had been admitted to hospital felt that service provision was inappropriate, mostly due to fears about their child being placed in a mainstream, rather than a specialist learning-disabled environment, which left them vulnerable, exposed, and misunderstood.

Parents also felt that these services were inappropriate because of the non-specialist staff looking after their child.

“Those people were very mental, not like X with a slow learning difficulty, these were normal people but mental, its different...it was breaking me inside, my son there with those dangerous people...That place was not for him, they didn't know about him, having to explain things slowly and lots of times, him not understanding everything. They didn't know.” (5)

“X is different, not like them... And that worries me whether they [staff] have the know-how to deal with someone like him with his specific problems. But we have to make use of any resources they have got.” (8)

Some parents felt that the units their children were admitted to were also inappropriate because of age. The units were generally adult mental health resources, and therefore catered to adults of all ages, which parents perceived increased their child's vulnerability to abuse.

“She went to [local adult inpatient unit], a mental hospital. It wasn't suitable. The patients was putting too many ideas into her head. She was the youngest there, they used to call her the baby of the hospital, with her being the youngest. There was a lot of dirty old men in there. An adult place. She got touched up and everything in there. It wasn't suitable but at the time there was nowhere else to put her and she was in a mess and needed to go in.” (11)

Where the young person had been admitted to hospital on a long-term basis, or where the nature and severity of their mental health problems necessitated frequent inpatient admissions, the units they were admitted to tended to be out of borough because of inadequate resources in borough. As a result, the young people were placed at long distances from the family home, which restricted parents' access to their son or daughter and so resulted in further strain, both emotional (with respect to not being able to see their child on a regular basis) and practical (with respect to travelling long distances, with financial and time-consuming consequences). These parents tended to feel that their son or daughter had been abandoned by services and put in hospital because there was nowhere else for them to go, that services simply did not know what to do with them.

“The hospital being so far away, that is murder. I left here at 11:30 on Sunday and got to the hospital at 3. I could only stay for an hour and then I had to start making my way back. I'm really not happy about her being so far away...There should be more hospitals closer by for people like X. She

needs her family around, and we can't be around when she is so far away.”
(11)

“X was only meant to be in for 6 weeks. She was in there nearly 5 months. It was like she was just dumped there.” (11)

Mo *“He was basically just kept there. They did nothing for him, just kept out the way.”*

Fa *“It just kept him, it wasn't helping him. [Hospital] is not long term, it shouldn't be long term, he's been there 3 years, they can't be rid of him....he doesn't need to be there, he needs to be out now. But he can't go into the community.”* (8)

For these parents a stark lack of faith in services was apparent. Most believed their child's combination of problems to be a complete mystery to healthcare professionals, the result being that their child was subject to various pharmacological treatments that they perceived to be largely experimental.

“She has had this illness 5 years now and they still ain't got her medication right, it is not under control. I don't think they know what they are doing with her really, she just goes in when it gets too much, but she don't ever get better there, she just gets put there...These constant changes of medication is too much, I feel so sorry for her...I mean I had a lot of faith in the system at the beginning, but I am losing it now.” (11)

Lastly, the actual organisational structure of services contributed to parents' sense of inadequate service provision. The majority of parents described feeling overwhelmed by multiple sites of service provision, and felt that the responsibility fell to them to somehow link all the parts together. This additional sense of responsibility, as well as the actual practicalities of having to attend multiple appointments at different geographical sites with each service bringing with it a slightly different ethos and attitude, exacerbated already high levels of stress and anxiety.

“It's difficult when there are so many services at once, so many people to contact and think about with respect to X's life.” (1)

There was a consensus that services needed to be more coherent, fluid and seamless, to prevent a disjointed experience (where each service offers just one specific aspect of help), and promote a sense of clarity regarding where to go for help and what help can be expected. Parents felt that being able to access all different aspects of help from one central point would be highly beneficial.

"We need a place where other people with the same problem can go. Because there's too many places to go at the moment. Parents and children. With professionals there, in the same centre, all of them together, the education, the health ones, the mental health ones, the social services, so there is none of this to-ing and fro-ing, and so parents like me know where to go for everything." (10)

Despite dissatisfaction with many aspects of service provision, a few parents stressed that when help was eventually provided it was valuable and indeed crucial to their survival.

*Fa "I'm grateful for the help we had though, I am."
Mo "What would we have done without them? We'd probably have topped ourselves by now."
Fa "It's saved our bacon." (8)*

SUMMARY OF RESULTS

Parents struggled to understand their son or daughter's additional mental health problems, an experience that was entrenched in confusion. Their confusion was compounded by their child's learning disabilities, creating more difficulties with respect to detection and understanding of the additional problems. Parents tried to make sense of the additional problems by drawing on a wide range of factors, including adolescent life-stage issues and factors relating to their son or daughter's learning disabilities. Most parents wished for a diagnosis, based on a belief that this would leave them feeling more able to help, however those who had received a diagnosis still expressed confusion, not fully understanding the meaning of the diagnosis, either regarding the mental health problems, or regarding the pre-existing learning disabilities.

Their son or daughter developing mental health problems in addition to their pre-existing learning disability was conceptualised by parents as a new, and often raw, source of pain and grief, exacerbating and reminding them of their son or daughter's difference and vulnerability. The additional problems resulted in extra pressure, care burden and responsibilities for parents. Multiple losses for all family members were also seen as a consequence of the additional mental health problems, as were significant hardship and suffering, including physical and emotional health changes, fear and blame.

Parents' experiences of managing the mental health problems mostly seemed to focus on survival and existence. This was compounded by a sense of isolation from others due to fear of stigmatisation and from services due to lack of knowledge about how to access help. Parents' experiences of services were characterised by a sense of constantly having to fight for help, that they were struggling to be heard, to be taken seriously, to be understood, to receive what they considered to be appropriate help, and to understand the structure of the service system.

CHAPTER 4 ~ DISCUSSION

Overview

The findings of this study will be discussed in relation to the research questions and the existing literature. Where appropriate, thought will be given to my own contributions and influence on the research process where this relates to the findings, together with wider issues of reflexivity. Methodological issues addressing strengths and limitations of the study will be explored and potential areas for future research suggested. The clinical implications of this research and possible areas for improving practice will be considered.

Study Findings

The experience of parents of young people with learning disabilities and mental health problems: the notion of a “Double Whammy”

The overall aim of this study was to explore the experiences of parents of young people with learning disabilities who have additional mental health problems. Eleven interviews with parents' yielded rich qualitative data, which were analysed using the principles of interpretative phenomenological analysis (IPA). Confusion, loss and hardship were at the core of all of the themes. It was apparent that parents felt their experiences were made particularly difficult by their child's particular additive combination of problems.

So powerful was their sense of *additional* loss, that in my view, the overarching description of “double whammy” seems to fit well with the essence of all themes identified in the analysis. That is, the majority of parents appeared to experience their child developing mental health problems *in addition* to their learning disabilities as a “double whammy”. The consequence of this “double whammy” effect seemed to be clearly present throughout the analysis: in terms of additional difficulties recognising, understanding and making sense of

the mental health problems; with respect to both the emotional and practical impact of the additional difficulties; and with respect to how these difficulties were managed.

While parents appeared to perceive their experiences as a “double whammy”, and the major stresses experienced by these parents are evident throughout the analysis, it could be argued that their experiences are similar to those of any parent whose son or daughter develops serious mental health problems. As noted in an earlier chapter, mental health problems in non learning-disabled adolescents have been shown to increase parental negativity and ineffective disciplining practices (Berg et al. 2002), to develop parental feelings of incompetence and isolation (Turcotte, 1990), and to negatively affect parental well-being (Farmer et al., 1997). The extent to which the experiences of parents in the present study may in fact be similar, yet distinct and characterised by a “double whammy”, will be considered throughout this chapter.

Recognising and making sense of the mental health problems

Parents’ experience of recognising the signs of mental health problems in their child, and making sense of these problems, was largely characterised by confusion and bafflement (relating to the theme ‘The Struggle to Understand’). Importantly, with respect to considering how these parents’ experiences are different from those of young people with mental health problems but no pre-existing diagnosis of learning disabilities, recognition and understanding were perceived to be more complex by having to integrate, understand and make sense of these new behaviours and emotional states in the context of already ‘different’ behaviour associated with the learning disabilities.

So powerful was the sense of confusion regarding what was happening to the young person that I too at times came to experience a strong sense of confusion during interviews. The tendency to attribute these feelings to myself, as a novice researcher investigating a complex area, caused me to seek supervision as to how to ‘improve’ my research skills. However, it became clear through listening back to the taped interviews in supervision that, as often occurs in a therapeutic situation, the confusion was not in fact my own, but could be

understood as transference of the parent's emotional state. Once these issues had been understood, I was able to recognise more clearly what were participants' feelings and what were my own responses, which contained the sense of confusion and enabled the interview process to continue.

Initially at least, many parents seemed to make sense of their child's change in behaviour and emotional state by attributing these to the pre-existing learning disabilities. This tendency is in line with Reiss et al.'s (1982) concept of 'diagnostic overshadowing', where symptoms of a mental health problem are misattributed to the learning disabilities. Where such misattribution occurred it appeared to increase the risk of the young person being blamed for their difficult behaviours and emotional states. Given the enormous difficulties mental health problems present to professionals working with people with learning disabilities regarding identification and accurate diagnosis of the additional problems (e.g. Campbell & Malone, 1991), it is perhaps not surprising that parents have the same difficulties understanding their child's change in behaviour and mood. Indeed the confusion experienced by parents regarding mental health problems is strikingly similar to the confusion experienced by service providers working with young people with learning disabilities (Scior & Grierson, awaiting publication).

Moss and Patel (1993) have argued that the people who are usually first to notice significant signs and symptoms of mental health problems, in this case the young person's parents, are often inadequately equipped to understand and identify the changes, which frequently results in a failure to meet needs. Moss (2003) argues that stronger links are required between carers, the people who know the symptoms, and professionals, the people who understand the meaning of the symptoms. This appears to hold true for the present study, in that while parents found changes in behaviour and mood difficult to understand, most recognised that something was wrong with their child but were unclear what exactly, or how to respond. A range of factors, including uncertainty and fear regarding the changes, not knowing where to turn for help, and not being taken seriously by service providers, resulted in a failure to meet needs. This highlights the need to educate parents of young people with learning disabilities

about mental health problems and how they might manifest themselves, and to increase awareness of mental health problems in this population in the wider systems, such as school, colleges and social services.

Parents who had not yet fully understood or perhaps come to terms with their child's learning disabilities appeared to find it even more difficult to understand, let alone accept, the additional mental health problems. For the one parent who had received both a clear diagnosis of learning disabilities and an explanation which could be assimilated and understood, the development of additional problems did not seem to cause as much confusion. The literature regarding the initial diagnosis of learning disabilities and how to support parents of children with learning disabilities is extensive, and clearly highlights what constitutes good practice in relation to initial diagnosis and support for parents throughout childhood. Key recommendations include giving parents enough time to talk over the diagnosis, and maintaining contact with parents throughout childhood in order to ensure their understanding of the learning disabilities and the associated issues (e.g. Dale 1996). Such practice would of course fit with the concept of chronic or recapitulated grief (Wikler et al. 1981; Goldberg et al. 1995), which highlights the non time-limited and changing nature of the process of coming to terms with a child's disabilities, therefore implying the need to support parents throughout different stages of their child's life. However, the findings from this study would indicate that such guidelines for good practice perhaps do not go further than a theoretical vision, given that most parents in this study remained extremely unsure about the meaning or implications of their child's learning disabilities. The evident confusion about the pre-existing condition made additional problems all the more confusing and difficult to understand. A few parents noted how their difficulties coming to terms with the young person's learning disabilities were ongoing, and talked about the contributory effect this might have had with respect to the development of mental health problems. This finding also highlights the need for clear and reiterated explanations of a child's learning disabilities, especially in the context of transition and change when their difference becomes all the more evident to parents.

Parents looked to a variety of contributory or causal factors when trying to make sense of the mental health problems. Issues relating to puberty and adolescence were strongly implicated as key to their child's difficulties. Notably there are very limited research findings regarding puberty and adolescence in learning-disabled young people, for example regarding the psychological impact of delayed or absent puberty. This restricts the conclusions that can be drawn regarding the accuracy of parental perceptions and clearly points to a need for further research. Parents also struggled to understand which part of their child's make-up, the learning disabilities or their adolescent/pubertal/teenage stage, was causing their child's additional difficulties. This is in line with Scior and Grierson's (awaiting publication) study of service providers, which highlights this as an area of intense confusion for professionals as well, illustrated by the following observations by a college tutor in their study:

"It's all a bit of a scrabble really. It's this whole blurry thing of this could be that, that could be this, or growing up could be the whole lot. It's that whole "what a nightmare being a teenager" kind of thing is anyway, with learning disability and mental health on top". (p.12)

The young person's struggle to come to terms with a learning-disabled identity was also seen as contributory to the mental health problems by parents in this study. Identity issues are crucial to the tasks of adolescence. As many parents in the present study observed, these can be pertinent and difficult issues for these young people, as they start to notice their non-disabled peers and siblings making greater advances, achievements and independence than them. This fits with literature which points to: people with learning disabilities being aware of the stigma associated with the identity (e.g. Craig, Craig, Withers, Hatton & Limb, 2002; Sinason, 1992); those who assert that negative implications for self-definition and self-esteem are encountered by people with learning disabilities as members of this devalued social group (e.g. Jahoda, Markova & Catermole, 1988); and with those who argue that adolescence is a time when young people become more aware of their learning-disabled status (e.g. Barlow & Turk, 2001).

Jahoda et al. (1998) found two main ways that people with learning disabilities manage the impact of the stigma, and so protect themselves from its consequences: by describing oneself as non learning-disabled, or by emphasising one's difference from more severely

learning-disabled people. Parents' accounts highlighted attempts at the use of both these strategies: either by the young person denying the learning-disabled status, or by distancing themselves from more severely disabled young people as seen in relation to services. Given the mental health problems encountered by these young people, it could be proposed that these strategies did not seem to work entirely successfully for them. Perhaps it is their adolescent status that affects the success of these strategies, in that identity issues, and therefore the associated stigma of an identity, are of the utmost crucial importance to them at this time.

Related to this, adolescence also seemed to be the time when according to parents, the young people also seemed to become aware of their learning-disabled status through abusive encounters or bullying. 'Stupid', 'dumb', 'idiot', 'different' or 'slow' were terms noted as frequently directed to the young person by their peers, carers or sometimes even the parents themselves. Such verbal abuse was also often accompanied by physical abuse. Parents perceived these abusive experiences as contributing to the development of mental health problems. This is in line with a wealth of literature pertaining to mental health risk factors (e.g. Foundation for People with Learning Disabilities, 2002), and are perhaps more likely to be frequent experiences of young people with, rather than without, learning disabilities.

Other reasons parents believed to have contributed to their child developing mental health problems related to the absence of a 'normal life' for their child, including a lack of meaningful daytime or leisure activities or opportunities for employment. Such findings are consistent with research that points to the massive gap in resources for this age group during the transition years (e.g. Routledge, 2000; Ryan, 1998; Turner, 2002), and highlights the gap between the principles of normalisation (Wolfensberger, 1972) and a discourse of "choice" and "inclusion" which is central to current policies (Department of Health, 2001a), and the actual realities of provision for young people with learning disabilities.

Parents highlighted the importance of receiving a diagnosis, or at least an explanation, for changes in the young person's behaviour and emotional state. This helped parents to see the mental health problems as outside the control of the young person, and therefore reduced the tendency to see the difficulties as wilful or purposeful on the young person's part. Research indicates that where carers believe behavioural difficulties to be within the individual's control, they not only show more negative emotional responses to the person but are also less likely to offer help. If challenging behaviour is seen as within the person's control, more negative emotional responses such as anger or annoyance are made and behaviours such as rejection are common, whereas if the carer judges that the behaviour is not deliberate, greater sympathy or understanding is experienced and positive reactions such as support are made (Weiner, 1986; Stanley & Standen, 2000). Thus it is reasonable to suggest that where parents fail to get an explanation of likely causes of their child's difficulties, they may be at risk of blaming the young and showing more negative emotional and practical responses.

Impact and associated management strategies

Parents' accounts revealed that the additional mental health problems had a wide ranging impact on them, the young person and the wider family (see theme 'Changing Us'). The additional problems elicited both emotional responses and practical consequences for the parents.

A number of authors have highlighted the feelings of grief associated with a first diagnosis of a child's learning disabilities (Wikler et al. 1981; Bicknell, 1983). Goldberg et al. (1995) suggest that the initial feelings of grief over the loss of the hoped for "perfect child" may be re-evoked at major transition points in the family life-cycle, as the family is again faced with the loss of previously held expectations. Thus, at each major life-cycle stage or transition point, memories of previous losses and grief may be evoked for family members, termed 'recapitulated grief'. Goldberg et al. (1995) also stress that each succeeding grief response is constrained by previous responses, which can prove difficult if earlier feelings of grief are unresolved.

The concept of recapitulated grief seems especially salient in this study. The majority of parents spontaneously spoke of their feelings of loss around the time of initial diagnosis of their child's learning disabilities in the context of their current feelings about their child's mental health problems, although most had received such a diagnosis some ten or fifteen years earlier. The additional problems experienced by their child seemed to re-evoked painful feelings associated with previous grief relating to the original diagnosis. This highlights how important it is for service providers to be mindful and vigilant of unresolved feelings of grief and pain for parents, even if the diagnosis of learning disabilities was made and given to parents many years earlier. This is similar to findings from studies involving parents of adults with learning disabilities (e.g. Todd & Shearn, 1996a), which note that parents' recollections of having a child with learning disabilities still evoked a marked emotional response indicating that these issues were still being wrestled with in the present. However, in the current study, in addition to re-evoked feelings of grief and loss, parents seemed to perceive their child's mental health problems as exacerbating their pre-existing loss. The additional problems seemed to bring them again face to face with the painful realisation that they had lost their wished for 'perfect child'.

The notion of a 'family life cycle' (Carter & McGoldrick, 1989) is based on the observation that families tend to follow a similar order and timetable for key child and family transitions. Families of individuals who fail to fit with this notional timetable, such as those with a member with learning disabilities, face stark reminders every time they fall out of synchrony with the cultural norms. Carter and McGoldrick (1989) highlighted adolescence and reaching sexual maturity, and leaving school, as two likely sources of stress in the family life-cycle. Todd and Shearn (1996a) also note that adolescence is a major turning point in the parental career, as this is the time when the character of parents' own lives also began to depart significantly from those of their peers.

For the parents interviewed in this study, their child becoming a teenager did indeed appear to highlight their child's difference from peers, for example their child's experience of delayed or absent puberty, or lagging socially behind their peers who were engaging in normal

adolescent rites of passage, such as going to parties and finding a boyfriend or girlfriend. Importantly, parents appeared to perceive the development of mental health problems as further exacerbating their child's difference from their peers, in some way acting as a further marker of not fitting in and being different, thereby widening the gap between their child and his or her peers. This realisation was accompanied for parents by feelings of hurt and pain and resulted in them seeing their child as even more vulnerable and dependent. Such protective responses are perhaps similar to those experienced at the time of initial diagnosis of learning disabilities (e.g. Todd & Shearn, 1996a), but strengthened (and exacerbated) by the additional loss associated with the mental health problems.

These findings provide further evidence for the notion of the "double whammy". What is different for these parents compared to parents of non learning-disabled young people with mental health problems, is that their experiences of their child's mental health problems are superimposed onto already altered expectations, hopes, fears, and conceptions of their learning-disabled son or daughter. Unlike parents of non learning-disabled young people who experience mental health problems, they already have a history of mourning and worrying about their child and must integrate a further blow into an already grief-ridden system. Indeed, this fits with the issue of parents requiring not one-off but ongoing support around the diagnosis of learning disabilities, as discussed in the previous section, in order to assimilate and come to terms with the condition. If this is not achieved, and the support not given, the additional news of mental health problems seems to be even more confusing and difficult for parents to understand and accept, and may increase the negative impact of the mental health problems. Again, this highlights the importance of continued support for such parents, and suggests that services need to take a life-span approach to families of learning-disabled offspring, rather than viewing certain kinds of support as only appropriate at certain stages.

There was consensus that family life for all members had become significantly more difficult since the onset of additional difficulties (relating to the theme 'Changing Us'). In general, the mental health problems resulted in increased pressure, extra responsibilities, stresses and

demands for parents and the wider family system. Parents tended to view the mental health problems as making their child more dependent on them, both currently and with respect to the future.

Todd and Shearn (1996a; 1996b; 1996c), based on their research with parents of adults with learning disabilities, have described two groups of parents who differ "...in the salience they attach to the type of liberated lifestyles enjoyed by their peers" (1996b, p.53). 'Captive' parents yearn for a post-parental lifestyle, experience the tasks of parenting as limiting and as one they would like to give up, and are aware 'of not being free'. 'Captivated' parents, in contrast, have relinquished their personal aims and found enhanced positive meaning in their parental role and have fewer ambitions to have lifestyles like their peers. Importantly, Todd and Shearn (1996a) note that these groups are not fixed: that even the most 'captivated' parent has the potential to change (and vice versa), depending on other influences such as loss of day services or as a consequence of increased conflict between parent and offspring. With respect to the present study, it would seem that for many of the parents, the additional mental health problems increased the tendency for parents to become 'captive' where before they might have been 'captivated', in view of the additional stresses, demands and losses that are experienced. For a few parents, this captive/captivating parental role was mediated by culture and religion. Thus, one mother's view of her son's increased and likely life-long dependency was shaped by her beliefs of the additional problems being a "*test from God*", and that it was her "*responsibility as a Muslim*" to bear them. Such a culturally influenced rationale seemed to enable her to remain a 'captivated' parent, as she was then able to relinquish her aspirations for a life after parenting and found positive meaning in her new responsibilities.

The role of social support as a factor that may mediate carer stress or burden has been well researched. It is now widely acknowledged that social isolation contributes to higher levels of stress in families (e.g. Hodapp et al., 1998). Notably, informal support appears to be more strongly related to carer well-being than formal support (Seltzer & Krauss, 1989). The nature of the additional problems, namely that these were *mental* health problems, seemed to

exacerbate or in some cases cause the extra stresses and pressures faced by parents. Due to the fear and shame they perceived to be associated with mental health problems, parents tended to keep it in the family, resulting in high levels of isolation. In addition to this, some parents experienced outright rejection from their wider family or community also as a consequence of the nature of the problems, which compounded the tendency to avoid telling others. A fear of shame or being judged by others in their community, and even by professionals, prevented many parents from seeking help outside of the immediate family. Such attitudes are consistent with the wider psychological literature, investigating stigma and mental health in people from ethnic minorities, where their tendency to keep problems private has also been found (Cinnirella & Loewenthal, 1999). However, that this was observed regardless of ethnic group (i.e. including the white parents) differed from the Cinnirella and Loewenthal (1999) study. One possible reason for such a finding may be because of the geographical area sampled, a deprived inner city but close-knit working class community, where community views and opinions are still highly valued and respected.

As noted in the introduction chapter, early research regarding families of children with learning disabilities was largely focussed on pathology, tending to assume negative outcomes in families as a consequence of a child's learning disabilities. More recent research has revealed variations in parental care giving experiences, with both positive and negative outcomes (e.g. Blacher & Hatton, 2001) mediated by a number of child, parent and family factors (Bromley, 1998). Parents in the current study were overwhelmingly negative when describing the wide-ranging effects that the additional problems had had on their and the wider family's lives. So powerful were these negative effects that the strategies employed to try to manage the difficulties were in the main focussed on simply surviving, not least because many parents seemed to feel terrorised by their child. Maybe then mental health problems are an extremely powerful 'child' factor that predicts more negative outcomes, in the same way that a diagnosis of autism does (Olsson & Hwang, 2001). In addition, the nature and consequence of the mental health problems (that they elicited fear, self blame, concern about stigmatisation), combined with the particular demographic profile of this sample (low income, poor housing, high proportion of single parent families) meant that

many 'family' and 'parent' factors that might predict stress and negative outcomes were also present, for example social isolation, passive coping strategies and economic difficulties, which may also account for the perceived negative effects.

Further evidence for mental health problems being an important and powerful 'child' factor that mediates parental experience comes from the quantitative data collected. All young people exceeded the 85% percentile for their normative age group on at least one subscale on the Aberrant Behaviour Checklist (Aman & Singh, 1986), indicating 'extreme' levels of disturbance. The subscale most commonly above the 85% percentile was that relating to Irritability, Agitation and Crying (subscale I), achieved for nine out of eleven young people. Clearly, this has great implications for those living in their immediate system, with respect to the stress and distress that continual irritability, agitation and crying must cause. Interestingly, the subscale least commonly rated above the 85% percentile was that relating to Stereotypic Behaviour (subscale III), which is commonly assumed to be characteristic of people with learning disabilities, especially when autism is concurrent. Such findings perhaps emphasise the point made in the introduction, regarding the growing range of clinical problems that are now being recognised as occurring in the learning-disabled population.

The scores obtained on the Degree of Dependency Scale (Evans et al. 1981) are also of interest with respect to considering the impact of the young person's mental health problems on the parents and family. While there are no norms available, the young people did not seem to present as particularly physically dependent. Physical problems are known to be a 'child' factor that predicts family stress (Bromley, 1998). Given the low dependency scores in this study, parental distress and difficulties experienced do not seem to be a function of the young person's physical difficulties but may relate more to the young person's mental health problems and disruptive or difficult behaviour.

That hardly any positive outcomes were elicited deserves more thought, especially with respect to thinking reflexively about the research process. The research process itself can be viewed as a social construction; it could well be argued that by researching a concept such

as 'mental health problems', the very nature of the identification, pre-recruitment and recruitment processes were 'problem' focussed. In addition, society's view of the role of a clinical psychologist is perhaps strewn with constructions regarding talking about, understanding or sharing one's problems. Therefore the research interview was possibly skewed towards a 'problem' stance, even before the interview had begun. In order to make every effort to balance out this socially constructed negative bias, enabling questions specifically about positive outcomes and responses were posed, so that alternative, less problem-focussed avenues were opened up for exploration.

A number of other factors also seem to influence the experience of parents of these young people. The role of religion and culture played an important and complex role in mediating parents' experiences of the mental health problems, both in a positive and negative direction. For example, the few parents who were able to utilise more positive or active management strategies were those who used their religious beliefs in order to understand the additional problems. Conversely, for some, religious constructions of the problems resulted in negative outcomes, often relating to fear and shame surrounding the possibility of the young person's difficulties being caused by possession. Cultural expectations of the young person regarding independence and achievement also seemed to mediate parents' experiences: if the young person's additional problems were perceived as preventing expectations or hopes being met, a more negative outcome was experienced. Gender closely interacted with culture and religion, as both gender related and cultural constructions of the young person were affected by the additional problems, and hence expectations, aspirations and hopes relating to both had to be altered. As for culture and religion, the mediating influence of gender on parents' experience could work both positively (with respect to cultural and religious constructions of male entitlement) and negatively (with respect to cultural expectations regarding achievement for male first-borns).

Such findings highlight the need for service providers to be alert to cultural, religious and gender related factors when talking with families, as a 'colour blind' approach would risk not detecting important nuances and differences in their experiences. This could have important

consequences regarding appropriate intervention and outcome. However, while these differences and nuances existed and mediated experience, what was perhaps most striking was that overall, all parents, regardless of their ethnic and cultural background had similar experiences. This perhaps suggests that when people are faced with very major difficulties and stresses, experience is marked by universal strain, rather than diversity. That is, there appears to be something quite unifying about the enormous pressure experienced by these parents.

Whilst not overtly discussed by parents in this study, material wealth also seems to mediate parents' experiences. It is now acknowledged that families with a disabled child are more likely to experience poverty (Department of Health, 2001b), that caring for a disabled child costs around three times more than for a non-disabled child (Parker, 2000), and that 43% of children with learning disabilities live in poverty (Emerson, 2002). Furthermore, 55% of children with learning disabilities and mental health problems are estimated to be living in poverty (Emerson, 2002). This could be because living in poverty increases the risk of developing mental health problems, or because the occurrence of mental health problems increases poverty as parent have to give up paid employment to care for their child. Indeed all parents in this study were from low socio-economic backgrounds, the majority receiving benefits and living in council provided accommodation. This demonstrates a further aspect of the "double whammy": parents caring for a learning-disabled child with mental health problems are significantly more likely to live in poverty than parents caring for a non-disabled child who develops mental health problems or parents caring for a child who 'just' has learning disabilities.

Finally, it is perhaps useful to draw on the literature regarding family reactions to chronic illness and disability in children to help put these findings in a broader childhood disability context. Davis (1993) notes that physically ill children require such intensity of physical and personal attention that consequences are profound for all family members, especially parents. He describes as many as 33% of parents of children with cancer (even in remission) and 31% of parents of children with diabetes having such severe depression and anxiety that

they require professional help. He also notes that communication and relationship problems are reflected in increased marital distress, and sometimes in divorce, and that there is also evidence of increased disturbance in siblings. Chronic illness alone in a child is therefore a significant stressor for families, perhaps on a comparable level to the stress encountered by parents of a learning disabled young person. However, there is also evidence that children who are chronically ill are more likely to have behavioural and emotional problems than their healthy peers, and there are suggestions that this puts additional strain on parents who are concurrently struggling to cope with the illness in its own right (Carr, 1999). The similarities between parental reactions to childhood chronic illness and additional mental health problems, and parental reactions to learning disabilities and additional mental health problems are thus apparent. Perhaps then the “double whammy” notion is not exclusive to parents of learning disabled children, but is also a useful notion across the spectrum of childhood disabilities or illnesses when additional mental health problems are concurrent. In the absence of an answer to this question, this would certainly be an interesting and worthwhile area for further research and exploration.

Experiences of accessing help and of the actual help provided

Perhaps the most striking finding relating to parents’ experiences of help was how negated parents felt by services, leading to feelings of being badly treated or abandoned. Most parents felt they had not had the opportunity to tell their story, talk about their concerns, hopes and wishes, and feel listened to. This is perhaps alarming when considering the applicability of the Carers and Disabled Children’s Act (HMSO, 2000) to these parents, which states that all carers have the right to a full assessment of their needs and ongoing care from services in their own right. That these parents were identified for participation in this study meant that all were linked into services, whether statutory or voluntary, and services should, in theory, therefore be alert to their predicament. Given what is known about sustaining home placements for people with learning disabilities, i.e. that maladaptive behaviours caused by mental health problems increase the likelihood of home placements breaking down (McIntyre et al. 2002), it would seem in the young person’s, family’s and services’ interests to be highly attuned to the presence of mental health problems during this high-risk

period in order to provide necessary help for families. McIntyre et al. (2002) stress that management of these problems should be a high priority for services given the potential benefit not only to the individual but also to the family with respect to quality of life, which would also seem to fit with this study's findings. It could further be argued that by services giving priority to these families, the high cost of residential placements could perhaps be reduced by more timely and supportive service input.

Most parents powerfully described numerous instances in which they felt unheard and not listened to by services. This became particularly apparent when some chose to reflect on their experience of being interviewed for this study. All who did so commented on how validating and positive the experience had been, despite evoking painful and difficult feelings. There was a sense that some had actually found the process therapeutic through being able to speak, be heard, and understood. There was also a sense that for many the interview was the first time that any amount of time had been spent talking not just about the young person, but also about how they and the wider family had been affected, which was experienced as affirming.

By asking about the wider impact of the mental health problems, parents were given the opportunity to talk not just as parents to the young person, but also as people, with needs, desires and other relationships, thereby avoiding the tendency often seen in family research to be pre-occupied with the 'parent' rather than the 'person' behind the parental mask (McCormack, 1978, as cited in Todd & Shearn, 1996b). All parents who commented on the process signalled that this experience differed from what they had received from services, which of course has important service implications. As noted earlier, where services have theoretical visions or targets concerning good practice with respect to parents of learning-disabled children, these perhaps remain theoretical rather than realities. Perhaps also where services are stretched, one of the first aspects of input to be lost is 'talking time'. Services may become so focussed on 'doing' and 'arranging' that they forget just how helpful service users and their families can perceive having time to talk about their concerns and be listened to. Perhaps this focus on 'doing' has the function of protecting service providers from the

impact of having to listen to distressing stories and therefore confront the full impact that learning disabilities and additional mental health problems can have on the young person and those around them, thereby preventing them from having to confront their own uncomfortable feelings of hopelessness, worthlessness and frustration that are consequentially elicited (Thomas, 2001). As is noted, "it is perhaps by doing less, that we will paradoxically do more, as it is the feelings that will inform us most about the experience and needs of our clients" (Thomas, 2001, p. 28).

Because parents did not feel listened to, there was consensus that they needed to reach crisis point and have some kind of breakdown before services paid attention and intervened. This is consistent with other recent research investigating the experiences of parents of adolescents with learning disabilities (Turner, 2002), yet in clear contradiction with the apparent ethos and policies of services. Under current legislation, the needs of young people with significant learning disabilities should be fully assessed and regularly reviewed, with greater support provided at times of increased need (Department for Educational & Skills, 2001). The experiences of these parents suggest that there is some way to go to ensure that services are needs led and preventative, rather than reactive to a crisis. Not least, parents identified the lack of respite care, and therefore an opportunity for escape, as pushing them to breaking point and resulting in poor quality of life, which has clear service implications.

A few parents voiced feelings of being overlooked and marginalised by services due to what they perceived as racist attitudes by professionals. Given that service ethos strongly opposes racism and discrimination, allegations of individual and/or institutionalised racism deserve to be taken seriously and even investigated in their own right. However there are perhaps alternative explanations that should also be considered given that all parents, regardless of their ethnic status, spoke about services in the same way, finding the same aspects disappointing and dissatisfactory. Perhaps other factors, such as parents' educational status or professionals simply not knowing how to respond to such problems, also play a significant role in these parents being heard and attended to by services. There is some evidence that parents who have high levels of education, employment and therefore

material wealth are more successful at stating their needs and accessing help for their child (Turner, 2002). None of the parents interviewed in this study were, or had been, in professional employment. Furthermore, the inner city borough studied has a high level of social deprivation and as a result, demands on social services in particular are very high which may have implications for all parents' experiences of services, the reality perhaps being that services are simply too stretched to provide adequate support to such parents.

Service structure was also identified as problematic for these parents. There was agreement that there are too many necessary points of contact and that parents felt stretched between health, social services, education and voluntary agencies, with respect to geography, time and the subsequent financial effects. Parents were clear that a single point of contact would significantly ease their burden with respect to accessing help. This is in line with current service policy, which aims to make closer integration between social and health services and better "work in partnership" a reality over the next few years (Department of Health, 2001a). The consequences of closer service integration would clearly be very positive for these parents, whose children's particularly complex combination of problems necessitates multi-service input. Equally, closer integration, information sharing, and work in partnership between all services (including those in the voluntary sector) would not only improve coherence for parents and service providers alike (see Scior & Grierson, awaiting publication) but also enhance awareness of issues specifically relating to young people with learning disabilities and mental health problems for service providers in all agencies. This idea also fits with a recommendation made by the Mental Health Foundation (2002) regarding promotion of young learning-disabled people's mental health in school and colleges, thus facilitating improved monitoring of the young person's behaviour and mood and therefore early recognition and response to mental health problems.

The findings provide further evidence of the need for services to be highly attuned to the difficulties parents face when their child with learning disabilities and mental health problems becomes an adult. In the present study, this was especially salient with regards to parental involvement in their son or daughter's inpatient treatment, given the change in ethos and

attitudes parents experienced from child to adult services. Such findings are consistent with a number of authors (e.g. Department of Health, 2001b) who have reported on parents' sense of "shock" in relation to the transition from child to adult services.

Methodological Issues

The strengths and limitations of this study will be considered in terms of sampling issues, the interview and quality of the data, and broader issues in qualitative methodology.

The Sample

The adolescent offspring of the parents interviewed in this study spanned a wide range of presentations not only pertaining to the mental health problems but also in terms of severity of learning disabilities and additional diagnoses. The mental health problems ranged from specific diagnoses of psychosis, bipolar affective disorder and depression to less specific problems such as anger and aggression. In addition to these descriptions or diagnoses, all young people met the criteria for 'extreme' aberrant behaviour on at least 1 subscale of the ABC-Community. While this checklist was employed in order to situate the sample, it also provides some validation for the definition of 'mental health problem' employed. The term 'mental health problems' is still widely debated and disagreed upon within the learning disability literature and between professionals, as to how broad or narrow a definition to use and whether to include or exclude 'challenging behaviour'. Both professionals and parents seem to experience confusion as to what constitutes a mental health problem, which highlights the difficulties of investigating a construct that is still, and likely to be for the foreseeable future, under debate. However, the rich data obtained and the ability of professionals to identify appropriate participants would seem to indicate that despite these definitional debates, the definition employed for this study fit with both parental and professional perceptions of mental health problems in young people with learning disabilities, perhaps giving some validity to the definition.

With respect to severity of learning disabilities, the young people fell mostly in the mild to moderate range, with two outliers: one defined as having borderline and one as having severe learning disabilities. While perhaps not as wide a span as would be desirable, this sample seems to be in line with findings regarding the prevalence of mental health problems in learning-disabled young people. To date no clear association has been found between severity of learning disabilities and psychiatric disorder, but indications are that those with profound learning disabilities incur lower levels of disturbance than those with mild, moderate and severe learning disabilities (Einfeld & Tonge, 1996b). Those with more borderline learning disabilities may well fall into mainstream services, given that their learning disabilities may not be recognised or deemed severe enough to require specialist services, which might explain the absence of these young people in the sample. Diagnosing mental health problems in the more severely learning-disabled is even more fraught with difficulties than those with less severe levels for the reasons already outlined, which might also explain the absence of many of these young people in the sample.

More parents of male young people than female young people were sampled for this study. While small numbers prevent investigating significance, this trend is consistent with recent research that suggests that young men with learning disabilities are more prone to developing mental health problems than young women with learning disabilities (Emerson, 2003). Of course, only tentative conclusions can be drawn, given that evidence suggesting no gender related difference also exists (e.g. Einfeld & Tonge, 1996). A need for further rigorous, population-based prevalence studies, employing consistent definitional criteria is certainly indicated to increase our understanding of mental health problems in these young people.

The ethnic diversity of the parental sample clearly needs discussion. When I was in the first stages of planning, I expected a significant proportion of the sample to come from ethnic minorities because of the ethnic make-up of the borough. As such, the interview schedule was designed with questions relating to religion and culture. The very high proportion of ethnic minority parents interviewed (72.7%) was however unexpected. Nonetheless, the

percentage is perhaps not so surprising when the figures relating to the percentage of ethnic minorities in the borough (60.6%) are taken into account. In addition, the figure makes even more sense in conjunction with the finding that prevalence rates of learning disabilities in young people from the South Asian population are up to three times higher than in other communities (Emerson et al. 1997), especially given the high proportion of South Asians in the borough. These findings, together with the estimation that from 1991 to 2021 the number of people with learning disabilities from minority ethnic communities will increase by 70%, compared to a 3% increase in white people (Emerson & Hatton, 1999), clearly calls for services to think carefully about the needs (including those pertaining to mental health) of people with learning disabilities from ethnic minorities.

The above issues have resulted in a heterogeneous sample, both with respect to the young people identified (in terms of mental health problems) and the parents interviewed (in terms of cultural and religious backgrounds). The heterogeneity of the sample and the consequent variation in parental experiences was at times confusing and reduced the similarity of presentations. However, although experiences appeared to be mediated by issues of difference such as culture and religion, nonetheless the emergent themes were common across the sample. It could therefore be argued that such heterogeneity has increased the richness of the experiences obtained relating to being a parent to these young people. While a more homogenous sample might have resulted in a clearer picture of parents' experiences, the data yielded from such a sample might be less generalisable than that of a heterogeneous sample such as this. It could be, therefore, that themes and experiences explored in this study are more representative of the views of parents of young people with learning disabilities and mental health problems, as opposed to a select group. If this is the case, the study's findings are likely to be relevant to the wider population of such parents.

The Interview and Quality of Data

This sample comprised both mothers and fathers, in contrast to much research regarding parents of young people with learning disabilities, which have traditionally gathered only mothers' views. In line with parents' wishes, where fathers were interviewed, the mothers

were also present in the same interview. In order to respect parents' wishes, and because of the many insights that can be gained through interviewing both parents thereby gathering a variety of views, it was agreed to conduct joint interviews. Such an approach was not without difficulties however.

There was a tendency for the two South Asian fathers interviewed to take a dominant position in the interview; the dominant narrative elicited was therefore that of the fathers. This could have been for a number of reasons, including cultural issues regarding couple membership, gender and leadership, and practically, the tendency for fathers to speak better English than their wives. While every effort was made to encourage the mother to be heard, they still remained less verbal, which was perhaps culturally appropriate in such a situation. However, I was left with a feeling that these mothers' views were not heard. Therefore it is not possible to assume that these mothers' experiences would have matched the fathers' experiences.

Despite all participants being given the opportunity to be interviewed with an interpreter present, none of the parents who agreed to take part took up this option. All parents were visited prior to the interview; this enabled me to make a (subjective) decision about whether their level of spoken English was sufficient to take part in an in-depth interview. However, for a minority of parents, speech was frequently broken and parents often struggled to find words during interview. I quickly became aware of the need to set aside ample time for these interviews, so that time could be taken in the interview to clarify what parents said, ensuring understanding had been achieved. It could be argued that the validity of the data suffered as a consequence of these language difficulties. However, every effort was made to ensure accurate understanding and recording of parents' accounts: in order to enhance validity, I made every effort to transcribe interviews immediately after their completion.

These parents' English language abilities may seem at odds with their decisions not to use an interpreter in the interview. Indeed, I was curious about, and somewhat puzzled by, this issue throughout the process. However, the findings of this study may shed some light on

these decisions. One striking finding was parents' fears concerning the reaction of people in their community to their son or daughter's mental health problems. Many felt they would be judged as bad parents if their communities were to know, that they and their family would be shamed as a result, and they therefore preferred to keep knowledge about the additional problems within the immediate family. It could be that this was a key reason for not choosing to use an interpreter, who by definition would be part of their linguistic community, and possibly part of their actual community. Indeed Granger and Baker (2003) note that shame relating to the content of interviews is one factor that presents difficulties for interviewees when using interpreters. Tribe and Morrissey (2003) add that discussing mental health problems, which can be stigmatising in many cultural contexts, may seem all the more daunting through an interpreter.

Throughout the research process, I was very mindful about the difference between my own ethnic background (white British) and the backgrounds of a large proportion of the participants (first generation immigrants from South Asian countries). It could be argued that participants would feel unable to talk openly and freely with someone from a different ethnic and religious group. Indeed, this was a view that I was very mindful of when entering into the research process. However it is my view that in this study, being of a different ethnic background did not hinder dialogue: it seemed that parents actually felt less threatened and therefore freed up to talk about the mental health problems with someone outside their community frame of reference. Indeed, so powerful was the rapport formed with some parents and so desperate their need for help, that for some, with their consent, it was considered appropriate to make a referral to the learning disabilities team. Of course, it cannot be assumed that parents would not have disclosed to an in-group member, nor that their stories might not have been richer. Whatever the ethnic background of the professional, what seems key is that service providers should be prepared to ask explicitly about different beliefs and practices rather than assume knowledge and understanding. Such principles would seem essential in order to improve services for all people: these principles were also used for non ethnic minority parents with revealing results, highlighting the need not to

assume that just because someone is from the dominant ethnic group they do not have complex cultural and religious beliefs.

Broader Issues in Qualitative Methodology

The evaluation of qualitative methodology has been addressed by a number of researchers (Elliott, Fischer & Rennie, 1999; Stiles, 1993). Elliott et al. (1999) devised a set of evolving guidelines that can be used in order to review qualitative research in clinical psychology, with the aim of encouraging better quality control in absence of the statistical concepts of reliability and validity as used in quantitative research. These guidelines will be used to further reflect upon the present study.

Owning one's perspective

Elliott et al. (1999) state the importance of qualitative researchers recognising their own "values, interest and assumptions and the role these play in understanding" (p.221). The section 'Researcher's Perspective' (p.45), presents these. It must also be recognised that a researcher's perspective is not a fixed entity, rather as the data emerge perspectives change as new information is incorporated. Throughout the discussion thus far, I have tried to be reflexive, that is consider the impact of the research on me, and therefore on the research process.

The issue of context perhaps deserves more thought in this study. It sometimes seems that as a trainee clinical psychologist, due to the time pressures and stresses of training, life events must be acknowledged and then detached from one's work. Qualitative research approaches however have a place for discussing contextual issues that have in some way impacted on the research process. During training, I suffered a significant bereavement. My own issues of loss and mourning throughout the training process have been both significant and unavoidable. During an interview highly charged with parental loss and pain, I became acutely aware of how my own personal story of loss might impact on the interview and analytic process. Close use of supervision involving listening to excerpts of taped interviews, use of the interview schedule in order to guide the process and avoid becoming entrenched

in the loss, and independent researchers examining the transcripts and analysis at various stages enabled the research process to be independently audited, thereby increasing credibility. Such checks were invaluable tools for me, and although it would be naïve and against the principles of the interpretative methodology employed to assume that my beliefs, values and feelings have not in some way influenced the collection and interpretation of the data, that I was transparent about the issues enabled appropriate steps to be taken to enhance credibility.

Situating the sample

It is important for readers to be able to judge the range of people and situations to which the research findings may be relevant. Demographic data are helpful in contextualising participants' thoughts and experiences. In this study, information on young people's age, gender, learning disabilities, mental health problems, additional diagnoses, daytime occupation, place of residence, culture and religion were presented in the text and Table 1. Quantitative measures were also used to provide additional contextual information about the young people's physical dependency levels and difficult behaviours. At the outset of the study I considered the use of more standardised measures, for example to examine parents' physical and mental health status. However, given the relative infancy of this area of research, avenues for investigation seemed infinite; an even larger quantity of data would perhaps have been overwhelming and confusing rather than helpful for readers.

Grounding in examples

It is important that the researcher's ideas are supported by quotations and examples in the text in order to enable the reader to understand how the researcher has arrived at their interpretations and thematic labels, especially with an interpretative phenomenological approach. In the current study all themes were discussed in conjunction with examples from interview transcripts. In addition, a worked example of analysis has been provided, from raw quote, to preliminary notes, to thematic labelling (see p. 51), and a list of all quotes grouped into initial themes relating to one sub-theme have also been provided (see Appendix 5).

Providing credibility checks

Elliott et al. (1999) suggest several methods to check the credibility of the sub-themes and themes applied to the data. These include checking understandings with the participants and using multiple qualitative analysts or an analytic auditor for the verification of data. A second researcher with extensive experience in qualitative research and working with people with learning disabilities read some of the transcripts, and discussed tentative sub-themes and themes with the first researcher. Two further independent researchers also acted as analytic auditors for the data. The validity and credibility of this study would have benefited from a more collaborative process of analysis utilising the feedback and comments of the participants themselves. Gaining such respondent validation was unfortunately not possible due to time constraints.

Coherence

It is important that the understanding of a phenomenon is represented in a way that “achieves coherence and integration while preserving nuances in the data” (Elliot et al. 1999, p.222). The aim of this study was for the experiences and stories of participants to be amalgamated and condensed into an organised narrative of what it is like to be a parent to a learning-disabled young person with additional mental health problems, whilst doing justice to the diversity of views and experiences that were apparent in their accounts. Presenting the data in terms of four overall themes, each comprising a number of sub-themes, was aimed at enhancing coherence without losing important differences.

Accomplishing general versus specific research tasks

This study had a specific research task, namely to explore what it is like to be a parent to a learning-disabled young person with additional mental health problems. Elliott et al. (1999) propose that when the research task is specific the study must be systematic and comprehensive and address the limitations of extending the findings to other instances. This has been discussed in earlier sections regarding the sample, the interview and quality of data.

Resonating with readers

It is hoped that the researcher's themes, sub-themes and overall narrative of the experiences of parents resonate with readers, so that they are able to clarify and expand their appreciation and understanding of the topic, and ultimately think about the themes when engaging in clinical work or service planning. A preliminary presentation of the results to service providers from a range of agencies who work with young people with mental health problems certainly indicates that these aims have been achieved.

Suggestions for Further Research

The current findings point to a need for further research in a number of areas. Most importantly, it would be invaluable to investigate experiences of the young people themselves regarding their own understanding of their experiences of mental health problems; their perceptions of how the problems impact on their lives, their relationships, and their future opportunities; and their perceptions of the help provided to them (including hospital admissions). While this study has gone some way to help us understand how the problems affect those in their immediate system, until direct research is carried out with the young people themselves a full and informed understanding of their experiences will not be obtained.

The present results suggest that mental health problems in young people with learning disabilities may have far reaching and very profound effects on their siblings. Research with siblings would offer increased insight into their experiences and might well highlight important issues which service providers and commissioners may not be aware of. Given that the emotional needs of siblings of young people with learning disabilities have been neglected in both research and clinical forums (Department of Health, 2001b), and that these findings point to such negative experiences for siblings, such research is highly indicated. Replication of the current study would of course be valuable in itself, especially in an area

with a different socio-economic and ethnic make-up. Such work would enable further conclusions to be drawn with respect to the generalisability of the current findings.

It would also be useful to investigate the notion of the “double whammy” in more detail. In order to do this, a more large-scale comparison study could be conducted to examine how parents of youngsters with and without learning disabilities are affected similarly or differently by the mental health problems, for example through use of stress, health, social support and quality of life questionnaires. It would be also useful to measure financial standing in order to investigate the suggested links between poverty, mental health, and learning disabilities.

Large-scale longitudinal studies following young learning-disabled people from infancy, through childhood, adolescence and into early adulthood, would enable a greater appreciation of what promotes good and bad outcomes (with respect to mental health) for these youngsters and their families. Such research might enable risk and resilience factors to be more fully understood, and would facilitate insight into family members adjustment through the early stages of the life span.

Furthermore, there is a need for multi-centre population based prevalence studies. While there is certainly evidence of increased vulnerability to mental health problems in this population, there are also current debates concerning the magnitude of such problems (e.g. Moss, 2003). For example, there is a suggestion that prevalence rates are inflated because of issues such as sampling from a clinical population. Such research would enable services to understand the scale of the additional problems for their young service users, and therefore plan for their provision. It would also be useful to conduct more audit-focussed research with health services, monitoring the types of treatments and therapies offered to young people with learning disabilities and mental health problems, in order to find out exactly how service providers are responding to their needs. This was difficult to ascertain from parents, as most had had contact with so many different services that they found it difficult to pinpoint specific therapeutic input. In addition, researching clinicians’ attitudes to

treating mental health problems in young people with learning disabilities would also be valuable.

Lastly, with regard to aetiology, it would be valuable to further the limited research base regarding puberty and adolescence in people with learning disabilities, especially with regard to the psychological impact of puberty taking an altered course for the young person and their parents. Such research would enable further understanding regarding whether such altered courses contribute to mental health problems in young people.

Clinical Implications of the Study

Some of the clinical implications of this study have already been highlighted throughout this chapter. The main areas will be further outlined in this section.

One estimation of the number of young people with learning disabilities who will experience mental health problems at some point between the ages of 14 and 25 is that of 130 000 people – 40% of the young learning-disabled population (Emerson, 2002). While this figure has been questioned by some with regards to magnitude (Moss, 2003), nonetheless it remains a concerning figure given that until recently, little thought had been given to the specific requirements of this high need population. Indeed some assert that these young people have never been given priority in service provision to match the level of risk that they face (Morgan, 2003). Perhaps such lack of priority has resulted partially from the scarcity of research evidence, and the continued ambivalence by professionals to delineate the magnitude of the problems due to methodological, identification and recognition issues discussed earlier. This study goes one step to enhancing the research base and highlighting the difficult and sometimes desperate stories of these young people's families. Whatever the actual magnitude of the problem, it seems clear that these families and young people are in significant need of thought and input by services.

One area highlighted by this study is the lack of understanding, knowledge and information available to parents regarding mental health problems in young people with learning disabilities, including information pertaining to the signs and symptoms of mental health problems in young people with learning disabilities, and where to get help. Those who live with the young person are most frequently the first to notice significant signs and symptoms of mental health problems. Services therefore need to prioritise educational promotion and awareness of mental health for all families of young people with learning disabilities, especially if wanting to promote early intervention and avoid years of deterioration before help is provided. Information should be written in plain language, avoiding jargon and psychiatric terminology that can be meaningless to some parents (as should also be the case in face-to-face consultation with parents); it should be available in all languages relevant to the specific catchment area of the service. The information should include how mental health problems may present in children and young people with learning disabilities, should clearly state what to do if parents have concerns about their child (including contact telephone numbers and addresses of relevant services) and should describe the roles of different professionals that families may have contact with. Such an approach should also focus on normalising the problems, so that the sense of stigma and isolation experienced by parents is tackled.

Parents in this study found themselves unsupported in the recognition of difficulties even when they or their child was in touch with services. This direct informative approach with parents and families must therefore also be supplemented by educating others in the young person and parent's network, specifically primary health care professionals (including GPs), social services, those in the voluntary sector, and those in schools and colleges (especially at times of transition). This also fits with recommendations made by the Foundation for People with Learning Disabilities (2002), who stress the importance of enhancing emotional well-being and mental health in educational settings. This should also focus on the potentially damaging consequences of bullying in schools for young people with learning disabilities by reviewing bullying policies and action, and consider how inclusive educational policy might be affecting these youngsters' mental health.

Findings from this study would imply that for services to intervene only once the mental health problems have developed would simply be to paper over the cracks. There was a real need for parents to be heard regarding their feelings of loss about their child's learning disabilities, as well as their mental health problems. Therefore this study also points to the need to consider the understanding and adjustment of parents to the diagnosis of learning disabilities throughout childhood and adolescence. As good practice would state (e.g. Dale, 1996), this diagnosis should be revisited a number of times in order to promote parental understanding and adjustment. This study would imply that these processes are rarely in place, but are of great importance.

Such a systematic approach, while perhaps costly in the short term, would ensure that services monitor progress of the young person with respect to all health needs, mental or otherwise, and would perhaps be cost-effective in the long-term. Given parents' confusion concerning their child's mental health problems even when a diagnosis had been given, and their significant sense of loss, extra pressure and hardship in relation to the additional problems, continuing support seems crucial with respect to these additional problems. This would enable parents or carers to more easily access assessment of their own needs, as is their right under the Carers and Disabled Children's Act (HMSO, 2000). By providing counselling for parents or linking them into voluntary sector support networks, the crisis intervention approach that appears to be worryingly common in relation to these young people's mental health problems may be prevented.

The mental health promotion approach described above will be less successful if parents do not have a clear understanding of the pre-existing learning disabilities, or a poor "relationship to help" (Reder & Fredman, 1996). Undoubtedly, the quality of support during the childhood years can greatly affect parents' expectations of services and their attitude towards outside help. Support throughout the childhood and adolescent lifespan could improve relations with parents, who feel unheard and negated, and therefore increase the probability of successful help seeking behaviours and positive experiences of services in

relation to mental health issues later on. Continued support might also instil enough trust in professionals that the threat of stigmatisation (due to disclosure of the mental health problems) might be alleviated as a result of having an established and respectful relationship with services, and give parents a known and trusted point of contact when concerns arise, again helping prevent a crisis intervention approach. This would also go one step to helping parents become integrated with services, and reduce feelings of isolation.

Study findings would also point to services needing to consider developing and prioritising respite and inpatient care resources for young people with learning disabilities and mental health problems. If indeed the notion of the “double whammy” experience is valid, evidence for the greater needs of these families and young people is obvious. That parents reached such levels of desperation that they are driven to be physically violent to their child is surely alarming for services. The suggestions described above may help alleviate parents’ desperation, but it seems that services must also be willing to allocate resources to these families in order to prevent such crises, and indeed provide concrete support for parents in times of high need.

More specialist in-patient provision that can meet the complex needs of these young people is also urgently required. Parents need to have confidence in the expertise of staff regarding the complexities of the often multiple diagnoses of the young people and the safety of the unit. Psychiatric hospitals should not simply be a ‘dumping ground’ for these young people; they should be able to access specialist assessments and a range of appropriate treatments. It is now increasingly recognised that conventional psychotherapies can be tailored to people with learning disabilities (e.g. Kroese, 1998; Moss, 2003), however, this does require a level of expertise that perhaps is not available in generic mental health units.

Services need to consider further how to enable young people with learning disabilities to take part in activities that appeal to teenagers, rather than providing them with resources more suited to younger children. Activities such as going to the cinema, going shopping or

bowling might help promote a sense of growing up and therefore enhance self-esteem and emotional well-being in these young people. A less homogeneous approach to people with learning disabilities might also be appropriate, so that those with milder learning disabilities engage in activities appropriate to their level of ability. This would seem especially important given parents' perceptions of the damaging effects on the self-esteem and well-being of young people as a result of using the same services as others with much more severe disabilities. However, care would need to be taken not to segregate or stigmatise those with more severe disabilities even further.

As is proposed by current policy (Department of Health, 2001a), services must work towards creating more robust links between health, social workers, education and the voluntary sector. This would relieve parents' confusion regarding where to turn to for what, and ease the practicalities of staying in contact with multiple services. Such a recommendation is also in line with Scior and Grierson (awaiting publication) when considering the needs of service providers. They found that education providers in particular seemed to feel left out on a limb and not provided with vital information regarding the young people in their care. Striving for more co-ordinated care could aid early identification and therefore treatment of mental health problems, as information is shared between services regarding the emotional well-being of the young person.

Finally this study would point to the need for services and professionals to pay increased attention to cultural issues through training and in service planning. The need to pay closer attention to families' experiences, beliefs and expectations to ensure that they feel fully involved and that professionals have gained a thorough understanding of the situation is crucial. For example, if parents understand the young person's mental health problems to be caused by possession by evil spirits, these beliefs must be taken on board and thought given to how best to help the family in a culturally sensitive manner. However, service providers must be sensitive to the cultural beliefs and needs of all families, not just those from ethnic minorities, especially as this study points to the similarities of parental experiences, such as issues of fear of stigma and subsequent social isolation, regardless of cultural background.

Conclusion

An as yet uncharted but important area – the experiences of parents of young people with learning disabilities who have additional mental health problems – was explored in this study. Young people with learning disabilities are at significant increased risk of developing mental health problems, but little is known about how these additional difficulties affect them, their parents and wider families. In failing to ask parents about their views and experiences, researchers have neglected an invaluable source of information about how these problems are perceived, their impact, and how successful services are in meeting these families' needs.

The results indicate that parents' experiences are characterised by confusion, loss and hardship. Experience appears to be mediated by a number of factors, including culture, religion, gender, social support, fear and blame. Generally services do not seem to be attuned to the high level of need of these families. It therefore seems imperative that this first step to an increased understanding of such families' experiences will give rise to further research avenues and service development.

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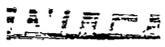
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Appendix 1

Letter Granting Ethical Approval

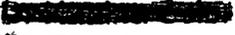
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09 AUG 2002


 Community Health Team
For People with Learning Disabilities

7th August 2002

Our ref: DO/SG/N/02/082

Dear 

Re: N/02/082 - Mental health problems in adolescents with learning disabilities: the experience of young people and their parents

I acknowledge receipt of your letter dated 30th July 2002 enclosing the following provisos:

- Letter confirming Indemnity
- Amended versions of the consent form.

I am now happy to approve and for you to proceed with the study on Chair's Action.

Yours sincerely



 DORA OPOKU
Chair
NELHA Research Ethics Sub-Committee

Chairman: Professor Elaine Murphy
Chief Executive: Carolyn Regan

Covering the London Boroughs of Barking and Dagenham, Hackney, Havering, Newham,

Appendix 2

**Participant Invitation to Participate
Information Sheet
Consent Form
Summary of Results for Parents**

Invitation to Participate

Dear (Parents)

My name is Hannah Faust. I am a Trainee Clinical Psychologist with the Community Team for People with Learning Disabilities.

I am completing a study looking at young people with learning disabilities who have experienced some emotional and / or behavioural problems. **I am interested in the experiences of their parents and families.** I want to find out what it has been like for everyone dealing with these additional difficulties and their views of any help received.

(Name of Professional) has suggested that you may be able to help me with this project and that you might find it interesting.

I have enclosed an information sheet for you which tells you more about the project and what taking part would involve.

I would be very grateful if you would complete the reply slip below indicating whether you are interested in finding out a bit more about the project, and return it to me in the stamped addressed envelope provided. If you indicate on your reply slip that you would like to find out more, I will contact you by telephone in order to arrange a time for us to meet to discuss the project further. Please note if you agree to such a meeting this does not mean that you necessarily agree to take part in the project and you can change your mind about taking part at any time.

Thank you for taking the time to read this information, and I look forward to hearing from you.

Yours sincerely

Hannah Faust
Trainee Clinical Psychologist
Supervised by Dr. Katrina Scior, Clinical Psychologist

Name:-----

Telephone number:-----

Please Tick

- I would be happy to discuss this project further
- I do not wish to be contacted about the project
- I will need an interpreter to be present for a brief introductory meeting
- I will not need an interpreter for the introductory meeting, but would need an interpreter for any longer conversation about my child's difficulties

Information Sheet

Mental Health Problems in Young People with Learning Disabilities: The Experience of Their Parents

I am a Trainee Clinical Psychologist linked to the Community Team for People with Learning Disabilities.

We are doing a study about parents of young people with learning difficulties who have also experienced some emotional and / or behavioural problems. We are very keen to speak to parents to find out what it's been like for everyone in the family when such difficulties have occurred, how they have managed and what it's been like getting help.

It is now fairly well known that lots of young people with learning disabilities experience additional emotional problems and / or behavioural problems during their teenage years or in early adulthood. Unfortunately it does not seem they always get the help they need when they need it. We hope this study will help other young people and their families in a similar situation get better help when they need it.

What will this involve?

I will arrange to see you on one occasion at home or another comfortable place and ask about the difficulties your son or daughter has had. I will also ask about any help you as a family or your son or daughter have received. In addition we will ask you to fill in two questionnaires – I would be very happy to complete these with you if you wish. I will usually see parents alone. Anything you say will be confidential.

In the first place, I would like to visit you to tell you a bit more about this study and answer your questions. You can then decide if you want to take part. It is up to you if you want to take part or not. If you decide not to take part, this will not affect any other support you or your son or daughter receives. If you do decide to take part, you can still change your mind later on and stop at any point.

You can contact me if you have any questions at:
XXXX Community Team for People with Learning Disabilities
Address & phone number provided

Thanks for your time!

Hannah Faust

Consent Form

**Mental Health Problems in Adolescents with Learning Disabilities:
The Experience of Parents**

CONSENT FORM

I.....(Name)

Understand what this study is about. I have had the chance to discuss the study and ask questions. I know what I am being asked to do. I know how the study may affect me. I understand that the interview will be tape-recorded.

I know I can stop taking part in the study at any time without it affecting the support I or my son or daughter receives in any way.

I understand that personal information is strictly confidential.

I have been told how to contact the researchers if there are any problems.

Signed.....

Date.....

As the researcher I confirm that I have explained the nature and purpose of the research to be undertaken.

Signed.....

Date.....

Summary of Results for Parents

Mental Health Problems in Young People with Learning Disabilities: The Perspectives and Experiences of Parents

This is a summary sheet for all parents who very generously gave up their time to speak to me about their experiences. The summary is in three sections: the first will give some of the background information about what we know about mental health problems in young people with learning disabilities; the second section will describe the main results of the study; and the third section will describe what will happen with the study findings.

1. What do we know about mental health problems in young people with learning disabilities, and how it affects their families?

There is now evidence that young people with learning disabilities are at significant risk of developing mental health problems. Despite this evidence, little is known about how such additional problems affect the lives of these young people, their parents and wider family members. This study aimed to further our understanding by investigating the experiences of parents who have an adolescent son or daughter with learning disabilities and additional mental health problems.

2. What are the findings of the study?

Eleven interviews were conducted with a total of fourteen parents (some chose to be interviewed as a couple). Four main themes were found to be at the root of parents' experience. These themes will now be described:

- *The Struggle to Understand*

Most parents described the process of recognising, understanding, and then making sense of the changes in their child's behaviour and emotional state as very confusing. Parents felt that their child's learning disabilities made detecting and understanding their new problems even more difficult. Parents described many things that they felt had contributed to the development of their child's emotional and behavioural problems, including: puberty and hormone changes, bullying, their child feeling behind their peers because of their learning disabilities, their child having difficulties accepting the learning disabilities, their child feeling frustrated by their learning disabilities, a lack of social and employment opportunities, changes at school or college, inappropriate educational opportunities, possession by evil spirits and bereavement. Most parents felt that knowing what was wrong with their child by receiving a diagnosis would make their experience easier. However many parents who had received a diagnosis still felt confused, either regarding the diagnosis of learning disabilities or the mental health problems.

- *Changing Us*

Parents described how the emotional and behavioural problems had greatly affected them, the young person and other family members. For many parents, the new problems felt like a fresh wound or new blow, causing more pain, hurt and feelings of grief. The new problems seemed to remind parents of their son or daughter's difference from others and of their increased vulnerability. These problems resulted in extra pressure, care burden and responsibilities for parents. Multiple losses, significant hardships (including physical and emotional health changes), fear and blame were also perceived as consequences of the additional problems.

- *Managing the Best We Can*

Parents' experiences of managing the mental health problems mostly seemed to focus on survival, existence and getting by. However some parents described how their religion had helped them to cope. Some parents described feeling isolated from others, which made it even harder to cope. Some parents felt isolated because they tended to keep the problems in the family because of a fear of being stigmatised or even outcast by their communities. Some parents also described feeling isolated from services, sometimes because of worry about what professionals might think and sometimes because they didn't know where to go for help.

- *The Battle for Help*

Most parents' described having to constantly fight for help, and that they were struggling to be heard, to be taken seriously or believed, to be understood and to receive what they considered to be appropriate help. Some parents actually felt discriminated against by services because of their ethnic background. Parents often felt that they were pushed to breaking point by services, with services waiting until a crisis was reached before they intervened. Most parents felt that there are little or no appropriate services (including respite care) for their child. Those whose child had experienced hospital admissions expressed concern about non-specialist units, that the admission was not helping their child get better, and described how long-distance placements meant that they weren't able to visit their child as often as they wanted.

3. What will happen with the study findings now?

It is important for GPs, teachers, social workers, psychiatrists, managers and those who commission services to understand better what it is like to be a parent to a young person with learning disabilities and emotional or behavioural problems, so that future services can be improved, and parents like yourselves might get better help. It is therefore very important that these findings are communicated to those who organise, arrange and provide services.

Locally, the results of this study are currently being presented to senior service providers and commissioners in (name of borough) in a number of different formats. It is also planned to publish the detailed results of the study in a journal, so that the findings become useful not just at a local level, but also at a national level. In addition, the results will be presented at a conference for all psychologists working in the North Thames region.

It is hoped that these different levels of feedback will inform and educate professionals and service providers, and hopefully lead to changes in practice.

And finally...

I would like to thank you very much for your participation. I greatly appreciated your time, openness and honesty. I hope that I have represented your views fairly. Please do contact me if you have any questions about the information on this sheet at the address or telephone number below.

Hannah Faust
Address & telephone number supplied

Appendix 3

Interview Schedule

SEMI-STRUCTURED INTERVIEW SCHEDULE

Mental Health Problems in Young People with Learning Disabilities: The Experience of Parents

BEFORE TAPE IS TURNED ON:

Introduction about interview & questionnaires: focus on the mental health problems
Seek consent and remind re. confidentiality

TURN TAPE ON!

Getting to Know the Family

- So that I can build up a picture of what X's life is like, I'd like to ask you some questions about your family.
- Who lives at home?
- What do parents do?
Prompt: Is anyone out at work?
- Do you have friends and family around you?
- What cultural background is your family from, and does this play a part in your lives?
- Does the family come from a particular religious background? If yes, does this play a part in your lives?

Process of Identifying the Mental Health Problems

"I understand from (name of professional) that (Y years ago / recently) you were in contact with the (Team/Agency) because X was / is experiencing serious emotional / mood changes and / or behavioral problems....."

*Prompts: When things were very difficult / stressful....
When things were extra hard.....*

(Name of Professional) told me a little bit about them, but I'm very interested to hear in your own words what the difficulties were.

- Who first noticed something was wrong?
- Can you tell me in detail what happened?
*Prompts: Were there any changes in X's behaviour? If so, what changed?
Were there any changes in X's mood? If so what changed?
Were there any changes in X's relationships with family/relatives/friends?*
- At the time these problems began, was X affected by anything going on at school/work?
- At the time these problems began, was X affected by anything going on at home?
- What do you think X knew about the difficulties he/she was experiencing?
*Prompts: Where did X get those ideas from?
How did X let you know these ideas?*
- Who else in X's life noticed something was wrong?
*Prompts: Teachers, keyworker, other family members, friends?
What did they notice?*

Understanding of Mental Health Problems

- How do you understand or explain X's difficulties?
Prompts: What do you think brought the problems on?
- What were you told by professionals about X's difficulties?
- What were you told might be the cause of X's problems?
- What do you think about these explanations? *OR (if in the past) What did you think about these explanations at the time? Has your opinion changed since then?*
- How do your relatives and friends explain the difficulties X has been experiencing?
- How do you think X may be explaining these difficulties to him/herself?
- What was X told and who by?
- I remember from earlier on that you said you were (religion). What would your religion say about the problems that X was experiencing?

- Prompts: Do you agree with this?
How does this affect you?*
(If) This is different from how the professionals explained the problems. Does this cause you difficulties? If so how?

- What would your culture / community say about the problems X was experiencing?
*Prompts: Do you agree with this?
How does this affect you?
This is different from how the professionals explained the problems. Does this cause you difficulties? If so how?*
- Do you think X's learning difficulty may have contributed to, or even caused these difficulties?
- Do you think people without a learning difficulty may also experience these problems?
- What would your religion say about people who are affected by both learning difficulties and additional emotional / behavioural problems (use parents language)?
- What would your culture say about people who are affected by both learning difficulties and additional emotional / behavioural problems (use parents language)?

Impact of Mental Health Problems

- In what way have the difficulties affected X? (*what do they do now, what did they do before*)
 - How has it changed what they think about themselves? Is this good or bad?
 - How has it affected their family relationships (parents, siblings, extended)? Is this good or bad?
 - How has it affected their social relationships (their friends, your friends? Is this good or bad?
 - How has it affected their daytime activities or occupation? Is this good or bad?
 - How has it affected their leisure or social activities? Is this good or bad?
 - Do you think that their difficulties made a difference to their future prospects? Is this good or bad?
- Who in your family has been most affected by the difficulties X has experienced? How have they been affected?
- Who in your family has been least affected? And why?
- How has family life been affected by X's difficulties?
*Prompts: What was family life like before?
What was family life like when they were experiencing these problems?*
What are you doing different as a family from how you were before X was having these difficulties?
- In what way have X's difficulties affected your lives as parents?
- In what way have X's difficulties affected siblings lives?
- In what way has your relationship with X been affected by these problems? Is this good or bad?

Informal Coping Strategies

I'd like to find out a bit more about things you have tried to manage X's difficulties.

- What kind of things have you tried to do to deal with or manage X's difficulties?
- Which of these strategies or ideas have helped make things better?
- Which strategies or ideas seemed to make things worse?
- Were there any things that X did to try to help themselves?
- Have relatives offered any advice or suggestions? Have these been helpful or unhelpful?
- Have friends offered any advice or suggestions? Have these been helpful or unhelpful?
- Has your religion offered any advice or suggestions? Have these been helpful or unhelpful?
- Has your culture offered any advice or suggestions? Have these been helpful or unhelpful?

Experience of Professional Help

"I'd like to find out a bit about your experiences with services during the time when X was experiencing the difficulties that we have been talking about (use their language)."

- Did you ask for help from services? Or did someone else ask for the help?
*Prompts: If yes: What were you hoping they could do?
 If no: Why did you not ask for help? Was this for example because you did not know services were available, or because you did not think they could help? Or another reason?*
- Did you know where to go for help?
- What was it like trying to get help for X?
- In your opinion, how could getting help be made easier for other parents with a son or daughter in a similar situation?
- Which services have you been in contact with?
Prompts: Health, Social Services, Education, Voluntary
- What was the most useful help?
- What was the least useful help?
- Do you think that your views were listened to?
- What about X's views? Were they sought?
Prompt: If yes: were they listened to?
- What happened when yours and the professional's views were different?
Prompts: Can you give me an example of this?
- Was anything else offered or tried?
- In your opinion, what should be done to improve the help provided locally?

Closing the Interview

Thank you very much for participating in the study.

- Do you have any questions that you'd like to ask me?
- How do you feel now after talking to me?
- Is there anything else you would like to say?

TURN TAPE OFF
 Do Questionnaires

Check have covered:

- Daytime activities / occupation
- Leisure time
- Diagnoses, sensory or physical disabilities

Appendix 4

Excerpt from an Interview Transcript

Interview 8

I So what did it mean to you that he went to hospital, the first time?

Mo *When he first went to hospital I was relieved. We came back to that car park and we were like, yes! We knew then that he had to go, he had to go.*

Fa *And whatever criticism I give to the hospital, they have been a lifesaver to us, we just weren't coping, I dread to think what might have happened if he had stayed at home. It took some time, and a breaking point, but when the system finally did kick in it certainly saved us. It gave us our family back again.*

I So I was going to ask you about that, how did family life change after X developed his behavioural and emotional difficulties?

Fa *We didn't have people round. We didn't. We just couldn't handle the hassle and embarrassment. He took this place over, he ruled the roost. We couldn't have a bit of privacy at any point. We never had any space. We could never just sit together and relax, always worried about what he'd do next.*

Mo *Because he never had any friends, nothing to do, so he was here all the time.*

Fa *It was the all night vigils he used to keep. We didn't sleep properly for years. Years. And we had to go to work, earn a living. We were only in the next room. We couldn't sleep. He'd be in and out all the time, open the door, shut the door, tapping, TV blaring, out the garden looking at the neighbours, acting like a cat crawling all over. I mean at the time I continually thought he was acting and that sounds ludicrous now I say it, how could I have thought that? But we really didn't know what to do. We had no idea what was happening, what help we could get. I just thought he was weird, I didn't know what to think.*

Mo *Because no one ever explained to us.*

Fa *If you've not got no experience of people with mental illness you just don't know. We couldn't understand how he could look so normal but do these things, thought it was just him acting badly. I know it sounds ludicrous but we went for years like that, with his behaviour getting worse and worse, and as he got older more aggressive.*

I What about X's relationships with his siblings, how did that change?

Mo *Well they were never in, they was always out, that was how they coped. And when they did come in they used to go up to their room and lock the door, that was it. And they'd stay round at people's houses, their friends. They stayed out.*

Fa *Which is what I wished I could do. But we had no way out, no escape, no help.*

I And how do you think these problems have affected how X thinks about himself?

Fa *He's got very very low self-esteem X, very much so. He'll say things like I'm nothing, I'm a no one. It is sad, it really is sad. There is no self-confidence there at all. As a parent it is hurtful to hear your son say such things as well. I feel so sad about it you know, that he has lost his happy life, when ok he wasn't clever, but he was happy. That's been a blow I tell you.*

Mo *He says things like he wishes he could touch the sky and things like that. He says he is ugly he runs himself down physically.*

I And what about his social relationships, how were they affected by his behaviour and emotional problems?

Fa *Well no-one wanted anything to do with him when he became ill, weird. His peer group disappeared, X couldn't keep up with them and they found him difficult and different.*

Mo *And also you know at the age of 12 or 13 they are all talking about girls and things. X wasn't. They were way ahead of him, he was so much behind. It was so sad because he used to go to birthday parties, be out on his bike with them. Then it all stopped and he was so lonely I think, and I reckon that actually made his illness worse, because everyone needs friends to feel happy, loved you know. Moving over to the big school, he couldn't cope, and then when mum died then he withdrew even more, his ally. Everything all just came together. The school, my mum, not coping at big school, bullying. He withdrew. And we should have interacted with him more, but he had a telly in his room so he used to go up and I was glad of the peace. I regret that now.*

Fa *We know now, we should have done it then. But we didn't have a diagnosis then, we didn't know he had these problems, so we just didn't know how to handle it. Didn't realise it then.*

I Who do you think has been most affected in the family by X's behavioural and emotional difficulties?

Fa *I would say the girls. It has left a mark on them, it really has. Because they are good girls really, but their attitude towards X is denial I think. I've never spoken even to (wife) about this but I think there is a strange attitude that they've got towards him. It is almost like they feel they don't have a brother, because they very, very rarely if ever go to see him, they don't really want to talk to him on the phone. It seems really strange to me that they haven't got that bond. Before he got so aggressive, I know it wasn't his fault now, but his behaviour alienated those girls. I'm sure of that. I don't believe it is that they have got selfish, I don't want to believe that, I think it has affected them deeper than they've ever told us. We've never asked them.*

Mo *But they don't know how to handle it either do they.*

Fa *So we are his mum and dad, we've taken the burden on, we don't burden them with it, I don't lecture them about going to see X, never. You could count maybe 5-8 times they've been in 3 years. It's upsetting you know, like a split between my girls and my son. But the girls, it did affect them. They wouldn't bring their friends home. We were adults, but they couldn't bring their friends home at the age they should have been able to.*

Mo *But if he was physically disabled or looked disabled like Down's I think they would have. You know, there is so much bad attached to having a mental illness.*

Fa *Absolutely, absolutely, stigma, especially in an area like this. You know, at the time, we didn't really want to explain X's problems to anybody, because we were embarrassed. You know I'm from a male family, where if we break our leg we smile and carry on at work, laugh it off. This type of problem, well they just don't understand it, and neither did I, I thought he was being difficult, bad, acting.*

Appendix 5

Full set of quotes for the sub-theme 'Living with Blame'

‘Living with Blame’

Key: *Quote, participant number, line number of transcript*

Failed protector

Feeling that mental health problems are a sign that the parent has failed to protect their child

- Sometimes there’s nothing we can do and that is depressing because we feel bad for X because he is having a negative experience and there’s nothing we can do about it to make it better so we feel guilty about that, that we can’t protect him from it. 1, 1126
- So at times I really feel sad and guilty about it, that I haven’t been able to look after her myself like the other children, I couldn’t protect her, and I found it so difficult to be there for her all the time, because I had to work to get earnings for the family. 3, 245
- Because I wasn’t there for her, I am her mother, I should have been there for her. The way people treated her at times, it breaks my heart. 3, 306
- I get worried that people take fun of him, take advantage because he is slow, so I don’t think they are real friends, it is a shame to watch, breaks my heart 5, 797
- To tell the truth I feel guilty about his emotional problems, I feel like I should have been able to protect him from all his troubles. I’ve failed him really. Mothers should be there to protect their children. And I feel guilty that he is so low, so down, it breaks me you know, I feel his pain as well. 7, 564
- Three years of being picked on and she didn’t say word. I felt so guilty I can’t tell you, for not noticing you know, not protecting her. Maybe if I’d noticed before she wouldn’t be like she is now, wouldn’t have this illness. 11, 120

Feeling guilty & inadequate

Feeling guilty & inadequate about the mental health problem related experiences of their child

- It makes us feel guilty, because we know that there is something wrong and we sometimes feel that we are not doing enough to deal with that 1, 616
- I wish I could do better but what can I do? So you see, something like that oh it hurts it hurts, it really put me down, it really really did, it was not easy not easy at all. 3, 313
- I tried, I tried, I did my best to help her, but sometimes....sometimes I couldn’t make it better. 3, 528
- I and my mum as well often feel really guilty that he is having these negative experiences and that we are not able to do as much as we are able to do. 1, 620
- You know it’s really really difficult, so me and my mum we are trying to juggle lots of things at one time, and sometimes we don’t do it very well. 1, 634
- We do recognise him as a child who is totally dependent on us, we do recognise these responsibilities, but we can only do what we are physically and mentally capable of doing, and sometimes we feel like we aren’t doing a very good job. 1, 716
- I feel so blamed for his behaviour, like it’s something I’ve done as a mother, gone wrong somehow, not done enough. 5, 175
- I feel guilty too you know, that I could have stopped it happening maybe. Or I could have done something earlier, but I just didn’t know what to do, didn’t know what was going on, so confused 5, 772
- He says if only they had listened and given me the right support in school. And that affects me, it makes me feel hurt, I wasn’t heard, or I wasn’t a good enough mother to be heard, I wasn’t good enough. 7, 54
- But the bullying, we didn’t realise, he wouldn’t open up. To be honest with you it makes me feel guilty that we didn’t see it. Maybe we could have stopped it and things would be better? Who knows. 8, 217
- No-one likes to admit defeat I suppose in a way, especially on your own son, like we couldn’t cope, not good enough. 8, 346

- We weren't short of money, we gave him all the equipment, took him on holiday, nothing helped. We couldn't make him better, and that made me feel so inadequate you know, I wasn't good enough 8, 1485
- I felt guilty because it looked like we'd had him put away just for being naughty, inside my head that is what I thought people thought. 8, 1341
- It felt like we let her down. I thought that kind of thing always happened to other people's children. Not our own. It was gutting to find that out, that she was so miserable, she wanted to hurt herself. She needed help and we couldn't get it for her, that was hard, like we weren't good enough parents like. 10, 291
- I'm her mum, I should be looking after her. I suppose it felt like I'd failed with her, every time she got ill, I felt I should be able to manage, because mum's should be able to manage. 11, 681
- I felt that I weren't being a proper mum anymore. Like I wasn't doing what I should do. I've been on my own since X was a baby, so I should have been able to cope. I go over and over this all the time in my head. Because every time I told about her being ill, she'd get put back in hospital, like I was abandoning her. 11, 689

Blaming ourselves

Parents blaming themselves for their child's mental health problems

- We were blaming ourselves you know, thinking maybe it is something we have done to make him like this. So that made family life really hard, we felt like we were failures. 7, 626
- You know, my husband has always been a bit, well psychologically angry and aggressive, and well when X started also I thought maybe it can be passed on, you know these emotional problems, like genetic cause? And me, everyone has labelled me as an emotional wreck. So is it me as well, that I could have passed it on to him, these mental problems? That worried me. 6, 645
- We have done, you know you can beat yourself up so many times wondering did this cause it, was I too strict, I beat myself up all the time. Was it because I was intimidating towards him? 8, 1395

Blame from others

Parents experiencing blame from others regarding their child's additional mental health problems

- At that time I would be on the bus with her and she'd be banging on the seat and one time she was banging so hard that someone said, could you control that child, would you control that child, and I kept quiet I kept going, but this woman was shouting so I say hey listen, you think I can control her, you come and tell her. Oh I was so mad, I was so mad, you don't know what I faced. So something like that, it really breaks my heart for her. I wish I could do better but what can I do? So you see, something like that oh it hurts it hurts, it really put me down, it really really did, it was not easy not easy at all. 3, 311
- It changes you, no matter how happy you are, you will change, you will change. You standing there in the cold, and she would just sit on the pavement, she won't move, and people go passing by watching you, as if they are watching you thinking you are mad, and you are letting her do that, or you've done something to her that she is sitting. Oh. 3, 552
- (other people thinking) you've done something to her that is why she is behaving like that, or why did you have such a child 3, 562
- He always blamed me, blamed me, he still does, he blames me for how his life is, problems learning, problems with the family. 5, 135
- I feel so blamed for his behaviour, like it's something I've done as a mother, gone wrong somehow, not done enough. 5, 175
- now they are laughing behind he back of us, I know because X has so much problems, and they know how much we have gone through with him at home, they laugh, think it is my fault, a bad mother. 5, 268
- And husband say it is my fault he is like that, slow, something I did wrong. That is painful 5, 401

- And he starts swearing, it's all your fault that is why I do this. 5, 439
- The GP he would laugh, he just thought it was me I think, probably blamed me as well, stupid mother can't control her son. 5, 906
- My parents have already labelled us as bad parents with a bad child. It makes me feel like a failure as a mum. And my husband feels as failure as a dad. 7, 415
- It hurts because they labelled me as depressed, and yes I was a bit low, but just because I am a bit depressed I am not valued. The GP, school, every body, they labelled me as an anxious mum. An over-anxious mum, a depressed mum, a neurotic mum. I've been called all sorts. But I don't care, I just wanted the right support for my son. That's what happens, you chase and try and get the right support in a school for your son, and you get labelled, that is what happens. Especially if you are a woman and get a bit emotional 7, 57
- One time X got so angry that he threw the table. I didn't know what to do. I explained all this to the GP but he didn't believe us. The stress of it all was, well I can't describe it. That GP told me so many bloody lies, said he seemed ok to him, there was nothing wrong, it was me, I was being neurotic, I was causing it. 7, 623
- And you'd see people looking at me, like on the plane when he'd start up, and they'd look at me like saying why doesn't she whack him, why can't she stop him.8, 850
- I mean she attacked me in a shoe shop just up the road, she just went for me, she got this idea in her head that everyone was taking the mickey out of her in the shop...all those people who was standing around, staring at us, gawping, straining their heads to have a look in the window. I don't get embarrassed easy you know, but I felt mortified then, because it was in public, my daughter attacking me. She was swearing, calling me f-ing b and c-u-n-t and everything. It was awful. I said stop swearing, everybody is looking at us, then I've said the wrong thing, because then she is going for the people in the street. Them people were laughing at us. Standing and watching and laughing. Like they are thinking, it's your fault as a mother. 11, 462

The paradox of looking 'normal'

Parents' sense that their child's 'normal' appearance exacerbates the blame form others

- Mental illness, it's a subject that is not to be talked about, no don't go down that road. If you have a bad arm you can cope with it, you can see it. Because you can't actually see what is going on they don't get it. Same as with X's learning disability, he doesn't look wrong or stupid so they don't know and don't go there. If they could see it like if he was Downs then maybe they'd be a bit more understanding. 8, 13
- And you'd see people looking at me, like on the plane when he'd start up, and they'd look at me like saying why doesn't she whack him, why can't she stop him. But because he looks so normal people don't realise that he's not well. Like if he was in a wheelchair you'd get the reaction like, poor boy, poor parents, but they don't know he's not well. It was so humiliating. 8, 850
- If X was a Down's syndrome or physically disabled, I think that they'd be able to cope with it easier, if they could take him out in a wheelchair, because people would feel sympathy. 8, 1301
- He wears modern clothes and he looks normal, he had his hair cut short, and looks normal, so they don't understand. 9, 935

Feeling punished

Parents sense that their child's mental health problems are a punishment

- Well all his life, my dad used to say to me that I'd had X, been given X, because I was such a rebellious child myself. You know, that it was because of what I had done, that is why he had learning disability and all the illness. To teach me. See you was bad, so Allah has repaid you. 7, 344
- They'd think he deserves it, we deserve it as a family, that's what caused it. Sad isn't it, because none of us deserve it. They'd look at him as if he was a loony if they all knew. That is the way they are. 7, 412

Appendix 6

List of Initial Themes, Sub-Themes and Themes

List of Themes, Sub-Themes and Initial Themes

Themes	Sub-Themes	initial Themes
Struggle to Understand	Struggling in the Dark	Noticing a difference What is this difference? Struggling in the dark
	Playing Detective	Playing detective The young person's struggle
	Searching for a Cause	Conceptual Confusion Abuse/Bullying Educational issues Not being helped No friends Struggling to accept the LD Comparing to others Puberty Independence No occupation Possession Bereavement Wilfulness
	Needing to Know	Helplessness Needing to know Relief at knowing Diagnostic confusion
Changing Us	Fresh Wound	Fresh wound Another difference Double vulnerability
	Extra Pressure and Care	Extra pressure Extra care Juggling roles Greater responsibility Needing to escape No escape/No respite
	Suffering & Loss	Parental physical suffering Parental emotional distress Parental loss of hopes Parental loss of time Parental relationship losses YP's loss of independence YP's loss of skills YP's loss of friends YP's loss of occupation & leisure Sibling relationship losses Sibling loss of schooling Sibling loss of time Loss of family life
	Living with Fear	Feeling terrorised and scared We are victims Dilemma of caring for multiple children How long will it last? Genetic fears Fear of possession
	Living with Blame	Failed protector Feeling guilty & inadequate Blaming ourselves Blame from others The paradox of looking 'normal' Feeling punished