

## **Volume 1: Major Research Project**

**The loss of the healthy child: Exploring the relationship between mothers' early attachment relationships and their reaction to their child's learning disability**

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## ABSTRACT

The distress experienced by parents, on learning that their child has a diagnosis of a learning disability, has been well documented. Goldberg, Magrill, Hale et al.(1995) proposed that parents go through a process of grieving the loss of the healthy or perfect child to whom they expected to give birth. Some parents appear able to resolve loss and trauma surrounding their child's condition fairly quickly, whilst others continue to experience difficulty for many years. This study explored the relationship between mothers' states of mind with respect to early attachment relationships and their reaction to discovering their child has a learning disability.

Forty three mothers of children with learning disabilities (aged 5-12 years), were interviewed using the Adult Attachment Interview and the Reaction to Diagnosis Interview. Data was also collected regarding recent stressful life events (using part of the Parenting Stress Index), mothers' symptoms of psychopathology (using the SCL-90) and their networks of social support. The results of the study indicated that less than half of the group of mothers were resolved regarding their child's diagnosis. Mothers who received social support from their families were significantly more likely to be resolved regarding their child's diagnosis. Mothers who were unresolved regarding their child's diagnosis reported experiencing a significantly higher number of recent stressful life events, and had received their child's diagnosis more recently, than mothers who were resolved. There were no associations between mothers' states of mind with respect to attachment and their resolution of loss and trauma surrounding their child's learning disability.

The findings of this study indicated that the experience of proximal loss and trauma regarding the child's learning disability over-powers mothers' attachment systems and reduces the impact of previous protective, or deleterious experiences in the mothers' lives. Clinical implications are discussed, including the importance of parents being given clear information regarding diagnosis and prognosis of their child's learning disability. The findings provide support for developing services which work within the wider family system, as opposed to more child-focused interventions.

## INTRODUCTION

*You think you've accepted it all but I don't think deep down you've completely accepted it because you always, when they're younger you always have this hope that when they get older they might grow out of it, or it's going to get better, it's going to get easier and it doesn't get any easier. I'm not sure it's going to get any better, it's just different to be honest...it's much harder when you've got a nine year old girl walking down the road screaming her head off or throwing a wobbly than it is to have a two year old sitting in a pushchair throwing a wobbly.....and as you get older you realise that in actual fact you could have this adult of 30 on your arm screaming or throwing a wobbly and that's very difficult to come to terms with. (Excerpt from interview with the mother of an eight year old girl with severe learning disabilities and autism)*

### Overview

This study aims to explore the relationship between mothers' current states of mind with respect to early attachment relationships and their reaction to discovering that their child has a learning disability. Particular attention is given to the relationship between resolution of past losses or traumas, associated with the mother's attachment figures, and resolution of grief and trauma surrounding the child's condition.

The introduction will be divided into seven different sections. The first section will discuss the concept of learning disabilities including discussion regarding terminology, diagnostic criteria and epidemiology. This will be followed by a review of the literature describing parents' reactions to discovering that their child has a learning disability. The third section will discuss the process of parental resolution of loss and trauma surrounding their child's learning disability. Attachment theory and care-giving systems will then be described prior to consideration of the impact of learning disabilities on the mother-child relationship. The sixth section will provide an overview of the difficulties

encountered in families who have a child with learning disabilities. Finally, methodological considerations of the research base will be considered and the aims and hypotheses of the study will be introduced.

## **Learning disabilities**

### Diagnosis

The American Association on Mental Retardation (AAMR) has developed a system to define and classify intellectual disabilities (1992). Hatton (1998) describes the AAMR system as the most widely accepted and comprehensive diagnostic system and a 'gold standard' which may not be met by all UK Learning Disability Services. The AAMR definition of learning disabilities states that an individual must have substantial limitations in their present functioning; their intellectual functioning must be significantly below average compared to the general population and they must have limitations in at least two areas of adaptive functioning (e.g. self-care, social skills, communication). The individual's difficulties must be evident before adulthood in order to be described as a learning disability. The AAMR guidelines do not differentiate between the severity of learning disabilities. However, it is common practice for clinicians and researchers to do so, typically using intelligence quotient (IQ) scores from standardised assessments. The International Classification of Diseases (ICD-10) guidelines state that IQ scores between 50-70 reflect a mild learning disability which is typically identified during the individual's school years. People diagnosed with mild learning disabilities may experience difficulties in school work but are usually able to live independently and engage in employment. IQ scores of 35-49 reflect a moderate

learning disability which is typically identified between three to five years of age. Individuals who are diagnosed with moderate learning disabilities may be employed, typically requiring support and normally also require support in activities of daily living. IQ score of 20-34 reflect a severe learning disability which is usually identified before two years of age. Individuals who have severe learning disabilities require a significant amount of support with daily living tasks and are typically only able to speak using single words.

#### Difficulties with diagnosis

Standardised IQ tests are reported to be unreliable, particularly for those people with IQ scores of 70 or less and Whitaker (2003) recently initiated a debate as to whether it is appropriate to rely on IQ scores to define the severity of a person's learning disability. Greater recognition is now being given to those people who may have low average IQ scores but experience significant deficits in their adaptive functioning and social interactions, e.g. individuals with high functioning autism, who may be turned away from services because their intellectual functioning is above the cut-off for learning disability services.

#### Signs and symptoms associated with learning disabilities

The World Health Organisation (WHO) Guide to Mental and Neurological Health in Primary Care (2004) reports that children with learning disabilities may be born with unusual facial features (dysmorphia) and have difficulties in feeding and gaining weight.

They are typically delayed in reaching developmental milestones such as sitting up, walking, speaking and toilet training. When such children reach school-age they experience difficulties completing school work and managing interactions with other children. Children with learning disabilities frequently present with behavioural problems, particularly hyperactivity and poor social skills. They are often at risk of being bullied by other children because of the stigma associated with their learning disabilities and differences in their appearance and / or behaviour. In addition, people with learning disabilities frequently suffer from additional motor impairments, sensory impairments, challenging behaviour and psychiatric disorders (Hatton, 1998).

### Epidemiology

The majority of individuals with learning disabilities in the UK have mild learning disabilities. There is no known organic cause and their difficulties are felt to be associated with social deprivation and primarily environmental factors such as poverty and inadequate housing (Sinason, 1992). The majority of severe learning disabilities are associated with genetic disorders, (e.g. Down syndrome, Rett syndrome) and/or brain damage occurring in-utero or at birth. Severe learning disabilities are equally prevalent across all social classes (Sinason, 1992). The WHO (2004) reports that 30% of individuals with moderate to severe learning disabilities have a disorder within the Autistic Spectrum. Developmental delays may also be associated with malnutrition and chronic medical illnesses such as epilepsy. Most causes of learning disabilities cannot be cured, however, treatable causes of learning disabilities include phenylketonuria, hyperthyroidism and lead poisoning, (WHO, 2004).

## Terminology

The terminology used to define learning disabilities has gone through many historical changes (Sinason, 1992). This may reflect the fact that many terms used to describe learning disabilities have also been used in an abusive or stigmatising manner by society. At present in the UK the term learning disabilities is used to describe people who have significant impairments in their intellectual functioning and adaptive functioning (e.g. ability to carry out daily living tasks). This is equivalent to the term mental retardation which is used in the USA and other European countries. To prevent confusion the term learning disability will be used in this study to replace mental retardation when discussing research from other countries.

## **Parent's reactions to being informed that their child has a learning disability**

Research has documented the deleterious impact giving birth to a learning disabled or chronically ill child has on parents (Blacher, 1984; Bowlby, 1980; Burden & Thomas, 1986; Seligman & Darling, 1997; Waisbren, 1980). One of the explanations proposed by Goldberg et al. (1995) is that parents go through a process of grieving the loss of the healthy or 'perfect' child they had expected to give birth to. However, a small body of research has described families who report positive experiences associated with having a child with a learning disability (Singer & Powers, 1993; Trute & Hauch, 1988; Turnbull, Patterson, Behr et al., 1993). The literature base tends to group children with intellectual disabilities with children suffering from chronic medical conditions because parental responses to both types of condition have been reported to be similar. However, there may be important differences between the responses of parents who have children with

chronic medical conditions and those who have children with learning disabilities (in the absence of medical conditions). In addition there may be differences depending on the characteristics of the child's learning disability. The literature has been grouped together because of similarities in the *early* responses to diagnosis. Further longitudinal research is required to examine parental responses to their children at primary to middle school age, adolescence and adulthood. In addition the research uses a number of terms interchangeably to describe the ability of parents to adapt to their child's disability and grieve the loss of their child's healthy status. Commonly used terms are adaptation, adjustment, acceptance, resolution and coping. As there are no clear definitions or evidence to suggest that the terms refer to distinct processes the term resolution will be used within this study. However, Barnett, Clements, Kaplan-Estrin & Fialka (2003) prefer to use the term adaptation in their work with families because it does not assume an endpoint, rather an ongoing process.

### Emotional responses

It is well recognised that parents report experiencing distress when discovering that their child has a learning disability or chronic medical condition. Many parents experience shock, disbelief and sadness, similar to the emotions experienced after a loss or bereavement (Blacher, 1984; Bowlby, 1980; Marshak & Seligman, 1993; Waisbren, 1980). The nature of the child's disability has an impact on when the parents will discover that their child has a learning disability. Children with Down syndrome are usually diagnosed within the first few weeks of their life whereas other conditions such as hearing impairment, autism and global developmental delay are not recognised until

the child is older. Delays in diagnosis can lead to increased levels of stress as the parents are usually aware that their child has a problem and wish for diagnosis so that they can provide the best support and interventions. Dickman & Gordon (1985) report that parents whose children are diagnosed after a lengthy process report feelings of relief rather than shock because of the stresses associated with being unable to understand the nature of their child's condition. In support of this Seligman & Darling (1997) report that Baxter (1986) found that parents who sought diagnosis or had gradually realised that their child was different reported less distress after receiving the diagnosis. Therefore it appears that it is the parent's realisation that their child has a disability rather than diagnosis *per se* which is associated with distress and shock.

Although diagnosis has been reported to be difficult for parents of children with learning disabilities, there are some difficulties and stressors which are felt to be unique to families who have a child with autism. There are a range of different and confusing terms given such as Pervasive Developmental Disorder (PDD), or developmental delays in social and language functioning (Marcus, Kuncze & Shopler, 1997). As a result of this diagnostic confusion parents report that professionals may not clearly state the diagnosis of autism (Nissenbaum, Tollefson & Reese, 2002). Such diagnostic confusion can add to the stresses involved in coping with a child with learning disabilities and behavioural problems. There may also be a pattern of uneven cognitive skills which can make it difficult for the parent to understand their child's level of functioning and therefore harder to accept the chronicity of their condition (Koegel, Schreibman, Loos et al., 1992).

## Models of grieving

### Chronic sorrow

Olshansky (1962) developed the term 'chronic sorrow' to describe parents' ongoing emotional state with regard to their child's disabilities. He described chronic sorrow as a normal reaction to having a disabled child and hypothesised that the feelings of sorrow would change over time in response to changes in the child and the family system. Roos (1995) states that Olshansky's concept of chronic sorrow has not been well defined or developed over the past 40 years. As a result clinicians continue to confuse chronic sorrow with other types of grief and with dysthymia and depression. Roos (1995) believes that it is important to differentiate between chronic sorrow and pathological or complicated mourning in order to provide appropriate services and support. She believes that chronic sorrow is not subject to resolution because it is a response to a living loss that cannot be removed.

### Stage models

Some researchers have postulated that parents need to go through different stages of grieving for the loss of the healthy or 'perfect' child they had expected to give birth to, before they are able to adjust to their child's disability (Bicknell, 1983). Such stage models assume that parents' feelings of grief will eventually be worked through and replaced by acceptance of their child and resolution of their loss.

### Developmental models

A number of researchers have criticised stage models and have suggested that resolution is an ongoing, developmental processes related to life transitions (Blacher, 1984; Bruce, Schultz, Smyrnios & Schultz, 1994; Wilker, Wasow & Hatfield, 1981). Wilkner et al. (1981) suggest that parents' unconscious expectations about their learning disabled child's development are discrepant with their child's actual development. As a result parents experience new losses and grief (which require resolution) as each developmental milestone passes and is not reached by their child.

### Life stages

Korff-Sausse (1999) and Goldberg, Magrill, Hale et al. (1995) suggested that resolution is a cyclical process which is affected by developmental transitions such as going to school, adolescence, leaving home/launching (Olson, McCubbin, Barnes et al., 1984). They state that it is unrealistic to expect families to completely resolve their mourning and that they may continue to re-experience grief at key, transitional points in the family life cycle. A number of researchers have found evidence to support a developmental rather than stage model of grief with the findings that age of child and time since diagnosis were unrelated to parents' resolution of their grief (Bruce et al., 1994; Holder, 2000; Pianta, Marvin, Britner & Borowitz, 1996; Walsh, 2003). Goldberg et al. (1995) described therapeutic work with families who are having difficulty completing tasks which will move them from one family life cycle stage to the next. They hypothesised that each transition involves change and therefore loss, which stimulates grieving. Grieving current losses is thought to stimulate past losses and provides the opportunity

to re-grieve past losses in a more adaptive manner. Their case studies are an interesting illustration of the long term impact of unresolved grief within family systems which have a child with a learning disability. Goldberg et al. (1995) also made connections between the initial grief response experienced by parents and their later behaviour when re-experiencing/capitulating their grief. For example, they described one mother's angry response to the news that her daughter had a learning disability and how she reacted angrily to each successive loss within the family system. Goldberg and colleagues formulated that parents may get stuck at a particular life stage through trying to protect their children from the consequences of their learning disability. This can lead to difficulties in separating from their child, e.g. at school age or at the time at which other children are leaving home. They also suggested that unresolved grief concerning the loss of the 'perfect' child may result in rigid relationships between children with learning disabilities and their parents. In addition, patterns of relating between generations may have a constraining effect on the family's ability to grieve and resolve losses. The aim of their family therapy is to introduce change in the family's current relationships and pattern of grieving. This will help the family to progress in their grieving and undergo transition to the next stage in the family life cycle.

### Cultural beliefs

Each family will respond differently to discovering that their child has a learning disability. Reactions will be determined to some extent by the family's own cultural beliefs about disability, their ethnicity, religious beliefs, socioeconomic status and also the culture of the society within which they live (Krauss-Mars & Lachman, 1994;

Miltiades & Pruchno, 2002; Seligman & Darling, 1997). Krauss & Lachman (1994) conducted a cross-cultural study in South Africa. They found that white parents were more likely to report having received an explanation of their child's diagnosis and the opportunity to ask questions, compared to black parents. Interestingly, they reported that white parents were more likely to deny their child's diagnosis of a learning disability than parents from other ethnic groups. Ryan & Smith (1989) compared responses of Chinese-American versus non-Asian parents in America, regarding their reaction to the news that their child has a learning disability. They found that parents from both ethnicities reported reacting with sadness, guilt, anger, fear and frustration. However, Chinese-American parents showed poorer understanding and knowledge regarding their child's condition and furthermore, their beliefs about causation and treatment were influenced by Asian culture. Seligman and Darling (1997) described the conclusions reached by Schorr-Ribera (1987) that cultural beliefs influence each family's adaptation to having a child with a disability and also have an impact on their uptake of services which provide care. However, it is also important to remain curious about the impact of the beliefs of each family since these may differ significantly between families from the same ethnic, religious and socio-economic background and culture.

#### Reactions of fathers, siblings and the wider family system

Traditionally the majority of research and clinical work focused on the mother-child relationship and maternal adaptation and resolution. However, clinicians and researchers are becoming increasingly interested in exploring the family system as a whole. A review of the literature describing the reactions of fathers, siblings and the wider family

is beyond the scope of this introduction. In addition it is difficult to report any conclusions because of the paucity of research and conflicting results (Holder, 2000). See Seligman & Darling (1997) for a comprehensive review.

### Summary

On discovering that their child has a learning disability, the majority of parents go through a process of grieving the loss of the healthy child they expected. The evidence suggests that resolution of grief is a cyclical process related to transitional points in the family life cycle. Each family's reaction to their child's diagnosis will be affected by their cultural beliefs, ethnicity and socio-economic status. These factors may impact on the family's ability to access help from others and their relationship with services.

### **Resolution of loss and trauma regarding the child's learning disability**

Hornby (1994) and Holder (2000) reported that some parents appear able to resolve loss and trauma surrounding their child's condition fairly quickly whilst others continue to experience difficulties for many years. An important area of study is to determine which factors facilitate or interfere with the process of parental resolution of grief. Marvin & Pianta (1996) proposed that attachment theory is a helpful framework within which to better understand the process of resolving the loss and trauma associated with having a disabled child. Bowlby (1980) wrote extensively about grief processes following the loss of a close loved one and Marvin and Pianta (1996) proposed that his theory is applicable whether the loss concerns actual death or intrapsychic loss of the expected healthy child.

Bowlby's (1980) research suggested that resolution of grief may be associated with the extent to which parents are able to interact sensitively with their children and provide 'effective' parenting. Barnett et al. (2003) reported that parents go through a process of grieving for the loss of the healthy child they had hoped for before replacing the expectations they had with the reality of their disabled child. If parents are not able to develop an internal representation of their child's *actual* abilities rather than the *wished for* abilities then this may impede their ability to parent sensitively and develop a secure attachment with their child (Atkinson, Chisholm, Scott et al., 1999).

#### Research using the Reaction to Diagnosis Interview

Pianta & Marvin (1992a) developed the Reaction to Diagnosis Interview (RDI) to assess the extent to which parents are resolved regarding losses and trauma surrounding their child's disability or medical condition. The interview aims to explore the parent's state of mind with regards to their child's diagnosis, how their feelings have changed over time and their beliefs about why they have a child with a disability. The interviews are coded using a standardised procedure and parents are classified as resolved or unresolved regarding their child's condition. Parental resolution refers to the integration of parent's emotions and information regarding their child's disability within the parent's representational system of themselves, their child and their relationship with their child. Parents who are unresolved continue to experience disorientation associated with grieving and have not yet integrated information about their child's condition without distorting reality (see method section for further details of the coding system). It is important to note that Pianta & Marvin assume that there are some elements of being

both resolved and unresolved in each interview and that this may change over time. The interviews are classified according to whether the parent shows more signs of being resolved or unresolved. Naturally the extent to which parents are resolved lies along a continuum. One criticism of the RDI is that the concept of categorising parents as resolved or unresolved is at odds with theories and research which view adaptation and resolution as a continuous process. Therefore it may be useful to develop a continuum or scale which depicts the extent to which the interview reveals signs of being resolved or unresolved.

Pianta and Marvin theorised that if parents are unresolved with regard to their child's diagnosis, this will impact on their relationship with their child and their care-giving skills. They carried out a number of research studies to explore this theory with mothers of children with cerebral palsy and epilepsy, aged 15-50 months. They found that resolved mothers were more likely to have secure attachments with their children and unresolved mothers were more likely to have insecure attachments with their children (Marvin & Pianta, 1996). However Pianta, Marvin & Morog (1999) did not find an association between mother's resolution of past losses and traumas measured by the Adult Attachment Interview (AAI) and whether they were resolved regarding their child's diagnosis of cerebral palsy or epilepsy. This finding was unexpected because in other populations research has found that mothers who are unresolved regarding past losses and traumas are at greater risk of having problems with attachment and care-giving relationships (Main, Kaplan & Cassidy, 1985). Interestingly, Pianta et al. (1999) did not find an association between AAI status and resolution on the RDI or between

AAI status and security of the child-caregiver relationship within a group of mothers whose children had epilepsy. Pianta et al. (1999) suggested that results within the sample of mothers whose children had epilepsy may be different because of the unpredictable nature of their child's condition, compared to the chronic and stable nature of cerebral palsy. Pianta et al. (1999) suggested that resolution is more likely to be attained when the illness or disability has a predictable course. Conditions where there is hope of improvement or abatement appear to be problematic for resolution. The unpredictable nature of epilepsy may act as a constant threat to the caregiver's ability to protect their child from harm. Pianta et al. (1999) suggested that further research needs to be carried out with children who have a range of diagnostic conditions. However, they cautioned against using participants whose children have varying symptoms and diagnoses because the relationship between resolution of diagnosis and attachment may be disrupted by the nature of proximal losses and traumas associated with the child's condition.

Walsh (2003) carried out a study of mothers whose children had cerebral palsy and epilepsy. She found that mothers in the cerebral palsy group who were classified as secure/autonomous on the AAI were significantly more likely to be resolved on the RDI. However, this relationship was not found within the group of mothers whose children had epilepsy. Contrary to the research hypothesis and previous research (Pianta et al. 1999), there was no significant relationship between adult attachment status and child attachment security. Walsh (2003) found that mothers who were unresolved with regard to their child's diagnosis of cerebral palsy were more likely to have children classified as insecure on a measure of child-caregiver attachment. This was the case even when

mothers were resolved with respect to past losses, as measured by the AAI. Again, this relationship was not significant for the group of mothers whose children had epilepsy. Mothers who were unresolved on the RDI engaged in more negative and unhelpful behaviours during a joint problem solving task with their child. Walsh (2003) concluded that the impact of the loss of the healthy child may overpower the care-giving system resulting in the child having an insecure attachment style.

### Summary

Some parents appear able to adapt to their child's disability fairly quickly whilst others continue to experience difficulties for many years (Hornby, 1994; Holder, 2000). An important area of study is to determine which factors facilitate or interfere with the process of resolution of grief and loss surrounding the child's disability or medical condition. The Reaction to Diagnosis Interview was developed to assess parental responses to their child's diagnosis. Resolution appears to be positively related to attachment patterns and care-giving skills in mothers who have children with cerebral palsy. The current research base has explored associations between attachment patterns and resolution in parents whose children have cerebral palsy and epilepsy. At present there is no evidence of a significant relationship between mother's resolution of past losses / traumas and their resolution regarding their child's diagnosis. Current research has found evidence of a significant association between mothers' states of mind with respect to early attachment relationships and their reaction to receiving the news that their child has cerebral palsy. However, this relationship has not been demonstrated in

parents whose children have epilepsy. This study aims to explore these associations within a sample of mothers who have children with learning disabilities.

### **Attachment and care-giving systems**

A brief overview of attachment theory and relevant research will be provided. This will review the impact of losses and traumas to the attachment system on parents' care-giving, risks associated with early insecure attachment style and intergenerational patterns of attachment.

#### **Attachment theory**

Bowlby's Attachment Theory (1969) was developed from his empirical observations that 'the young child's hunger for his mother's love and presence is as great as his hunger for food' (p13). He observed that children responded to their mother's absence with a 'powerful sense of loss and anger' (p 13). On being reunited with their mother after a separation children were seen to respond either by clinging intensely to their mother or by rejecting their mother and being detached from her. This led Bowlby to hypothesise that the loss of the mother figure, in combination with other unidentified variables, generates responses similar to those observed in adults who are thought to be suffering from emotional disturbances. He suggested that the study of personality and psychopathology could be informed by these observations and help our understanding of personality development. Bowlby (1969) therefore made connections between the

different responses seen in children following separation from their mother and in the style of personality functioning which may follow an early experience of separation.

Attachment theory proposes that humans have developed behavioural systems which aim to protect their children from harm. The attachment and care-giving systems are thought to be represented in terms of patterns of behaviours and also as internal representational systems. The internal representational systems organise and regulate the smooth functioning of the behavioural systems. Bowlby (1969) hypothesised that the development of a secure relationship is dependent on a smooth interaction between the parent's care-giving behaviours and the child's attachment behaviours. If parents are not available (physically or emotionally) when the child is anxious or distressed then the child may react by inhibiting their attachment systems and developing an avoidant, ambivalent, or disorganised attachment style. Children's attachment styles have been studied extensively using the Strange Situation (Ainsworth, Blehar, Waters & Wall, 1978) which is carried out in a controlled laboratory. This experiment involves the child being separated from and then reunited with their mother. The child's reactions are videotaped and then coded according to their responses.

Main, Kaplan & Cassidy (1985) suggested that the way in which an individual interacts with other people is based on their underlying attachment model. This model is created through the child's interactions with their caregivers although it remains susceptible to changes in environmental and interpersonal factors throughout most of childhood (van IJzendoorn, 1995). As the child grows older this representation becomes more stable and

less vulnerable to environmental factors. In favourable conditions it is assumed that children form secure relationships with their mothers and other important figures which serve a protective function. A secure attachment allows children to explore away from their parents in safe, non-threatening, situations whilst returning to the safety of their parents in threatening circumstances for comfort and protection. Children who have secure attachments appear to have an internal model of their caregiver in which they expect their mother to be available and responsive to them. Research has found that children with secure attachment styles are more resistant to stress and better able to recover from adverse life experiences (Pianta, Egeland & Sroufe, 1990). Children with insecure attachment styles appear to have an internal working model of their caregiver that expects they will not be available and responsive. Those with avoidant attachments try to manage rejecting behaviours from their caregiver by minimising their display of attachment behaviours. Children with ambivalent attachments appear to maximise their attachment behaviours by remaining close to their mothers but getting little comfort from them (Ainsworth et al., 1978). Main & Hesse (1990) observed that in an anxiety-inducing situation such as the Strange situation, children who may have been frightened by their caregivers experience a dilemma. Although they may behave in ways which indicate secure or insecure attachment patterns, they also behave in unusual ways such as freezing, exhibiting signs of fear and disorientation. Such patterns of behaviour are described as a disorganised attachment style and are frequently observed in children who have been maltreated (Main & Solomon, 1986). Insecurely attached children (avoidant, ambivalent or disorganised) have been found to be more at risk of psychological and interpersonal problems (Main, Kaplan & Cassidy, 1985).

### Intergenerational attachment

Research exploring the intergenerational transmission of attachment styles has focused on the disruptive nature of losses and traumas in relation to attachment figures. For example, Main, Kaplan & Cassidy (1985) have reported that experiencing the loss of an attachment figure or experiencing abuse from an attachment figure may lead to the development of insecure attachments. This places an individual at increased risk of later depression and problems in parenting. However, it is important to note that some people are able to resolve losses and traumas to their early attachment relationships. Those who are not able to resolve their experiences of loss or trauma are at greater risk of problems with attachment relationships and care-giving (Main et al., 1985). The loss of an attachment figure is overwhelming and causes severe distress and grief. Reactions include searching for the lost person, disbelief that they are gone, fears of having caused the loss and disorientation in situations where the lost person would normally have been present. Resolution of the loss indicates that the individual is able to accept the loss as permanent and stop searching for their loved one. They are also able to access memories of the lost person without becoming disorientated and no longer fear that they caused the loss. Those who are unresolved continue to experience symptoms of distress and disorientation and have conflicting internal models of their self and others. The experience of intense fear and helplessness associated with trauma can lead to psychological and behavioural disorganisation, particularly if the child is mistreated or abused by their caregiver. (Main & Hesse, 1990). There is evidence to suggest that mothers who are unresolved regarding past losses /traumas on the AAI are more likely to have children with a disorganised attachment style (Main & Hesse, 1990). The

disorientation experienced by unresolved mothers is thought to cause them to behave in ways which unpredictably frighten their child. The child therefore wishes to approach their caregiver for protection and comfort but is not able to because they are the source of fear.

### Research using the Adult Attachment Interview (AAI)

The Adult Attachment Interview (George, Kaplan & Main, 1985) is a structured interview which aims to elicit information regarding the individual's current state of mind with respect to early attachment relationships. The interview asks questions relating to early relationships with parents, experiences of separation, rejection, abuse, bereavements and traumas. The interviews are classified according to a standardised procedure (Main & Goldwyn, 1984, 1998). Each interview is classified as either secure/autonomous (F), dismissing (D), preoccupied (E) or unresolved (U). If the interview is classified as unresolved regarding loss or trauma then another forced classification of D, E or F is given (see method for further details of the classification system). It is possible that an individual with a past history of insecure attachment may be classified as secure on the Adult Attachment Interview (AAI) and vice versa. This is because the AAI is a measure of the individual's current state of mind which may have been affected by environmental or interpersonal experiences in adolescence or adulthood, such as being in a secure romantic relationship (Fox, 1995).

Solomon & George (1996) report that mothers' care-giving representational systems will be influenced by their state of mind with respect to attachment figures. Fonagy, Steele &

Steele (1991) studied the predictive power of the AAI and suggested that the ability to predict attachment style is not related to past experiences *per se* but in the 'overall organisation of mental structures underlying relationships and attachment related issues' (p. 901). There is a large body of research which has found that mothers' attachment patterns, as measured by the AAI, are predictive of their child's attachment style, measured by the Strange situation (Benoit & Parker, 1994b; Fonagy et al., 1991; George & Solomon, 1996; van IJzendoorn & Bakersman-Kranenburg, 1996). Fonagy, Steele, Moran, Steele & Higgitt, (1993) attribute the relationship between mother's secure / autonomous AAI classifications and their child's secure attachment behaviour on the Strange situation to the parent's self-reflective functioning. Fonagy et al. (1993) state that parents who have greater capacity for self-reflection are more sensitive to their child's perspective and emotions. This means that they are better able to respond sensitively to their child's attachment behaviours and meet their needs.

#### Past and proximal losses

Pianta, Marvin, Britner & Borowitz (1996) suggest that parents' care-giving systems can be disrupted by *past* losses and traumas to the attachment system, or by *proximal* losses and traumas such as giving birth to a child with a disability or chronic medical condition. Such an experience presents a threat to the parent's attachment care-giving system as the parent is unable to protect their child from the threat to their health and development. This means that parents have the task of caring for their children under unique circumstances where they are unable to protect their child from harm. Such a situation may disorganise the care-giving system and cause conflict and anxiety which

arouses the parent's own attachment systems. The process of resolving the child's diagnosis is similar to resolution of other losses and traumas. It involves integrating new information about their child into their existing representational models without distorting information (Pianta et al., 1996). Walsh (2003) reported that mother's interactions with their children were significantly associated with whether they were resolved with regards to their child's diagnosis of cerebral palsy or epilepsy but not whether they were resolved with respect to past losses / traumas relating to attachment figures.

#### AAI and culture

van IJzendoorn & Sagi (1999) presented a review of cross-cultural patterns of attachment and reported that the three main patterns of attachment (secure, avoidant and ambivalent) have been found in every culture where attachment has been studied. They acknowledged cultural variations but concluded that, in general, cross-cultural studies provide support for attachment theory. The Adult Attachment Interview assesses the *meaning* that interviewees attribute to their own experiences rather than assessing the *actual* experiences, which may vary between different cultures. Therefore, at present it appears valid to assess attachment relationships in people from different cultures and ethnic backgrounds.

### Criticisms of the AAI

Fox (1995) presented a detailed critique of the AAI. Two of his main conclusions were that (at the time of writing) there was no evidence that attachment is stable over time and that the AAI may well be 'just another interesting personality measure' (p 409). Fox considered that retrospective reports of attachment and coherency of speech are significantly affected by the individual's current psychological state and environmental factors. Therefore he argued that there is no evidence that retrospective reports on the AAI are related to earlier security of attachment in the individual. van IJzendoorn (1995) published a reply to Fox's article in which he persuasively argued against Fox's claims. van IJzendoorn (1995) clarified that the AAI is not meant to represent the adult's childhood attachment style, but aims to access the adult's current state of mind and representations with regard to attachment. He also stated that there is convincing evidence that adult attachment representations and infant's attachments are strongly related, although more research needs to be carried out to explore the transmission of attachment style. Benoit & Parker (1995) examined the stability of adult attachment and transmission across three generations (infants, mothers and grandmothers). They found that AAI responses were stable over 12 months in 90% of the mothers in their sample. They also found that mothers' patterns of attachment predicted their infants' classifications on the Strange situation in 81% of cases. In addition mothers' patterns of attachment predicted their own mothers' (the grandmothers) attachment patterns in 75% of cases. Crowell, Treboux & Waters (2002) examined the stability of AAI classifications in 157 couples, three months prior to marriage and then 18 months after marriage. They found that 78% of the sample received the same AAI classification at

both time points. Observed changes over time indicated that some couples became increasingly secure in their patterns of attachment as a result of their beliefs and emotions regarding their marriage. These results provide support for both the stability of adult attachment and the intergenerational transmission of patterns of attachment within families.

Dunn (1993) criticised the AAI for being overly 'deterministic' and for reducing attachment to a dichotomous classification. She also criticised the notion that attachment is either secure or insecure and considered the relevance of a dimensional approach. However, while dimensional approaches have an appeal because they steer clear of categorical judgements, the published AAI literature, including many reports of reliability and validity, depends more often than not on the presentation of classification data.

### Summary

Experiencing loss or trauma in relation to attachment figures may increase the risk of developing an insecure attachment style. Children with insecure attachment styles are at future risk of developing psychological and interpersonal problems. The way in which an individual interacts with others is based on their underlying attachment model. Mothers' adult attachment patterns have been found to predict their child's attachment security. Adults who are unresolved regarding past losses or traumas are thought to experience difficulties in parenting and may behave in a disorganised and frightening manner towards their children. There is evidence to suggest that mothers who are

unresolved with respect to past losses /traumas are likely to have children with a disorganised attachment style. Parents' care-giving systems can be disrupted by both past and proximal losses, for example, giving birth to a child with a disability. This threatens the adult's care-giving system as they are unable to protect their child from harm. The process of resolution of past and proximal losses is similar. It involves integrating new information into existing representational systems without distorting information. Cross cultural attachment patterns have been reported to be broadly similar.

### **Impact of learning disabilities on the mother-child relationship**

Hodges (2003) described the impact diagnosis of a learning disability may have on the early relationship between a mother and her child. Grief and feelings of loss in the child's parents may make it difficult for them to respond appropriately to the child's needs. Mothers of young children frequently rely on their parents and partners for additional support, however, they may be unavailable because of their own sense of grief and loss surrounding the child's condition. De Groef (1999) expanded upon the idea developed by Freud that parents have certain unconscious hopes and fantasies about their child and think of them as an extension of their self. Therefore, giving birth to a learning disabled child is damaging to the parent's ego and a narcissistic 'blow' (Solnit & Stark, 1961). Sheppard (2003) suggested that the impact of a family's struggle to overcome feelings of loss and sadness regarding their child's disability may interfere with the development of parents' attachment to their child.

### Mother-child interactions

A number of studies have reported important differences in the way mothers interact with their disabled children. Nind and Hewett (1994) presented an overview of the way mothers and their children interact and the differences between non-disabled and learning disabled mother-child dyads. They reported that non-disabled infants are active and will initiate and maintain interactive games with their caregiver using gaze and vocalisations. In response caregivers alter their gaze, vocalisations and touch, to provide an appropriate level of social stimuli. Caregivers talk to their children as if they understand well before they are likely to and use 'motherese' speech which is slow, simple and varied in tone. Such interactions are typically enjoyable two-way processes in which both infant and caregiver are mutually engaged. However, learning disabled infants are frequently less responsive to their caregivers and do not initiate interactions in the same way. They may be 'floppy' and have reduced control over gaze and vocalisations. Nind and Hewett (1994) reported that mothers whose children are learning disabled have increased difficulty understanding their infant's signals and have to work harder in interactions. This can result in a lack of mutual pleasure in mother-child interactions and poor interactive 'fit' and timing between the mother and child. As a response mothers may become overly stimulating and directive in their interactions with their learning disabled child.

Stern & Hildebrandt (1986) and Stern, Karraker, Sopko & Norman (2000) reported that mothers interacted differently with infants (who were not known to them) depending on whether they were informed that the child was born prematurely or at full term. In

particular their interactions with the infants labelled as premature involved less frequent touching, more negative responses and less enjoyment. This research may indicate that some of the difficulties parent's experience in interacting with their disabled children are associated with their stereotypical beliefs. This has implications for parent's reactions to their child's diagnosis and early attachment experiences.

#### Attachment style in children with learning disabilities

A number of studies have assessed attachment security in children with learning disabilities using the Strange situation. However, there is debate as to whether it is valid to use this measure with families of learning disabled children. Van IJzendoorn, Goldberg, Kroonenberg & Frenkel (1992) carried out a meta-analysis of quality of attachment in clinical samples. They reported that children with learning disabilities and autism were more likely to be classified as insecure than children from normative samples. However, it is difficult to interpret whether this is due to differences in the children's communication skills or actual differences in the mother-child relationships (Clements & Barnett, 2002). There is also evidence to suggest that children with Down syndrome and other neurological problems are more likely to be classified as disorganised on the Strange Situation than children without neurological problems (van IJzendoorn, Schuengel & Bakersmans-Kranenburg, 1999; Vaughn, Goldberg, Atkinson & Marcovitch, 1994). Atkinson et al. (1999) found that parental sensitivity predicted attachment security but only for higher functioning children with Down syndrome. In considering this issue it is necessary to acknowledge that children with learning disabilities are reported to be at greater risk of being maltreated than children without

learning disabilities (Sullivan & Knutson, 2000). Therefore higher rates of disorganised attachment in learning disabled children may be associated with maltreatment rather than error of measurement. Further research is needed to explore this issue.

### Summary

Parents' feelings of grief and loss regarding their child's condition may impact negatively on their care-giving skills. Research has found important differences in the interactions between mothers and their children with learning disabilities compared to non-disabled dyads. In particular, mothers of children with learning disabilities experience increased difficulty understanding their child's signals and have to work harder in interactions. This is thought to result in reduced mutual pleasure and poor interactive fit and timing. There is a debate as to whether it is appropriate to classify learning disabled children's attachment security using the Strange situation. However, evidence suggests that children with learning disabilities do form secure attachments with their caregivers although they are at greater risk of being classified as insecure or disorganised in attachment style.

### **Difficulties encountered within families of children with learning disabilities**

#### Stress

Parenting a child with a learning disability is typically reported as being highly stressful (Siegel, 1997). Families caring for a child with a learning disability experience higher levels of stress than those caring for a child with a physical disability. Both groups

experience greater stress than parents of non-disabled children (Dyson, 1996; Murphy, 1982). In addition, mothers experience significantly higher levels of stress and distress compared to fathers, because the burden of care falls mainly to them. Siegel (1997) suggested that higher levels of stress are related to uncertainty concerning the prognosis of a child with a learning disability and what the future will hold. Physical disabilities may be stable and therefore easier to define and give a prognosis. Boyce, Behl. Mortensen & Akers (1991) found that parent-related stress was independent of the severity of their child's disability, but that having a son with disabilities was associated with higher levels of stress than having a disabled daughter. However, other studies have found that sex does not impact on the experience of stress (Beckman, 1983).

Beckman (1983) reported that single parents experience higher levels of stress compared to married parents. Their greatest needs were respite care, financial support and social support. Quine & Pahl (1986) reported that single parents experienced greater levels of stress than both married mothers who had supportive partners, and those whose partners were emotionally unsupportive. Beresford (1994) described a review of six studies carried out by Sloper & Knussen (1991). They concluded that, in married couples, spousal support was the most important form of support and is related to positive outcome and adaptation. However, Beresford (1994) noted that research into spouse support has not satisfactorily explored the different types of support such as emotional, practical, and financial, and urges that these findings are therefore treated with caution.

Dyson (1991) explored the relationship between socio-economic factors and stress in families who have a child with a disability. Financial status was found to impact in a number of ways from living in poor housing in a deprived area to struggling to manage money on a weekly basis. Many parents with disabled children are unable to work because of the increased amount of care their child needs and this also impacts financially on families (Seligman & Darling, 1997).

### Social support

Social support has been found to reduce the amount of stress experienced within families (Beckman & Porkini, 1988) and is often seen as a protective or buffering factor in coping with a stressful life event (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983). Families who have children with learning disabilities are at greater risk of suffering high levels of stress, but in addition are also more at risk of becoming socially isolated (Kazak, 1987). Marsh (1992) stated that receiving a diagnosis of a learning disability appears to 'quarantine' the family from mainstream society. This may be related to the stigma associated with learning disabilities and lack of understanding from other families. Parents of children with learning disabilities may also withdraw from other families. This may be due to feelings of shame and guilt surrounding their child's condition, fear of other people's reactions to their children and their children's difficult behaviour (Meltzer, Smyth & Robus, 1989).

Crnic et al. (1983) examined the relationship between levels of stress experienced by mothers of children with learning disabilities and the social support they receive. They

reported that higher levels of maternal social support were associated with more positive attitudes and behaviour towards their child. Kazak and Marvin (1984) reported that larger social support networks were associated with successful parental adaptation to their child's disability. Holder (2000) found that parents who were resolved with regard to their child's diagnosis reported lower levels of stress than those who were unresolved. Holder (2000) postulated that resolved parents may be better able to enlist the support they need from others. Studies that have used objective measures of family's social support have indicated subtle differences and Kazak (1987) suggested that it is the family's *perception* of social support which is key. Seligman and Darling (1997) reported that informal and formal social support networks can help families to cope with and adapt to their child's condition. If a family is socially isolated then they will require additional support from formal agencies such as social services. However, many families are not aware of the services they are entitled to and do not receive the support which should be available through formal services (Ayer, 1984; Parker & Lawton, 1991). Families from ethnic minorities may experience increased difficulty engaging with services and ensuring they are receiving the services they are entitled to (Murray, 1992).

In general, larger social networks (formal and informal) and perceived social support have been found to reduce parents' distress and encourage positive parent-child relationships and family functioning (Dunst, Trivette & Cross, 1986). Many parents have reported benefits from attending peer led support groups with other parents who have children with learning disabilities (Seligman, 1993).

### Behaviour problems and stress

Baxter (1986) reported that families who have children with learning disabilities report their main stressors to be concerning problems managing their child's behaviour and their child's continuing dependency. As children grow older, parents' concerns about their behaviour increase. Parents whose children have learning disabilities and autism report that family recreation is most affected because their children have difficulty adapting to new and unpredictable social environments. Parents experience stress in response to their child's unusual behaviour but also distress related to their child's anxiety in a new setting. This may lead families to become increasingly socially isolated. Hastings (2002) reported that there is a strong association between the severity of behaviour problems in children with learning disabilities and their parent's psychological well-being. Families who report more severe and frequent behaviour problems in their children are more likely to suffer from stress, depression and anxiety. There is no clear model to explain the nature of this association, whether parental distress is caused by children's behaviour problems or whether the child's behaviour is in response to adult factors. It is likely that the relationship is complex and due to a combination of both child and parent factors.

### Difficulties specific to autism

Parents who have children with autism report higher levels of distress regarding their children's behaviour, difficulty socialising and lack of empathy/guilt. Noh, Dumas, Wolf & Fisman (1989) found that parents of children with autism rated their children as more demanding, less acceptable and less adaptable than mothers of children with Down

syndrome. Dumas, Wolf, Fisman & Culligan (1991) found that parents of children with autism reported higher levels of stress and dysphoria than mothers of children with Down syndrome and children with no disabilities.

### Summary

Parenting a child with a learning disability is highly stressful. Single parents experience higher levels of stress and are particularly vulnerable to social isolation. Higher levels of stress and dysphoria are reported by parents who have children with social impairments and behaviour problems typically seen in autism. Social support is thought to be protective and to buffer against the impact of stress. Research has indicated that the size of mothers' social networks and extent to which they feel supported is associated with successful adaptation to their child's disability. Parents who are resolved with regard to their child's condition report lower levels of stress, possibly because they are better able to enlist the support they need from their network

### Limitations of the literature reviewed

It is very difficult to draw conclusions from the above literature because many of the studies draw participants from a widely heterogeneous group of families who have children with different disabilities and medical conditions. This compromises the ability of professionals to draw conclusions from research to inform clinical practice and further research. Although there are some areas of agreement, the literature is steeped in contradictory findings from research studies which suffer from small samples and design

flaws. Much of the research has no control or comparison group and replication studies provide contradictory findings. There are no rigorous studies which have been able to compare the reactions, experiences and adaptation of families whose children have different disabilities and medical conditions. This may be due in part to the complex combination of difficulties experienced by children with disabilities. Chronic medical illness has an impact on intellectual functioning just as severe learning disabilities have an impact on a child's physical functioning. However, the paucity of research may also reflect a lack of interest and funding for researching this population.

### **Aims of the present study**

The primary aim of this study is to explore the relationship between mothers' states of mind with respect to attachment and resolution of loss and trauma surrounding their child's learning disability. At present, no research has been published exploring this relationship with families who have children with learning disabilities. Research has not found an association between past losses / trauma in relation to mothers' attachment figures and resolution of diagnosis of cerebral palsy and epilepsy (Pianta et al., 1999; Walsh, 2003). Pianta et al. (1999) found that within a group of mothers whose children had cerebral palsy, those who were classified as secure on the AAI were more likely to be resolved regarding their child's diagnosis. However there were no significant associations between AAI status and resolution on the RDI within the sample of mothers whose children had epilepsy. Pianta et al. (1999) suggested that the lack of association in the epilepsy sample is due to the unpredictable nature of their condition compared to the chronic stability of cerebral palsy. If this is true then we can hypothesise that the current

sample of children with learning disabilities will be similar to the cerebral palsy group in Pianta's study, because learning disabilities are chronic and stable conditions. The current study aims to explore the association between attachment status and resolution of diagnosis within a group of mothers whose children have learning disabilities as their primary diagnosis. In addition, this study builds on research by Holder (2000) to consider resolution of grief and trauma surrounding children's learning disabilities within mothers of children aged 5-12 years. This is in order to further our understanding of parental resolution of their child's diagnosis during school years. The relationship between mother's adult attachment status, resolution of diagnosis, symptoms of psychopathology and social support will be explored using statistical analyses. The results will be discussed in relation to the impact they may have on care-giving and the experience of stress and distress in families of children with learning disabilities.

### **Principal research questions**

1. Is there an association between mothers' states of mind with respect to attachment and whether they are resolved or unresolved with regards to their child's diagnosis?
2. Is there an association between mothers' resolution of *past* losses and traumas with respect to their attachment figures and resolution of *proximal* losses and trauma in relation to their child's learning disability?

### **Secondary research hypotheses**

1. Mothers who are resolved with regards to their child's diagnosis will have wider networks of social support and report feeling more supported than unresolved mothers.
2. Higher global symptoms of psychopathology on the SCL-90-R will be associated with i) mothers who are unresolved on the RDI, ii) mothers who are classified as insecure on the AAI and iii) mothers who are unresolved regarding past loss and trauma on the AAI.
3. The number of recent stressful life events occurring within the mother's family will be associated with mother's resolution status on the RDI. Mothers who have experienced a higher number of proximal stressful life events will be more likely to be unresolved.

## **METHOD**

### **Overview**

This study explores the relationship between mothers' states of mind with respect to attachment, as measured by the Adult Attachment Interview (George, Kaplan & Main, 1985) and their reaction to discovering that their child has a learning disability, measured by the Reaction to Diagnosis Interview (Pianta & Marvin, 1992a). Mothers' reported symptoms of psychopathology were measured using the Symptom Checklist-90-Revised. The number of recent stressful life events occurring within the participants' family system was measured using part of the Parenting Stress Index – 3<sup>rd</sup> Edition (Abidin, 1990). Additional information regarding mothers' beliefs about the severity of their child's learning disability was collected using a Disability Index (Trute & Hauch, 1988). Mothers were also asked to list the people who provide them with social support and to rate how supported they felt by family, friends and professionals.

### **Participants**

Potential participants were identified by contacting the schools that their children attended and sending information packs to the mothers with a covering letter from the Head-teacher (see appendices 1-4). Recruitment was carried out through all the Junior and Middle schools for children with moderate to severe learning disabilities within Harrow and Hillingdon, (Middlesex) and Radlett, (Hertfordshire). During the second phase of data collection all the mainstream Junior and Middle schools within Harrow

were contacted to identify children with learning disabilities attending mainstream schools. Twenty of the thirty one mainstream schools contacted agreed to participate.

### Inclusion criteria

The inclusion criteria of the study were that the participants were mothers of a child with a learning disability, aged between 5 to 12 years. Fathers and other primary carers (e.g. adoptive parents) were excluded from the study as the majority of the children were primarily cared for by their birth mother. The inclusion criteria for children's age was chosen in order to study children who were attending school but had not yet reached transition to Secondary school and were most probably pre-pubertal in terms of their physical development. The participants were also required to speak English fluently in order to be able to participate in the interview. The method of coding the interviews relies on detailed analysis of the participant's speech and therefore it was not possible to interview participants using an interpreter. The criteria were that the participant's children should be described as having a learning disability on their Statement of Special Educational Needs and have been through the statementing process at least two years prior to recruitment. This was to ensure that all parents would have been informed that their child has a learning disability and requires significant additional learning support at school. The criteria that the child should have been through the statementing process two years prior to the study was in order to increase the likelihood that mothers had some time in which to process this information and start to resolve their feelings regarding their child's difficulties.

### Exclusion criteria

The Head-teachers and Special Educational Needs Co-ordinators (SENCO's) discussed each child with me to ensure they met the inclusion criteria. Children with sensory impairments, physical disabilities, emotional and/or behavioural difficulties, who did not have additional learning disabilities were excluded from the study. In addition children with Asperger's Syndrome who were functioning within the average range intellectually, were excluded from the study. Children who had previously had normal intellectual abilities prior to a traumatic head injury were also excluded from the study. The Head-teachers excluded some mothers from being invited to take part where they were aware of traumatic circumstances occurring in the family at the time of recruitment, for example, severe mental health problems, traumatic bereavement.

### Sample size

On the basis of power analysis it was found that 32 participants were required in each group to provide 80% power to detect significant differences between the two groups (mothers who were resolved and those who were unresolved with regard to their child's learning disability). Information packs were sent to 333 mothers inviting them to take part in the study (see appendices 1-4). Replies were received from 52 mothers who wished to take part. Forty three mothers replied saying that they did not want to take part and 238 did not respond at all. Of the 52 mothers who agreed to take part 43 participated in the study: five people were excluded because they were not fluent in English, three people dropped out due to stressful life events and one mother decided she did not wish to take part.

### Participant characteristics

Forty three mothers of children with learning disabilities participated in the study, their ages ranged from 30-49 years (mean = 37.6 yrs, SD =5.31). All participants lived in the region of Greater London. Twenty seven mothers described their ethnic origin as White UK, six as Black African, three as Black Caribbean, two as Irish, two as Black UK, two as White Other and one as Indian. Twenty five of the participants were married, six were divorced, six were single, four were co-habiting, one was separated and one was widowed. The annual incomes of the participant's families ranged from £4,800 to £80,000 (mode = £10,000). Twenty mothers were employed outside the home. Seven mothers worked full-time whilst 13 mothers worked part time. One mother was a student and two mothers engaged in part time voluntary work.

### Children's characteristics

There were 32 male and 11 female children aged between five to twelve years of age (mean = 8.8 yrs, SD = 1.9). 37 children attended schools for children with special educational needs and six attended mainstream schools. Three children were reported to have mild learning disabilities, 26 children were reported to have moderate learning disabilities and 14 were described as having severe learning disabilities \* . Twenty two mothers reported that their children had been diagnosed with Autistic Spectrum Disorder, eight had not been given a diagnosis to account for their learning disability, four children had been diagnosed with Global Developmental Delay, two with Pathological Demand Avoidance, two with Attention Deficit Hyperactivity Disorder,

\*see measures section for details of the disability index used to determine the severity of the child's disability

one with Prader Willis Syndrome, one with Hearing Impairment, one with Rett Syndrome, one with Down Syndrome and one with Coffin Sirius Syndrome. The duration of time since diagnosis ranged from 2-10 years (mean = 5.10 yrs, SD = 2.26)

### **Ethics**

Ethical approval to carry out the study was obtained from Brent Research Ethics Committee and Harrow Research Ethics Committee (see appendix 5).

### **Procedure**

Information packs were sent out by post through the children's schools with a covering letter from the Head-teacher (see appendix 1). The packs included a covering letter from the researcher (see appendix 2), an information sheet describing the study (see appendix 3), a reply form (see appendix 4) and a stamped addressed envelope. After reply slips were returned, the mothers who agreed to participate were contacted by telephone and a date was arranged for the interview to take place. A follow up letter was sent to those parents who did not reply after a four week period. All the participants chose to conduct the interviews in their own homes. Prior to the interview the study was explained and the participants were given the opportunity to ask questions before signing the consent form (see appendix 6). The participants were then interviewed using the Adult Attachment Interview followed by the Reaction to Diagnosis Interview. The interviews were audio-taped and later transcribed for analysis. The duration of the interviews ranged from 45 to 90 minutes and the participants then completed three questionnaires which took

approximately 10-20 minutes. After the interview I ensured that the participants were not distressed and asked them to contact me if they later became upset about anything we had talked about.

### **Design**

A cross-sectional correlational design was used to explore the relationship between mothers' intergenerational attachment patterns (and resolution of losses and traumas in relation to attachment figures) and their reaction to discovering that their child has a learning disability.

### **Measures**

#### **Adult Attachment Interview (AAI)**

The Adult Attachment Interview (George, Kaplan & Main, 1985) is a structured interview which explores the participant's early attachment experiences and the impact these have had on the individual as an adult. The interview comprises 20 questions which have standardised follow up probes/questions and normally lasts for approximately one hour (see appendix 7). The participants are asked to choose five words or adjectives to describe their early relationship with their mother and father and to recount memories or incidents which support their descriptions. The participants are also asked to recall experiences of separation, rejection, abuse, bereavements and traumas. Participants are then asked about their understanding of their parents' behaviour and how this has impacted on them as an adult and also as a parent.

Interviewers must be trained in the standardised administration of the interview and are required to memorise the questions and probes. The interview is transcribed verbatim including errors and hesitations according to guidelines detailed by Mary Main (1991). The transcripts are then coded by a judge who has been trained in the standardised interview coding system (Main & Goldwyn, 1984, 1998).

All interviews were administered by one researcher who was trained in the standardised administration of the interview. The interviews were audio-taped and then transcribed according to guidelines provided by Main (1991). Each transcript was then checked against the audiotape to identify and correct any omissions. The interviews were then classified by three judges who have received standardised training in classifying the AAI and undergone reliability checks. The judges were blind to the Reaction to Diagnosis Interviews and classifications.

#### Adult Attachment Interview coding system (Main & Goldwyn, 1984,1998)

The AAI is analysed in three stages. In the first stage the judge rates the participant's probable childhood experience with each parent, in relation to the extent to which parents were loving, rejecting, neglecting, role reversing or pressurising to achieve. The second stage requires the judge to code the participant's current state of mind with respect to those early experiences. This is done by analysing the way in which the participant speaks about her childhood experiences, whether she is coherent, able to speak relatively easily, any apparent distortion of memories and the overall organisation

of the interview. The final stage involves analysing the participant's discourse regarding her experiences of loss and trauma in order to look for signs that the participant has resolved these experiences. Lack of resolution is indicated by signs of disorientation such as speaking in the present tense about a deceased person, eulogistic speech, extreme attention to detail or extreme behavioural disorganisation such as attempting suicide in response to the loss of a close loved one. Finally the participant's current state of mind with respect to attachment is classified as Secure/Autonomous (F), Dismissing (D), Preoccupied (E), Unresolved (U) or Cannot Classify (CC). If participants are classified as U or CC then they are also given a 'forced' classification of D, E or F.

Participants are classified as Autonomous if their responses are clear, coherent and reasonably succinct. In addition such participants appear to have considered the value and impact of their attachment relationships (regardless of whether these have been positive or negative) whilst remaining objective in discussing their early relationships and experiences. Those classified as Dismissing describe their parents in favourable terms but are unable to support these statements with memories or may provide contradictory information. They are dismissing of attachment relationships and typically provide overly brief answers. A classification of Preoccupied indicates that the participant is preoccupied with their past attachment relationships and experiences. They may appear angry, fearful or passive and often speak for an excessively long period of time. Unresolved classifications reflect that the participant shows a lapse in monitoring of their discourse or reasoning whilst discussing losses or abuse, for example, eulogistic speech, speaking in present tense about a deceased person.

### Reliability and validity

The AAI has been widely used and is reported to have good reliability and validity (Bakersmans-Kranenburg & van IJzendoorn, 1993; Benoit & Parker, 1994; Crowell, Waters, Treboux et al., 1996). In a meta-analysis of 14 studies van IJzendoorn, (1995) reported 70% concordance between mothers' AAI classifications and their children's attachment classification.

### Reaction to Diagnosis Interview (RDI)

This is a standardised, structured interview developed by Pianta and Marvin (1992a) designed for research with parents who have children with some form of disability or chronic illness. The interview consists of five questions exploring parents' reaction to their children's diagnoses, how their feelings have changed over time and their beliefs about why they have a child with a disability (see appendix 8). The five questions aim to elicit parents' emotional reactions, beliefs and memories of the time they were informed of their child's disability. The interview takes 15-20 minutes to administer and is designed to be administered by researchers who are trained in using semi-structured interviews and have received specific training in how to administer and code the Reaction to Diagnosis Interview. The interview can be video or audio-taped and transcribed verbatim, including hesitations, speech errors and nonverbal communications such as crying.

### Reaction to Diagnosis Interview coding system

The interviews are coded from the transcripts using a standard procedure for which training is required (Pianta & Marvin, 1992b). The coding system analyses content, discourse style and coherency of responses (similar to the coding system for the AAI) in order to clarify the parent's representational or mental models of their relationship with their child. Each interview is coded with respect to the extent that the parents have resolved the loss and trauma surrounding their child's disability.

Each interview was coded independently by two researchers who were trained in the standardised administration and coding of the interviews (the coders were independent to the researchers who coded the AAI's and blind to the AAI classifications). The coders read through each transcript twice and took notes detailing any specific elements which reflected signs of the interview being resolved or unresolved. The coders then classified each interview as being resolved or unresolved on the basis of the interview content (verbal and nonverbal), discourse style and coherency of responses. For those transcripts where the coders disagreed on the overall classification, a third trained researcher was asked to code the interview (after inter-rater reliability was calculated) to give a final classification. Each interview was also coded using two 1-5 point scales. The first scale rated the extent to which each mother showed signs of being resolved with regard to her child's learning disability. A score of 1 indicated that there was little or no evidence of the participant being resolved and a score of 5 indicated strong evidence of being resolved. The second scale rated the extent to which each mother showed signs of being unresolved with regard to her child's learning disability. A score of 1 indicated little or

no evidence of being unresolved and 5 indicated strong signs of being unresolved. After calculating inter-rater reliability the scaled scores were combined and divided by 2 to provide a final resolved scaled score of 1-5 and a final unresolved scaled score of 1-5 for each interview. See results section for details of inter-rater reliability.

### Classifications

Resolution is the integration of parent's emotions and information regarding their child's disability within the parent's representational systems of themselves, their child and their relationship with their child. It is assumed that receiving the news that your child has a disability is a crisis for parents and has a destabilising influence on the parent's internal representation systems. Parents who are classified as resolved with regards to their child's diagnosis are focused on the present and able to identify changes in their feelings since the time of diagnosis. They indicate that they have moved on from their initial grieving to concentrate on the task of parenting their child and have suspended their search as to why this has happened to their child. Parents who are described as resolved are able to discuss their child's abilities accurately and their discourse is coherent. Any emotional experiences related to diagnosis are clearly talked about in the past tense with an appropriate level of affect. Resolution is seen as a continuing process and it is expected that parents will re-experience periods of crisis, particularly around times of transition (Wilker et al., 1981) and that the extent to which they are resolved will vary over time depending on the child's and parent's circumstances.

Parents who are coded as unresolved continue to experience disorientation which is associated with grieving. They may appear stuck in the past and have difficulty focusing on the present and moving on with their tasks of parenting. These parents appear to have not yet integrated information about their child's condition without distorting reality in one or more of the following ways:

- Minimising or denying the child's true condition (cognitive distortions)
- Continuing to search for the reason that their child has a disability
- Focusing too much on information to the exclusion of present day realities (stuck in the past and preoccupied)
- Denying the pain and impact of the diagnosis on the parent (cut-off)
- Displacing the pain and sadness to anger at the medical or educational systems

These parents may appear emotionally overwhelmed throughout the interview, showing distress which indicates that they are still grieving, or presenting with extreme anger towards professional services and systems. Parents who are described as unresolved may also speak in a confused or incoherent manner, telling a story which is hard to follow or inconsistent. Parents may also appear cut-off from the pain and in denial of the impact of their child's condition. Pianta and Marvin (1992b) suggest that unresolved coping strategies may have a negative impact on the parent-child relationship as such cognitive distortions may prevent the parents responding to their children in a sensitive balanced way which best meets their needs.

### Reliability and validity

The RDI has been reported to have good validity and reliability in research conducted so far. Pianta, Marvin, Britner and Borowitz (1996) reported overall inter-rater reliability of 92% for the major classifications of resolved/unresolved with no differences between diagnostic groups. In addition the RDI has been strongly associated with security of child attachment as measured by the Strange Situation (Marvin and Pianta, 1996; Pianta et al., 1996). Morog (1996) reported significant relationships between mothers' classifications on the AAI and resolution status on the RDI with mothers of children with cerebral palsy.

### Symptom Checklist – 90 - Revised (SCL-90-R)

The SCL-90-R is a 90 item self-report symptom inventory designed by L.R. Derogatis to measure psychological symptoms. It has normative data available for both clinical and normal adult populations and also for adolescents. It can be administered using a paper version or completed online and takes between 12-15 minutes to complete. The inventory has three global indices of distress and nine primary symptom dimensions. The Global Severity Index (GSI) is the best overall indicator of an individual's psychological distress and reflects the number of symptoms reported and the intensity of distress related to each symptom. The Positive Distress Index (PDI) reflects the average level of distress reported for the symptoms experienced and the Positive Symptom Total (PST) reflects the number of symptoms each respondent reports experiencing, regardless of the level of distress reported. The nine primary symptom dimensions assess the following areas:

- Somatisation
- Obsessive-Compulsive
- Interpersonal Sensitivity
- Depression
- Anxiety
- Hostility
- Phobic Anxiety
- Paranoid Ideation
- Psychoticism

See SCL-90-R manual for further details of the symptom dimensions.

The SCL-90-R was administered using the paper version (see appendix 9). The participants were asked to look at each symptom and indicate how much they had been bothered by the symptom during the past seven days on a 0-4 scale ranging from not at all bothered to extremely bothered. The SCL-90-R was scored using the standardised scoring system in which raw scores are converted to a T-Score which has a mean value of 50 and a standard deviation of 10. T-scores of 63 or above on the Global Severity Index indicates that non-psychiatric participants are considered a positive risk or a 'case'.

#### Validity and reliability

The SCL-90-R has been shown to have acceptable reliability and validity by an extensive number of studies (Derogatis, Rickels & Rock, 1976; Horowitz, Rosenberg,

Baer et al., 1988; Peveler & Fairburn, 1990) and has been used with participants from a diverse range of ethnic and cultural backgrounds.

### **Parenting Stress Index – 3<sup>rd</sup> Edition**

The Parenting Stress Index – 3<sup>rd</sup> Edition (Abidin, 1990) is a 120 item self report questionnaire which aims to identify parent – child systems which are under stress. It has three separate domains: child characteristics, parent characteristics and situational/demographic life events. In addition there is an optional Life Stress Scale which consists of 19 items which describes stressful circumstances beyond the participant's control, for example, loss of a job or death of a relative. In this study participants were asked to complete the Life Stress Scale only, (see appendix 10) to provide an index of the amount of stress outside of the parent – child relationship that the parent has experienced over the past 12 months. Abidin (1990) reported that high life stress scores tend to intensify the total stress that the parent is experiencing and suggested that those parents who obtain a score of 17 or above should be referred for professional assistance.

### **Reliability and validity**

The Parenting Stress Index is a widely used measure that has acceptable validity and reliability and maintains its validity with participants from a diverse range of ethnic backgrounds and cultures (Abidin, 1990). However, there is no data available regarding

the validity and reliability of using the Life Stress Scale separately as has been done in this study.

### **Disability Index**

The Disability Index (Trute & Hauch, 1988) is a short, four item measure which was designed to assess the severity of children's physical and mental disabilities (see appendix 11). Parents were asked to complete the measure which asks about the extent to which the child's cognitive and physical development will be affected by their disability (ranging from not at all to severely). The parent is also asked how much assistance their child may require to perform everyday activities such as bathing, eating, toileting and whether they will need ongoing specialised medical attention in the future.

The Disability Index was administered to determine the extent of the children's learning disability taking into account the parent's views about the child's cognitive functioning, need for medical input, level of assistance for everyday activities and the type of school the child attended. The children were classified as having mild, moderate or severe learning disabilities. It was ensured that the severity of disability was congruent with current diagnostic classification systems (AAMR and ICD-10).

### **Reliability and validity**

There is sparse data available on the validity and reliability of the Disability Index. Trute & Hauch (1988) report an alpha coefficient of .80 which is at an acceptable level. There were no other disability indices available at the time of the study.

### **Demographic Information and Social Support**

Mothers were asked to complete a demographic information sheet to provide information about their age, ethnicity, family composition, marital status, employment status, income and their child's learning disability. The author also designed a brief measure of social support which was incorporated into the demographic information sheet (see appendix 12). Mothers were asked to list the people who provide them with social support (e.g. friends, family, professionals) and then to rate how supported they felt using a four point scale (from not at all supported to extremely well supported).

## RESULTS

### Overview

The results section will be divided into four sections. The first section will present descriptive information about the data and inter-rater reliability for the Reaction to Diagnosis Interview (RDI). The second section will examine the relationship between demographic variables (age, income, ethnicity, severity of learning disability etc.) and mothers' resolution status on the RDI and attachment status on the Adult Attachment Interview (AAI). The third section will present analysis of the principal research questions and secondary research hypotheses. The first principal research question aims to explore the association between mothers' states of mind with respect to attachment and whether they are resolved or unresolved with regard to their child's diagnosis. The second principal research question explores the association between mothers' resolution of *past* losses and traumas with respect to their attachment figures and resolution of *proximal* losses and trauma in relation to their child's learning disability. The secondary hypotheses of the current study are that: 1) mothers who are resolved with regard to their child's diagnosis will have wider networks of social support and report feeling more supported than unresolved mothers. 2) Higher symptoms of global psychopathology on the SCL-90-R will be associated with i) mothers who are unresolved on the RDI, ii) mothers who are classified as insecure on the AAI and iii) mothers who are unresolved regarding past loss and trauma on the AAI. 3) The number of recent stressful life events occurring within the mothers' family will be associated with mothers' resolution status on the RDI. Finally a brief summary of the results will be presented.

## **Descriptive information**

### **Distribution of data and normality**

The data was examined for normality, skewedness and kurtosis. The majority of the data had a normal distribution and was not significantly skewed. One variable (hours of respite care received) was significantly positively skewed. This was transformed using square root and logarithm but still remained significantly skewed because of a high number of mothers receiving no respite care for their child. This variable was therefore recoded as a dichotomous yes/no variable indicating whether respite care was received by the family. Outliers were screened for by converting the data to Z scores and checking for scores of three or above. There was one outlier for the variable of size of social support network (case 34). This was removed from analysis.

### **Missing data**

Part of the data set for one participant (case 1) is missing and therefore the sample size (n) is 42 for analysis of social support, psychopathology on the SCL-90-R and the number of recent stressful life events measured by the Parenting Stress Index. The rest of the data set is complete.

### **Reaction to Diagnosis Interview codings compared to those in the literature**

Interviews were coded as to whether mothers were resolved or unresolved with respect to their child's diagnosis of a learning disability. Of the 43 participants, 44% (19) were

resolved and 56% (24) were unresolved. These results are consistent with those reported by previous studies using the RDI with mothers of children aged 15-50 months with cerebral palsy and epilepsy (Marvin & Pianta, 1996; Pianta, Marvin, Britner & Borowitz, 1996; Pianta et al., 1999). Analysis of group differences revealed that there were no significant differences between the distribution of classifications in the current sample compared to previous studies ( $\chi^2 (2) = 1.48, p = .48$ ). This is in contrast with research carried out by Holder (2000) in which parents of school aged children with learning disabilities were interviewed using the RDI. Holder (2000) found a significantly higher proportion of resolved mothers (68%) compared to previous research and the current study ( $\chi^2 (3) = 14.12, p = .003$ ).

#### Initial reactions of mothers classified as resolved compared to mothers classified as unresolved

The interviews were examined by the author to determine if there were any obvious differences in the way resolved and unresolved mothers described their initial reactions to discovering their child's learning disability. The majority of mothers reported feelings of distress, shock and anxiety. There were no obvious differences between the feelings reported by mothers who were resolved and those who were unresolved regarding their child's diagnosis. However two mothers reported feeling 'thrilled' and 'happy' when they were informed of their child's diagnosis. Both mothers were classified as unresolved because they consistently minimised or denied the impact of their child's disability and were not able to report any concerns or negative emotions. None of the mothers in the resolved group reported feeling happy to receive their child's diagnosis.

### Inter-rater reliability

The interviews were coded independently by two researchers. There was initial agreement on 36 (84%) of the interviews which is an acceptable level ( $\chi^2 (1) = 19.88, p < .001$ ). To control for chance agreement Cohen's Kappa was calculated and found to be significant ( $K (1) = .67, p = < .001$ ). A third researcher coded the seven interviews on which there was disagreement to give a final coding of resolved or unresolved. In addition to the categorical coding system each interview was rated using two continuous 1-5 scales, one for signs of resolution and the other for signs of being unresolved (see method section). There was a highly significant positive correlation between the researchers' resolved scaled scores ( $r = .70, p < .001$ ) and unresolved scaled scores ( $r = .82, p < .001$ ). This indicates an acceptable level of inter-rater reliability. The scaled scores from each of the two researchers were combined and the average calculated to provide an overall resolved scale score (1-5) and an overall unresolved scaled score (1-5). These were included in analyses as a continuous measure.

### Adult Attachment Interview classifications

Interviews were classified into one of four categories: Dismissing (D), Preoccupied (E), Autonomous / secure (F) and Unresolved (U). Four interviews did not fit any one category and were therefore classified as CC (cannot classify). Those interviews classified as U or CC were also given a forced classification of D, E or F, therefore all interviews were included in the analysis. The AAI's can also be considered using three-way and two-way classifications. In the three-way classifications (D, E, F) those classified as unresolved were grouped according to their forced classification. In the

two-way classifications (resolved / unresolved, secure / insecure) those classified as D and E were coded as insecure.

#### Attachment classifications compared with normative published data

In the current study five mothers were classified as dismissing (11%), eight as preoccupied (19%), 21 as autonomous (49%) and nine as unresolved (21%). Of the nine mothers classified as unresolved, three were classified as dismissing, five as preoccupied and one as autonomous. These results were compared to the expected frequency of classifications in non-clinical samples (van IJzendoorn & Bakersmanns-Kranenburg, 1996). The results of the current study are broadly consistent with their findings (see Figure 1). However there are a slightly higher percentage of Preoccupied and Unresolved classifications in the current study and a lower percentage of Dismissing and Autonomous classifications. Analysis of group differences revealed that there were no significant differences between the distribution of classifications in the current sample compared to the normative data ( $\chi^2 (3) = 5.30, p = .15$ ).

#### Reliability of classifications

As is the convention in much of the AAI literature (e.g. Routh, Hill, Steele et al., 1995), one judge trained to reliability with the Berkeley standard, coded each interview. Three different judges coded an equal number of the interviews for this study. Chi squared analyses were carried out to test for any significant differences in the proportion of different classifications assigned by each judge. The results for the four-way

classifications approached significance ( $\chi^2 (6) = 11.26, p = .08$ ). Examination of the data indicated that one of the judges classified a lower number of interviews as dismissing than predicted whilst another judge classified a higher number of interviews as dismissing than predicted. Inspection of the interviews suggested that this was due to the interview content rather than judge bias. There were no significant inter-judge differences for the three-way ( $\chi^2 (4) = 4.46, p = .35$ ) and two-way classifications for secure / insecure ( $\chi^2 (2) = .96, p = .62$ ) and resolved / unresolved ( $\chi^2 (2) = 2.03, p = .36$ ).

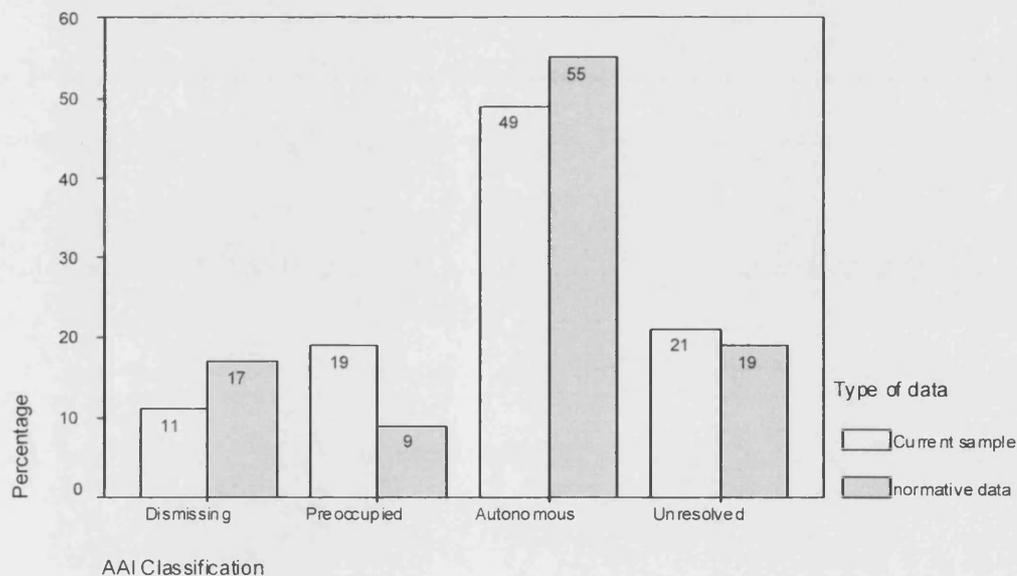


Figure 1: AAI classifications in current sample compared to normative published data

### History of abusive relationships

Within this sample 33% (14) of the mothers reported having been physically or sexually abused. Four mothers reported having been sexually abused, six mothers were physically abused and four were both physically and sexually abused. Analysis of group differences

revealed that there was no association between whether mothers had been abused (or type of abuse) and AAI or RDI classifications.

### Diagnosis of Autistic Spectrum Disorder

Of the 43 children within the study, 53% (23) had been diagnosed as having Autistic Spectrum Disorder (ASD). Analyses of group differences were carried out to determine whether there were any associations between ASD and resolution on the RDI, attachment status on the AAI and the demographic variables. There were no significant associations between diagnosis of ASD and any of the variables of interest.

### Independence from demographic variables

The data was analysed using chi-squared and independent t-tests to determine whether mothers' attachment status and reaction to diagnosis were associated with demographic variables. The demographic variables of interest were: age of mother, ethnic background, marital status, number of children living at home, number of adults living at home, employment status, annual income, whether respite care was received, child's age, child's sex, diagnosis, severity of learning disability, number of years since diagnosis, type of school attended (mainstream or special) and birth order.

### Relationship between RDI and demographic variables

Mothers' resolution status on the RDI was independent from the majority of demographic variables (see Tables 1a, 1b). However, resolution status differed significantly depending on the child's sex and the number of years since the child's diagnosis. Analysis of group differences indicated that mothers of boys with learning disabilities are more likely to be unresolved on the RDI whilst mothers of girls are more likely to be resolved ( $\chi^2 (1) = 4.88, p = .03$ ). The mean number of years since diagnosis was significantly higher for resolved mothers (mean = 6.0, SD = 2.19) compared to unresolved mothers (mean = 4.4, SD = 2.1) ( $t (41) = 2.44, p = .02$ ).

| Categorical Variables           |                | RDI Classification |            |          |
|---------------------------------|----------------|--------------------|------------|----------|
|                                 |                | Resolved           | Unresolved | $\chi^2$ |
| Ethnic Background               | White UK       | 13                 | 18         | .23      |
|                                 | Black or Asian | 6                  | 6          |          |
| Married Yes/No                  | Yes            | 13                 | 12         | 1.48     |
|                                 | No             | 6                  | 12         |          |
| Employed Yes/No                 | Yes            | 9                  | 11         | .01      |
|                                 | No             | 10                 | 13         |          |
| Respite Care Yes/ No            | Yes            | 3                  | 7          | 1.06     |
|                                 | No             | 16                 | 17         |          |
| Child's sex                     | Male           | 11                 | 21         | 4.88*    |
|                                 | Female         | 8                  | 3          |          |
| Severity of Learning disability | Mild           | 2                  | 1          | .66      |
|                                 | Moderate       | 11                 | 15         |          |
|                                 | Severe         | 6                  | 8          |          |
| Type of school                  | Special        | 18                 | 19         | 2.14     |
|                                 | Mainstream     | 1                  | 5          |          |
| Diagnosed with ASD              | Yes            | 10                 | 13         | .01      |
|                                 | No             | 9                  | 11         |          |

\* significant at the .05 level    \*\* significant at the .01 level

Table 1a: Categorical variables grouped by RDI classifications

| Continuous Variables    | RDI Classification |          |            |          |       |
|-------------------------|--------------------|----------|------------|----------|-------|
|                         | Resolved           |          | Unresolved |          | t     |
|                         | Mean               | SD       | Mean       | SD       |       |
| Participant's age       | 37.26              | 6.18     | 37.79      | 4.63     | -.32  |
| Children's age          | 9.16               | 1.5      | 8.58       | 2.17     | 1.03  |
| No. of children at home | 2.80               | .92      | 2.67       | 1.13     | .38   |
| No. of adults at home   | 1.95               | .52      | 1.63       | .58      | 1.92  |
| Annual income           | 29231.58           | 21399.10 | 25125.00   | 20888.43 | .63   |
| Yrs since diagnosis     | 6.00               | 2.19     | 4.40       | 2.10     | 2.44* |

\* significant at the .05 level    \*\* significant at the .01 level

Table 1b: Continuous variables grouped by RDI classifications

#### Relationship between AAI and demographic variables

Mothers' attachment status on the AAI was independent from the majority of the demographic variables (see Tables 2a, 2b). However, marital status (married or unmarried) and employment status (employed/unemployed) were both significantly associated with attachment security. Analysis of group differences indicated that a significantly higher number of mothers with autonomous /secure AAI classifications were married compared to mothers with insecure AAI classifications ( $\chi^2 (1) = 6.78, p < .01$ ). Mothers who were classified as autonomous / secure on the AAI were also significantly more likely to be employed compared to mothers who were classified as insecure ( $\chi^2 (1) = 5.31, p = .02$ ). None of the demographic variables were significantly associated with mothers' resolution status on the AAI regarding past losses and traumas to the attachment system.

| Categorical Variables           |                | AAI Classification |          |          |
|---------------------------------|----------------|--------------------|----------|----------|
|                                 |                | Secure             | Insecure | $\chi^2$ |
| Ethnic Background               | White UK       | 16                 | 15       | .01      |
|                                 | Black or Asian | 6                  | 6        |          |
| Married Yes/No                  | Yes            | 17                 | 8        | 6.78**   |
|                                 | No             | 5                  | 13       |          |
| Employed Yes/No                 | Yes            | 14                 | 6        | 5.31*    |
|                                 | No             | 8                  | 15       |          |
| Respite Care Yes/No             | Yes            | 7                  | 3        | 1.85     |
|                                 | No             | 15                 | 18       |          |
| Child's sex                     | Male           | 17                 | 15       | .19      |
|                                 | Female         | 5                  | 6        |          |
| Severity of Learning disability | Mild           | 3                  | 0        | 4.31     |
|                                 | Moderate       | 12                 | 14       |          |
|                                 | Severe         | 7                  | 7        |          |
| Type of school                  | Mainstream     | 3                  | 3        | .004     |
|                                 | Special        | 19                 | 18       |          |
| Diagnosed with ASD              | Yes            | 13                 | 10       | .57      |
|                                 | No             | 9                  | 11       |          |

\* significant at the .05 level    \*\* significant at the .01 level

Table 2a: Categorical variables grouped by AAI secure/insecure classifications

| Continuous Variables    | AAI Secure versus Insecure |          |          |          |       |
|-------------------------|----------------------------|----------|----------|----------|-------|
|                         | Secure                     |          | Insecure |          | T     |
|                         | Mean                       | SD       | Mean     | SD       |       |
| Participant's age       | 38.68                      | 4.85     | 36.38    | 5.63     | -1.44 |
| Children's age          | 8.91                       | 1.90     | 8.76     | 1.95     | -.25  |
| No. of children at home | 2.68                       | .95      | 2.76     | 1.14     | .25   |
| No. of adults at home   | 1.77                       | .43      | 1.76     | .70      | -.061 |
| Annual income           | 33218.18                   | 23767.52 | 20361.90 | 15521.42 | -2.11 |
| Years since diagnosis   | 5.00                       | 2.20     | 5.21     | 2.37     | .31   |

\* significant at the .05 level    \*\* significant at the .01 level

Table 2b: Continuous variables grouped by AAI secure/ insecure classifications

## **Hypotheses:**

### **Social support and resolution of diagnosis**

Mothers were asked to describe the people who provide them with social support (e.g. family, friends, professionals) and to rate how supported they felt on a four point scale (from not at all to extremely well supported). Participants reported receiving social support from the following groups of people: family, friends, professionals (school and health), charities and church. Thirty mothers reported that they received social support from their families, 21 from their friends, seven from professionals, two from charities and one from church. One mother reported receiving no social support. The number of different supports for each mother was calculated as a measure of network size. For example if a mother reported getting support from family and friends she would be assigned a network score of two.

The mean number of different social supports for mothers who were resolved regarding their child's diagnosis (mean = 1.67, SD = .84) did not differ significantly from the mean number of social supports for mothers who were unresolved regarding their child's diagnosis (mean = 1.33, SD = .82). These results indicate that, contrary to the research hypothesis, there is no significant difference between the mean size of social support networks in resolved and unresolved mothers ( $t(40) = 1.29, p = .20$ ).

The relationship between resolution on the RDI and how supported mothers reported feeling was analysed using a Mann-Whitney U test. The results indicated that there were no significant differences between the extent to which resolved (mean rank 22.17) and

unresolved (mean rank 21.00) mothers felt supported by their social support networks ( $Z = -.33, p = .74$ ). In addition there was no significant association between size of social support network and how supported mothers reported feeling ( $r = .06, p = .73$ ). This suggests that the extent to which mothers feel supported is related to other factors and not size of social network.

Further analysis of group differences was carried out to determine if there were any particular types of social support associated with resolution on the RDI. The results revealed that mothers who were resolved on the RDI were significantly more likely to receive support from their families than mothers who were unresolved on the RDI ( $\chi^2(1) = 8.18, p = .004$ ). For those who were resolved regarding their child's diagnosis 94% (17/18) received social support from their families. In contrast for those who were unresolved regarding their child's diagnosis only 54% (13/24) received social support from their families. There was no association between mother's attachment status on the AAI and whether they received social support from their families.

There were no significant associations between mothers' resolution status and receiving social support from friends ( $\chi^2(1) = .39, p = .53$ ), professionals ( $\chi^2(1) = .70, p = .40$ ), charities ( $\chi^2(1) = .04, p = .83$ ), or church ( $\chi^2(1) = .77, p = .38$ ). These results indicate that social support from families is more important for mothers than social support from non-family members, in relation to resolving grief and trauma surrounding their child's condition

**Psychopathology and i) resolution of diagnosis, ii) attachment security and iii)**

**resolution of past losses and traumas to the attachment system**

i) Mothers' symptoms of psychopathology were assessed using the SCL-90-R. Forty four per cent of mothers (19/42) obtained scores of  $\geq 63$  on the Global Severity Index which indicates they were experiencing clinically significant psychopathological symptoms. The mean scores for groups of both resolved and unresolved mothers also approached the level which indicates clinically significant symptoms ( $\geq 63$ ). Table 3 illustrates the mean scores obtained by each group on the nine primary symptom dimensions and the global scales.

The mean scores on the Global Severity Index did not differ significantly between mothers who were resolved and unresolved on the RDI ( $t(40) = -.66, p = .51$ ). In addition there were no significant group differences on the nine primary symptom dimensions (somatisation, obsessive compulsive symptoms, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism). The results indicate that both groups report experiencing a broad range of psychopathological symptoms and that these symptoms did not differ significantly between resolved and unresolved mothers.

| SCL-90-R                               | RDI Classification |       |            |       | t     |
|--|--------------------|-------|------------|-------|-------|
|  | Resolved           |       | Unresolved |       |       |
|  | Mean               | SD    | Mean       | SD    |       |
| SCL-90 Global Severity Index           | 58.17              | 10.90 | 60.50      | 11.62 | -.66  |
| SCL-90 Positive Symptom Distress Index | 58.06              | 11.25 | 58.92      | 12.38 | -.23  |
| SCL-90 Positive Symptom Total          | 56.00              | 9.33  | 58.54      | 10.45 | -.82  |
| SCL-90 Somatisation                    | 54.11              | 11.89 | 59.29      | 12.36 | -1.37 |
| SCL-90 Obsessive Compulsive            | 59.11              | 9.92  | 60.75      | 12.31 | -.46  |
| SCL-90 Interpersonal Sensitivity       | 57.94              | 9.03  | 58.46      | 11.65 | -.16  |
| SCL-90 Depression                      | 59.28              | 10.49 | 59.46      | 11.93 | -.05  |
| SCL-90 Anxiety                         | 54.50              | 10.68 | 57.21      | 13.60 | -.70  |
| SCL-90 Hostility                       | 57.72              | 9.91  | 58.79      | 10.23 | -.34  |
| SCL-90 Phobic Anxiety                  | 50.56              | 8.69  | 51.92      | 9.20  | -.49  |
| SCL-90 Paranoid Ideation               | 54.89              | 10.28 | 58.63      | 10.23 | -1.17 |
| SCL-90 Psychoticism                    | 55.22              | 9.35  | 55.75      | 10.71 | -.17  |

\* significant at the .05 level    \*\* significant at the .01 level

Table 3: SCL-90-R scores for mothers who were resolved versus unresolved on the RDI.

ii) Analysis of group differences revealed that there were also no significant differences between the average Global Severity Index scores of mothers who were classified as secure compared to those classified as insecure on the AAI ( $t(40) = .38, p = .71$ ). Table 4 presents the mean scores obtained by each group on the nine primary symptom dimensions and the global scales. There were no significant group differences on the nine primary symptom dimensions. As with the results presented for the RDI, this indicates that both mothers who are classified as secure and those classified as insecure on the AAI report experiencing a broad range of psychopathological symptoms.

| SCL-90-R                               | AAI Classification |       |          |       | t    |
|--|--------------------|-------|----------|-------|------|
|  | Secure             |       | Insecure |       |      |
|  | Mean               | SD    | Mean     | SD    |      |
| SCL-90 Global Severity Index           | 58.86              | 11.56 | 60.20    | 11.13 | .38  |
| SCL-90 Positive Symptom Distress Index | 59.05              | 11.59 | 58.00    | 12.25 | -.28 |
| SCL-90 Positive Symptom Total          | 56.82              | 10.88 | 58.15    | 9.05  | .43  |
| SCL-90 Somatisation                    | 54.64              | 11.32 | 59.75    | 13.03 | 1.36 |
| SCL-90 Obsessive Compulsive            | 59.86              | 10.99 | 60.25    | 11.80 | .11  |
| SCL-90 Interpersonal Sensitivity       | 57.77              | 10.68 | 58.75    | 10.53 | .30  |
| SCL-90 Depression                      | 59.05              | 11.93 | 59.75    | 10.64 | .20  |
| SCL-90 Anxiety                         | 56.36              | 12.62 | 55.70    | 12.40 | -.17 |
| SCL-90 Hostility                       | 57.41              | 10.87 | 59.35    | 9.08  | .62  |
| SCL-90 Phobic Anxiety                  | 48.95              | 7.62  | 53.95    | 9.65  | 1.87 |
| SCL-90 Paranoid Ideation               | 56.32              | 10.77 | 57.80    | 9.97  | .46  |
| SCL-90 Psychoticism                    | 56.00              | 9.90  | 55.00    | 10.41 | -.32 |

\* significant at the .05 level    \*\* significant at the .01 level

Table 4: SCL-90-R scores for mothers classified as secure versus insecure on the AAI.

iii) The data was also analysed to compare symptoms of psychopathology reported by mothers classified as unresolved with respect to past losses and trauma on the AAI and those classified as resolved. Table 5 presents the mean scores obtained by each group. There were no significant differences between the mean Global Severity Index scores for mothers classified as resolved and those classified as resolved ( $t(40) = -.51, p = .61$ ). Further analysis of group differences revealed a significant group difference on the primary symptom scale of phobic anxiety ( $t(40) = -2.90, p = .006$ ). This indicates that mothers who are unresolved with respect to past losses and trauma in relation to attachment figures report significantly higher symptoms of phobic anxiety compared to mothers who are resolved. There were no other significant group differences on the remaining primary symptom indices.

| SCL-90-R                               | AAI Classification |       |            |       | t       |
|--|--------------------|-------|------------|-------|---------|
|  | Resolved           |       | Unresolved |       |         |
|  | Mean               | SD    | Mean       | SD    |         |
| SCL-90 Global Severity Index           | 59.03              | 11.12 | 61.22      | 12.18 | -.51    |
| SCL-90 Positive Symptom Distress Index | 58.18              | 11.87 | 59.89      | 12.04 | -.38    |
| SCL-90 Positive Symptom Total          | 57.06              | 9.95  | 58.89      | 10.42 | -.48    |
| SCL-90 Somatisation                    | 55.52              | 11.51 | 62.78      | 14.04 | -1.60   |
| SCL-90 Obsessive Compulsive            | 59.67              | 11.84 | 61.44      | 9.21  | -.42    |
| SCL-90 Interpersonal Sensitivity       | 57.82              | 10.24 | 59.78      | 11.86 | -.49    |
| SCL-90 Depression                      | 59.76              | 11.08 | 58.00      | 12.23 | .41     |
| SCL-90 Anxiety                         | 55.73              | 12.59 | 57.22      | 12.15 | -.32    |
| SCL-90 Hostility                       | 58.36              | 10.30 | 58.22      | 9.31  | .04     |
| SCL-90 Phobic Anxiety                  | 49.42              | 7.51  | 58.33      | 10.52 | -2.90** |
| SCL-90 Paranoid Ideation               | 56.70              | 10.15 | 58.22      | 11.38 | -.39    |
| SCL-90 Psychoticism                    | 55.61              | 10.28 | 55.22      | 9.64  | .10     |

\* significant at the .05 level    \*\* significant at the .01 level

Table 5: SCL-90-R scores for mothers who were classified as resolved versus unresolved on the AAI.

### Recent uncontrollable life events and resolution of diagnosis

The number of recent stressful life events occurring within each participant's family was assessed using the Life Stress Scale from the Parenting Stress Index. The maximum number of stressful life events is 19, with scores of 17 or above reaching levels of clinical concern.

Mothers who were resolved on the RDI obtained a mean score of 2.06 (SD = 1.39) and those who were unresolved obtained a mean score of 3.33 (SD = 2.35). Analysis of group differences revealed that mothers who were unresolved on the RDI had experienced a significantly higher number of recent stressful life events (within the past

year) than mothers who were resolved ( $t(38) = -2.20, p = .034$ ). There were no significant differences between the number of recent stressful life events experienced by mothers who were classified as secure on the AAI compared to mothers who were classified as insecure.

### **Attachment security and resolution of diagnosis**

Associations between resolution on the RDI and attachment security on the AAI were explored using analysis of group differences. Within the group of mothers who were resolved regarding their child's diagnosis 53% (10/19) were classified as secure and 47% were classified as insecure on the AAI. Within the group of mothers who were unresolved regarding their child's diagnosis 50% were classified as secure and 50% as insecure. These results indicate that there are no significant associations between resolution on the RDI and attachment security on the AAI ( $\chi^2(1) = .03, p = .86$ ).

### **Associations between continuous measures on the AAI and RDI**

Subsequent analyses were carried out using continuous measures from the AAI and RDI to further explore the relationship between mothers' states of mind with respect to attachment and their resolution on the RDI. On the AAI, Coherence of Mind and Coherence of Transcript are rated on a 1-9 point scale with higher scores indicating greater coherence with respect to attachment. Coherence is a significant indicator of autonomy / security in the coding system for the AAI. On the RDI the continuous 1-5 point scales reflect the extent to which the mother is resolved with respect to her child's

diagnosis. Data was analysed to explore associations between continuous variables of resolution on the RDI and coherence on the AAI. There were no significant associations between resolution on the RDI and coherence of transcript ( $r = .10$ ,  $p = .52$ ) or coherence of mind ( $r = .04$ ,  $p = .82$ ) on the AAI. This supports the hypothesis that there are no significant associations between mothers' state of mind with respect to attachment and resolution of the loss and trauma surrounding their child's learning disability.

#### **Resolution of past losses and proximal losses**

Associations between resolution of proximal losses on the RDI and past losses on the AAI were explored using analysis of group differences. Within the group of mothers who were resolved regarding proximal losses and trauma surrounding their child's condition 74% (14/19) were resolved and 26% (5/19) were unresolved concerning past losses and trauma relating to attachment figures. Within the group of mothers who were unresolved regarding proximal losses and trauma surrounding their child's condition 83% (20/24) were resolved and 17% (4/24) were unresolved concerning past losses and trauma relating to attachment figures. These results indicate that there are no significant associations between resolution of past (AAI) and proximal (RDI) losses ( $\chi^2 (1) = .60$ ,  $p = .44$ ).

### **Summary of results**

The results of the current study revealed that 44% of mothers were resolved with respect to grief and trauma surrounding their child's learning disability and 56% were unresolved. The majority of mothers reported feelings of distress, shock and anxiety on discovering their child's learning disability. There were no obvious differences in the way resolved and unresolved mothers described their initial responses. Resolution of diagnosis was significantly associated with sex of the child and the length of time since diagnosis. Mothers of boys with learning disabilities were more likely to be unresolved regarding their child's diagnosis whilst mothers of girls were more likely to be resolved. The length of time since diagnosis appeared important in the process of resolution. Mothers who were unresolved had received their child's diagnosis significantly more recently than mothers who were resolved.

Resolution of loss and trauma surrounding the child's condition was independent of the other demographic factors measured in this study. Therefore resolution of diagnosis was not related to the child's age, diagnosis, severity of their disability, birth order within family, or the type of school they attended. In addition there were no significant associations between resolution and family factors such as ethnicity, marital status of the mother, number of children and annual income.

Mothers' states of mind with respect to attachment were also independent of the majority of demographic factors measured in this study. However there were significant associations between attachment patterns and whether mothers were married and

employed. Mothers who were classified as autonomous / secure on the AAI were more likely to be married and employed compared to mothers classified as insecure.

Mothers who received social support from their families were significantly more likely to be resolved regarding loss and trauma surrounding their child's learning disability. However, the size of the mother's social support networks and the extent to which they reported feeling supported were not associated with resolution, contrary to the research hypothesis.

There were no associations between symptoms of psychopathology and mothers' resolution of loss and trauma surrounding their child's condition. Both resolved and unresolved mothers reported experiencing a broad range of symptoms and 44% obtained scores which reached the level of clinically significant psychopathological symptoms. Similarly there were no associations between mothers' attachment patterns and symptoms of psychopathology. However, mothers who were unresolved regarding past losses and traumas in relation to their attachment figures reported significantly higher symptoms of phobic anxiety compared to mothers who were resolved regarding past losses and traumas.

The number of stressful life events mothers reported experiencing within the past year differed significantly between mothers who were resolved regarding their child's learning disability and those who were unresolved. Unresolved mothers reported a

significantly higher number of stressful life events within the past year compared to resolved mothers.

There were no associations between mothers' states of mind with respect to attachment and resolution of loss and trauma surrounding their child's condition. In addition there were no associations between resolution of *past* losses and traumas in relation to mothers' attachment figures and resolution of *proximal* losses and trauma concerning their child's learning disability.

## **DISCUSSION**

### **Overview**

The primary aim of this study was to explore the relationship between mothers' states of mind with respect to their early attachment relationships and their resolution of grief and trauma surrounding their child's learning disability. The secondary hypotheses aimed to explore the relationship between resolution of the child's diagnosis and: social support, symptoms of psychopathology and recent stressful life events. First a summary of the main findings will be presented. The results will then be discussed in relation to the current literature base and theories of attachment and resolution. Following this, the limitations of the study will be considered and then the results will be discussed in terms of their implications for clinical work and further research. Finally, conclusions of the study will be presented.

### **Summary of main findings**

The main findings from this study indicated that there were no associations between mothers' resolution of proximal losses and trauma related to their child's learning disability and their state of mind with respect to attachment. This is surprising given that Pianta et al. (1999) found a significant association between attachment and resolution of diagnosis in a group of mothers whose children had cerebral palsy, which is similarly a chronic, stable and lifelong condition. In addition, no relationship was found between maternal resolution of *proximal* losses and traumas relating to the child's diagnosis and resolution of *past* losses and traumas relating to attachment figures. This is consistent

with the results of previous research studying mothers of children with cerebral palsy and epilepsy (Pianta et al., 1999; Walsh, 2003). Previous studies have found resolution of diagnosis to be unrelated to child and parent characteristics. However, in the current study sex and time since diagnosis were significantly related to resolution of diagnosis. Mothers of boys were more likely to be unresolved regarding their child's diagnosis whilst mothers of girls were more likely to be resolved. In addition mothers who were unresolved regarding their child's learning disability were likely to have received their child's diagnosis more recently than mothers who were resolved.

Mothers who received social support from their families were significantly more likely to be resolved regarding their child's diagnosis than mothers who did not receive social support from their families. However there was no relationship between resolution of diagnosis and the size of mothers' social support networks and the extent to which they reported feeling supported. In addition, there were no significant associations between global symptoms of psychopathology and i) resolution of diagnosis ii) attachment status and iii) resolution of past losses and traumas on the AAI. Therefore the results do not support the research hypotheses relating to social support and psychopathology.

Mothers who were unresolved regarding their child's diagnosis reported experiencing a significantly higher number of recent stressful life events compared to mothers who were resolved regarding their child's diagnosis. These findings therefore provide support for the hypothesis that recent stressful or traumatic life events impacts on mothers' resolution of their child's diagnosis.

## **Findings in relation to literature**

### **Attachment security and resolution of diagnosis**

The lack of association between attachment status and resolution of diagnosis in the current study is consistent with the findings reported by Pianta et al. (1999) and Walsh (2003) within the groups of mothers whose children had epilepsy. However, they are inconsistent with findings reported by both Pianta et al. (1999) and Walsh (2003) from the groups of mothers whose children had cerebral palsy. Pianta et al. (1999) expected to find an association between attachment status and resolution of diagnoses in both groups. However, they postulated that the lack of association in the epilepsy group may be due to the unpredictable nature of epilepsy, which acts as a constant threat to the caregiver's ability to protect their child from harm. They suggested that resolution is more likely to be attained when the illness or disability has a predictable course. In addition, they postulated that resolution of diagnosis is problematic where parents hold hope of improvement or abatement of the condition, which is frequently the case with childhood epilepsy.

If the lack of association in the epilepsy group is due to the unpredictable nature of the child's condition, we would expect to find a significant association between attachment status and resolution of diagnosis in the current study. This is because learning disabilities are known to be a chronic, stable and lifelong condition. The lack of association, therefore, poses a number of questions.

Firstly, is there an association between mothers' attachment status and resolution of diagnosis which was not detected because of design and measurement issues? It is

possible that the current study lacked power to detect such an association, however, there were no trends in the data to suggest such a relationship, even if the sample size were increased. In addition, the sample size of the current study is slightly larger than the sample size of each group in the research carried out by Pianta et al. (1999) and Walsh (2003). Alternatively, could the association be stronger when the child is younger and become harder to detect as the child grows older? Pianta et al. (1999) and Walsh (2003) studied mothers whose children were aged 15-50 months compared to the current sample of children aged 5-12 years. Further research with mothers of younger children with learning disabilities is required to answer this question.

Secondly, could the heterogeneity of the current sample mask associations between attachment status and resolution of diagnosis? Pianta et al. (1999) cautioned against using participants whose children have varying symptoms and diagnoses. He suggested that the relationship between resolution of diagnosis and attachment may be disrupted by the nature of proximal losses and traumas associated with the child's condition. Although all the children in the sample had learning disabilities, there were a wide range of different conditions associated with their learning disability. Therefore, it may be helpful to carry out research which focuses separately on individual diagnostic conditions which are associated with learning disabilities, for example: Down syndrome, Rett syndrome, Autism. However, in the current study, the severity of the child's learning disability and different diagnostic conditions were independent from all of the variables of interest. Although there may have been subtle group differences which were not visible during examination of the data, the lack of group differences does not

strongly indicate the need to separate different causes of learning disabilities in future research.

It is also important to consider differences between the health services and diagnostic systems in the USA and Great Britain. It is possible that parents are given clearer diagnoses and prognoses in America, due to the system of healthcare which requires health professionals to give clear information about medical conditions for insurance purposes. Therefore, it may be that British parents who have children with learning disabilities are not given clear information about their child's diagnosis and the long-term prognosis. This may be because health professionals find it hard to deliver bad news and prefer to state that they do not know what the future holds. Alternatively they may believe it is helpful to give parents hope of improvement in their child's condition over time. If this were true, then arguably the current sample may be similar to the epilepsy groups in previous research, because their child's condition *is* unpredictable with an unknown course from the parent's point of view. This view may be supported by the fact that, throughout the interviews, many of the mothers seemed unsure as to what the future held for their child and only a minority appeared clear that their child would, most probably, be unable to live and work independently.

Finally, the lack of associations between mothers' attachment status and resolution of diagnosis in groups of children with epilepsy and children with learning disabilities raises the question as to whether the cerebral palsy group is unique in some way. Perhaps cerebral palsy is more predictable and stable than other medical conditions and disabilities. It is possible that the association between attachment and resolution is

disrupted by loss and trauma surrounding the child's condition and that some conditions result in greater loss and trauma. Siegel (1997) suggested that parents of children with learning disabilities experience higher levels of stress because of the uncertainty surrounding their child's prognosis. Further research is required to explore whether parents experience greater trauma and loss when given a diagnosis of learning disabilities or epilepsy, compared to cerebral palsy. It is possible that loss and trauma regarding the child's diagnosis are related to stigma and parent's beliefs and expectations about their child's condition.

#### Resolution of past losses and proximal losses

In the current study there was no association between resolution of past losses and trauma in relation to attachment figures and resolution of proximal losses surrounding the child's diagnosis. These findings are consistent with previous research conducted by Pianta et al. (1999) and Walsh (2003). However, these findings are inconsistent with the theoretical underpinnings of representational and behavioural systems relating to attachment and care-giving. Main et al. (1985) found that mothers who were unresolved regarding past losses and traumas were at greater risk of developing insecure attachments and experiencing problems with care-giving relationships. This is thought to be because they continue to experience symptoms of distress and disorientation and have conflicting internal models of their self and others. The experience of intense fear and helplessness associated with trauma can lead to psychological and behavioural disorganisation, particularly if the person was mistreated or abused by their caregiver.

Pianta, Marvin, Britner & Borowitz (1996) suggested that the parents' care-giving systems can be disrupted by *past* losses and traumas to the attachment system, or by *proximal* losses and traumas such as giving birth to a child with a disability or chronic medical condition. They suggested that the loss and trauma connected with the child's condition may disorganise the care-giving system and cause conflict and anxiety which arouses the parent's own attachment systems. The disorientation experienced by unresolved mothers is thought to cause them to behave in ways which unpredictably frighten their child. The child therefore wishes to approach their caregiver for protection and comfort, but is not able to because they are the source of fear. This increases the probability that mothers who are unresolved, with respect to past losses and traumas, are more likely to develop disorganised attachment relationships with their children.

The results of the current study, in addition to previous research, indicates that resolution of past losses and traumas relating to attachment figures is not associated with mothers' resolution of their child's diagnosis and their care-giving skills. This is particularly interesting given the large body of research with normal participants and other clinical samples which has documented the relationship between resolution on the AAI, child-caregiver attachment style and care-giving skills (Main et al., 1985; Main & Solomon, 1986).

Walsh (2003) reported that mother's interactions with their children were significantly associated with whether they were resolved with regard to their child's diagnosis of cerebral palsy or epilepsy, but not whether they were resolved with respect to past losses

/ traumas relating to attachment figures. Therefore, the trauma and loss surrounding the child's diagnosis appears to overpower the attachment and care-giving systems and reduce the impact of protective or risk factors associated with the mother's early attachment related experiences. Although there is no evident relationship between resolution of past and proximal losses, it appears premature to conclude that mothers' early experiences of loss and trauma are unrelated to their relationships with their children and reaction to their child's diagnosis. In this study, nine mothers were unresolved regarding past losses and traumas. Of those nine mothers, four were unresolved regarding their child's diagnosis and five were resolved. Although this data illustrates that being unresolved with respect to past losses does not prevent mothers resolving grief and loss regarding their child's diagnosis, there may be subtle differences in the process of resolution. For example, the process may be more difficult for mothers who are unresolved with respect to past losses because it compounds past losses and traumas and recapitulates the mother's grief. This may have a disorganising impact on the mother's attachment and care-giving systems. An alternative hypothesis may be that parents who have experienced past losses and traumas have developed resources which help them to cope with adverse experiences (although they are not resolved with respect to those experiences), whilst mothers who have had secure early experiences may not have resources which help them to cope with proximal losses and traumas surrounding their child's condition. However, this is conjecture and further research is required to explore this complex theory within different populations.

### Recent uncontrollable life events and resolution of diagnosis

Prior to this study, the relationship between mothers' resolution regarding their child's diagnosis and experience of recent uncontrollable stressful life events had not been studied. This is surprising, given the theory proposed by Pianta et al. (1999) that both past and proximal losses and trauma may disrupt parent's care-giving and attachment relationships. The additional stresses involved in parenting a child with a learning disability are well documented. However, it is possible that uncontrollable life events, such as the loss of a relative, moving house, or being made unemployed, exacerbate the difficulties parents are already struggling to cope with.

The findings from this study indicated that mothers who were unresolved regarding their child's learning disability experienced a significantly higher number of recent uncontrollable life events than mothers who were resolved. These findings can be interpreted in a number of ways. Firstly, these results may indicate that some mothers have been unable to resolve loss and trauma regarding their child's condition because of additional proximal losses and traumas external to their child's condition. If the mother is grieving the loss of a relative, or experiencing problems at work, this may interfere with the process of resolution. If this hypothesis is correct then it may be possible that some mothers who *were* resolved regarding their child's learning disability *become* unresolved as a result of proximal stresses and traumas external to the child. This would be consistent with developmental models of resolution where families are thought to re-experience or recapitulate grief at transitional points in the life-cycle (Goldberg et al., 1995). Secondly, the number of recent stressful life events may be related to the child's

learning disability in some way, e.g. problems with schooling, and both may impact on the mother's resolution. Finally, some mothers may be predisposed to experiencing a higher number of uncontrollable life events due to other factors such as poverty or personality style. For example, some of the mothers in the study had a history of being physically abused by their parents and then were physically abused by their husbands, leading to traumatic separations or divorce. Such patterns of interacting with others may also impact on mothers' relationships with schools and health services causing additional proximal traumas, which may interfere with resolution of diagnosis. However, the lack of association between recent stressful life events and attachment status, in this study, means that this should be treated as a tentative explanation which requires further exploration.

#### Social support and resolution of diagnosis

The results from the current study do not support the hypothesis that mothers who are resolved regarding their child's diagnosis will have wider social networks and report feeling more supported. However, it is difficult to discuss these findings in relation to the literature because no previous study has examined the relationship between social support and resolution of diagnosis. It is possible that the hypotheses were not supported because of the crude measure of social support used within this study. In future, it would be helpful to use a standardised and reliable measure of social support. Previous research has explored the relationship between social support and positive adaptation in families who have children with disabilities (Kazak & Marvin, 1984) and between stress, social support and behavioural interactions between mothers and their children (Crnic et al.,

1983). Therefore the discrepancies between the findings from previous research and the current study may well be due to the difference in measures used and the concepts which were being studied. Clearly further research is required to determine whether the concepts of coping, adaptation, adjustment and resolution are related or discrete processes.

The findings from the current study revealed that mothers who received social support from their family were more likely to be resolved regarding their child's learning disability than mothers who did not receive support from their family. Interestingly social support from friends and professionals did not differ significantly between groups. These results suggest that mothers who do not receive social support from their families are at greater risk of being unresolved regarding their child's diagnosis. However, the importance of family support over support from non-family members means that professional services may not be able to compensate fully by offering social support. Further research, using a reliable standardised measure of social support, may indicate that families who have children with learning disabilities may require intervention within the family system to help provide support to mothers who have children with learning disabilities. Further research exploring reactions to diagnosis in fathers, grandparents and the wider family system is required, particularly in light of these findings.

Psychopathology and i) resolution of diagnosis, ii) attachment security and iii) resolution of past losses and traumas to the attachment system

Contrary to the research hypotheses, there were no associations between global symptoms of psychopathology and resolution of diagnosis, attachment status or resolution of past losses / traumas related to attachment figures. Mothers appeared to experience a high number and intensity of psychopathological symptoms, regardless of their attachment status or resolution of their child's learning disability. The results indicate that the experience of trauma and stress related to the children's learning disabilities causes mothers to experience unpleasant emotional symptoms, regardless of prior attachment-related experiences and social support. However, symptoms of psychopathology may be related to other factors which were not measured, or controlled for, within this study. This may include prior experience of mental health problems and a family history of psychopathology.

**Limitations of the current study**

There are a number of limitations which impact on the extent to which conclusions can be drawn from this study.

Sample size and heterogeneity

Firstly, the current sample had a limited sample size which may have reduced the power of statistical analyses to detect significant associations between the variables of interest. However, the current sample size was larger than the sample size of each group in the studies by Pianta et al. (1999) and Walsh (2003), where significant associations were

found between attachment status and resolution of diagnosis in the cerebral palsy group. In addition, visual examination of the data did not detect any trends in the direction expected. The small sample size was related to problems recruiting mothers to take part in the study. Of the 333 mothers invited to take part only 13% took part. Therefore, it is not possible to assume that this sample is representative of the general population of mothers who have children with learning disabilities. Of particular interest is the difference between the number of mothers who were resolved regarding diagnosis in this sample compared to the sample studied by Holder (2000). Holder (2000) recruited mothers of children with learning disabilities who were aged 5 -12 from a similar geographical location. Her study found that 68% of mothers were resolved regarding their child's diagnosis which is significantly higher than the percentage of mothers who were resolved in the current study. Holder (2000) suggested that the higher rates of resolution may be related to the older age of the children compared to research by Pianta et al. (1999). The significantly lower rates of resolution in the current study indicates that the samples may have come from different populations. One possibility is that a different sample of mothers may have taken part in the current study because they were interested in talking about their childhood experiences in addition to exploring issues concerning their child. A high proportion of the mothers in the current study commented that they found it helpful to talk through their experiences and appeared to experience the interview as a therapeutic experience.

It is also interesting that one third of the sample reported physically or sexually abusive experiences in their childhood. It is difficult to compare the incidence of abuse in the current study with normative data because reported prevalence rates vary widely and it is

possible that the incidence of abuse in the general population is much higher than reported because of the secretive nature of abuse. However, it may be that a number of mothers wished to have the opportunity to discuss their abusive experiences with an independent person without seeking counselling or other therapy and, therefore, took part in the study. Despite the differences in rates of resolution, the distribution of classifications on the Adult Attachment Interview did not differ significantly from non-clinical populations which indicates that the sample was not significantly different in terms of their attachment status.

Another limitation of the study was the heterogeneity of the sample in terms of parent, child and family characteristics. This may have reduced the power of the study to detect significant differences between the variables of interest. However, the heterogeneity can also be considered a strength because the results may be applicable to a broad cross-section of families from different ethnic backgrounds and for children with varying diagnoses and severity of learning disabilities. In addition, the lack of significant group differences between the demographic variables suggests that these factors were not associated with resolution of diagnosis or attachment status.

As with all research, it is possible that the significant associations found within this study reflect a type 1 error. This phenomenon occurs when statistically significant results, which suggest the participants are from different populations, occur when the participants are actually from the same population. This can be controlled for by replicating the study and by applying more stringent probability values (e.g.  $p = <.01$ ). In this study a less stringent probability value of  $p = <.05$  was used, despite the fact that

the number of statistical analyses may have inflated the risk of a type 1 error occurring. The reason for using a less stringent probability value was because all the statistical analyses were driven by theory and the measures of attachment and resolution of diagnosis used were the most valid and reliable measures available. These factors reduce the problems associated with type 1 errors which may cause spuriously significant results.

### Design

An additional limitation of the current study is the cross-sectional nature of the design. This is problematic because the study aims to gain a retrospective account of mothers' attachment style and reaction to their child's diagnosis. Longitudinal research would enable us to explore whether some mothers move from being resolved to being unresolved regarding their child's diagnosis and under which conditions this occurs. In addition, it would be helpful to study mothers' states of mind, with respect to attachment, over time to assess the extent to which this changes, under which conditions, and how this relates to resolution regarding diagnosis. A longitudinal design would also enable clinicians to monitor the outcome of therapeutic interventions, such as the model of family therapy described by Goldberg et al. (1995) and whether this impacts on resolution of diagnosis and child-caregiver attachment style.

### Measures

There are a number of limitations relating to the measures used within this study. The lack of association between attachment status and resolution of diagnosis, in this and

previous studies, leads us to question what the AAI and RDI are measuring and why they do not support the findings which would be predicted using Attachment Theory. As discussed previously, the lack of significant association could reflect a lack of power to detect significant differences. However, the AAI and RDI are both measures which aim to provide a retrospective understanding of events which happened many years ago. This raises questions as to whether the AAI and RDI are really measuring states of mind with respect to attachment and resolution of diagnosis. The AAI is reported to be the most valid and reliable measure of attachment status. However, both Fox (1995) and van IJzendoorn (1995) discussed the fact that attachment status is affected by the individual's life experiences during adolescence and adulthood and that a child who has an insecure attachment to their parents may be later classified as secure on the AAI. Benoit and Parker (1995) studied the stability of attachment status across generations and found that mother's patterns of attachment predicted their infant's attachment security in 81% of cases and that mothers' attachment status predicted their own mothers' status in 75% of cases. Although this research provides evidence for intergenerational transmission of attachment, it also raises questions as to what is different in the 19% of mother-child pairs who were classified differently to their children or the 25% of mothers who differed in attachment status from their own mothers. It is possible that the experience of traumatic or stressful life events, such as giving birth to a child with a learning disability, disrupts this relationship. This raises the question as to whether it is appropriate to use the framework of attachment theory in this area of research. It is premature to conclude that Attachment Theory and the AAI should not be explored further in studying parents who have children with learning disabilities.

However, any future research should consider carefully whether this theoretical framework is developing our understanding of the experiences of parents who have children with learning disabilities.

The RDI is a relatively newly developed measure which claims to assess the extent to which parents' have resolved grief and trauma surrounding their child's disability or chronic medical condition. However, as previously discussed, it remains unclear what 'resolution' is and how this relates to concepts of adaptation, adjustment, acceptance and coping. Although at face value, the interview appears to be measuring the extent to which parents have integrated the information about their child's condition into their mental representational systems, as yet there has been no research which has explored how parental resolution relates to caregiving skills and coping with the day to day demands of children with learning disabilities in the UK. Further research is necessary to determine the validity of the RDI for use in this population and to further explore the concept of resolution in relation to the existing terminology used in research in this area.

In addition, The Disability Index used to determine the severity of the children's learning disabilities is a subjective measure completed by the mothers. Therefore, there was no independent measure of the child's diagnosis or severity of their condition. In future, it would be helpful to assess the child's severity of disability independently, or involve a medical professional to confirm the child's diagnosis. It would also be interesting to compare the parent's views about their child's learning disability with those of the professionals involved in their care. This would allow exploration of the

relationship between agreement of parents and professionals regarding the child's disability, with resolution of diagnosis and the parent's engagement with services.

Another weakness concerns the fact that the majority of information collected focused on the mothers' experiences and characteristics. There was no measure of the children's characteristics and their strengths and weaknesses. This information would have strengthened the study and may have provided additional information to explain the finding that mothers of boys with learning disabilities were less likely to be resolved regarding their child's diagnosis than mothers of girls. For example, it is possible that the boys in this study exhibited greater symptoms of hyperactive or challenging behaviour than the girls and that this may be connected to resolution of diagnosis rather than the sex of the child per se. In future, it would be helpful to include a measure of child characteristics such as the Achenbach Child Behaviour Checklist to further our understanding of the type of characteristics which are related to parents' resolution of their child's condition.

Additional limitations concern the independent use of the Life Events Scale from the Parenting Stress Index. This scale does not have any reliability data or normative data. Therefore, it was not possible to compare the number of recent stressful life experiences reported by mothers, with the normal population. In future, it would be useful to administer the complete Index, which would provide further information relating to the mother's experience of parent and child related stresses and the relationship to resolution of diagnosis.

As previously discussed, social support was assessed using a non-standardised measure. In future, it would be helpful to administer a standardised measure of social support, to allow comparison between the research sample and other populations.

### **Implications for clinical work and further research**

The results of the current study have a number of implications for professionals working with families of children with learning disabilities. Most important is the finding that only 44% of the mothers were resolved regarding their child's diagnosis, despite the fact that the children in the study were aged 5-12 years. This indicates that more than half of the mothers continued to experience significant difficulties resolving loss and trauma surrounding their child's condition, a number of years after receiving their child's diagnosis. In addition, the majority of mothers reported experiencing a high number of psychopathological symptoms, which are likely to have a considerable impact on the mother's quality of life and that of their families. It is particularly interesting that even mothers who were resolved with regard to their child's diagnosis, with secure attachment status and high levels of social support, reported high global symptoms of psychopathology. In addition, one third of the participants had experienced abusive relationship during their childhood. Although some of the mothers had resolved these traumatic experiences, it is important for clinicians to be aware that parents may have had a number of traumatic experiences prior to the birth of their child, which may impact on their reaction to their child's disability. For example, mothers who developed insecure dismissing attachments with their parents may exhibit a similar pattern of

response in relation to their child's learning disability, whilst those who are preoccupied may respond in an angry manner. Therefore, each mother may require different types of support and intervention, depending on the way they relate to other people and this calls for thoughtful and flexible service planning.

A number of the mothers participating in the study spontaneously commented that it helped to talk about their difficult early relationships and to have somebody who was interested in them and prepared to listen to their experiences. It may be that the emotional needs of mothers' of children with learning disabilities are not being met and that the services they receive are mainly child focused (e.g. respite care). Although resources are sparse, outcome may be improved if mothers of children with learning disabilities were automatically offered a number of supportive, therapeutic, meetings with a trained professional. This would provide the opportunity to discuss their feelings regarding their child's diagnosis, assess their symptoms of mental health problems and provide appropriate support, where necessary. An increasing number of clinicians and researchers are suggesting using a systemic approach, when working with families with learning disabilities, in order to move away from child-focused interventions and work with the wider family system (Seligman & Darling, 1997; Goldberg et al., 1995).

The results of this and previous studies also indicate that it is important for parents to receive clear information about their child's diagnosis and the prognosis of their learning disability. Although professionals may not want to be the bearer of bad news, the current findings indicate that if parents are clearer about the course and prognosis of their

child's condition, they may be able to resolve their grief and form better attachment relationships with their children.

In order to improve services and overcome difficulties with recruiting participants for future research, it may be helpful to try and carry out research alongside clinical services. Therefore, all parents could be invited to take part in the research at the time of their presentation to services regarding concerns about their child's development. This would allow longitudinal research to take place and may also have a positive impact on the family's engagement with services and future welfare.

#### Further research

Further research is required to examine resolution of diagnosis and attachment in fathers, adoptive parents, and other primary carers, in order to better understand these processes in terms of the wider family situation. In addition, it would be helpful to replicate Walsh's (2003) study by exploring the relationship between resolution of diagnosis, adult attachment status, child-caregiver attachment style and the way mothers interact with their children on a problem solving task. This would provide a detailed study of the observable impact of resolution of diagnosis and attachment style on the way mothers respond to their children.

## **Conclusions**

The findings of the current study indicate that approximately half of the population of mothers who have children with learning disabilities will continue to experience significant difficulties resolving loss and trauma surrounding their child's condition into middle school years. This is likely to impact negatively on their ability to provide sensitive parenting which meets their children's needs and helps to form secure attachments. Mothers' resolution of losses and trauma surrounding their child's learning disability is not associated with their early attachment experiences, or resolution of past losses and traumas in relation to attachment figures. The experience of proximal losses regarding their child's condition and recent stressful life events appears to over-power the attachment and care-giving systems and reduce the impact of previous risk or positive protective experiences in the mother's life. Social support from families has a significant impact on the mother's ability to resolve proximal losses and traumas surrounding her child's condition. Clinical implications have been discussed, including the importance of parent's receiving clear diagnosis and prognosis of their child's condition and services which work with the wider family system.

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Dear parents

I have been asked to forward you the attached paperwork which describes a research project which you are invited to join. Please contact Helen directly to let her know if you would like to take part or not. Helen is very keen to hear from you and is happy for you to telephone her on **07887 980443** if you have any questions about the study or would like to reply via telephone rather than by completing the reply form.

I hope you will consider taking part in this research as it is hoped that the findings will be of future benefit to families who have children with Learning Difficulties.

If you have any other queries then please contact me or Helen on the telephone numbers detailed above.

Thank you very much for your help,

Mr/s.....  
Head Teacher

Dear parents,

I am carrying out a research study investigating the relationship between mother's childhood experiences and their experience of parenting a child with a learning disability. The enclosed information sheet has details of the aims of the study, what is involved and why you have been invited to take part in the research. The research takes the form of a single interview lasting approximately 45 to 90 minutes. I would be happy to come to your home, or another convenient place to talk with you. Because the research involves an interview it is helpful for me to know what your first language is, therefore the form includes a question about this.

Please could you complete this form indicating whether you would be interested in taking part in the study and return it using the pre-paid envelope. If you would prefer to telephone me to let me know if you are interested in taking part please call me on 07887 980443.

Thank you very much for taking time to read this information, I look forward to hearing from you,

Yours sincerely

Helen Fletcher  
Trainee Clinical Psychologist



**An investigation into the relationship between mother's childhood experiences and their experience of parenting a child with a learning disability**

**INFORMATION SHEET**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

**Aim of the study**

The main aim of the study is to explore the relationship between mother's childhood experiences (including being parented) and their experience of parenting a child with a learning disability. The study also aims to identify factors which make it easier to cope with receiving the diagnosis and the stresses involved in parenting a child with a learning disability.

**Why is the study being done?**

It is hoped that by conducting this research, it will be possible to understand mother's experiences of parenting a child with learning disabilities more fully and therefore meet parent's needs more effectively.

**Why have I been invited to participate in this study?**

You have been invited to participate in this study because we believe you have a child between 6-12 years of age who has a learning disability. The study aims to interview at least 32 mothers of children with learning disabilities whose children are within this age range.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or not to take part, will not affect the standard of care your child receives in any way.

### **How is the study to be carried out?**

In this study, mothers are interviewed by the researcher about their childhood experiences and experiences of parenting a child with a learning disability. The interview will last for between 1-2 hours and will be conducted in the parent's home (if this is convenient). The mothers will also be given 2 questionnaires to fill out which ask about life stresses and emotional experiences. If you agree, the interview will be audio taped so that it can be studied in detail at a later time. The tape will be held by the researcher and will be protected in accordance with the data protection act. All the information you give will be confidential and stored anonymously.

### **What are the possible risks and discomforts involved in taking part?**

There are no anticipated risks involved in taking part in this research. However, it is possible that you may experience some emotional distress if you recall sad memories from your past or from the time of receiving your child's diagnosis of a learning disability. If this does occur you will be offered appropriate support by the researcher and will be contacted by telephone 5-10 days after the interview to enquire if you would like any further support or the opportunity to discuss the interview. We also request your permission to inform your GP that you are taking part in this research project. This is to ensure that your GP is able to put in context any difficulties which may arise as a result of discussing sad memories during the interview.

### **What are the potential benefits?**

It is unlikely that the study will bring any immediate benefits to you. However, it is hoped that by increasing our understanding of the experiences of parenting a child with a learning disability, services may be better able to meet parent's needs effectively.

### **Will my taking part in the study be kept confidential?**

All information which is collected concerning you will be kept strictly confidential and will have your name/address removed so that you cannot be recognised from it.

### **What will happen to the results of the research study?**

The results of the research study will be written up and submitted as part of the researcher's clinical doctorate in June-July 2004. After this time the results will be submitted for publication to a number of psychological journals which other professionals

read. You will receive a letter summarising the results of the study. The information you provide will be confidential and therefore NOT identifiable in any report/publication.

### **Who is organising and funding the research?**

The research is organised and funded by University College London. You will not be paid for participating in this research.

### **Who has reviewed this study?**

The study has been reviewed by researchers at University College London and by Brent Research Ethics Committee.

### **Contact for further information**

You can contact the researcher to discuss any matters relating to this project at the following address:

Helen Fletcher  
Trainee Clinical Psychologist  
Sub-department of Clinical Health Psychology  
University College London  
1-19 Torrington Place  
London  
WC1E 6BT

If you need any assistance or advice as a consequence of participating in this research at any time, please contact the Harrow Learning Disabilities Team on 020 8424 1019

If you have any complaints about the way in which this research has been conducted please, in the first instance, discuss them with the researcher. If the problems are not resolved or you wish to comment in any other way, please contact Dr Juliet Holder, Clinical Psychologist at the Harrow Learning Disabilities Team on 020 8424 1019, or at the following address:

Dr Juliet Holder  
Clinical Psychologist  
Harrow Learning Disability Team  
P.O. Box 161  
4<sup>th</sup> Floor Civic Centre  
Harrow  
Middlesex HA1 2AY

**An investigation into the relationship between mother's childhood experiences and their experience of parenting a child with a learning disability**

**Reply Form**

Please indicate whether or not you wish to be contacted:

I do / do not wish to be contacted regarding participation in this study  
(please delete as appropriate)

Signed: .....

Print Name: .....

Telephone Number: .....

Date: .....

My first language is: .....

Please return this form in the pre-paid envelope to Helen Fletcher, Trainee Clinical Psychologist, Harrow Learning Disability Team, P.O Box 161 4<sup>th</sup> Floor Civic Centre, Harrow, Middlesex, HA1 2AY

**THE BRENT MEDICAL  
ETHICS COMMITTEE**

Central Middlesex Hospital  
The Old Refectory  
Acton Lane  
Park Royal  
London NW10 7NS

Tel: 020 8453 2461

Fax: 020 8453 2466

e-mail: [bervi.frost@nwh.nhs.uk](mailto:bervi.frost@nwh.nhs.uk)

e-mail: [david.hopkins@nwh.nhs.uk](mailto:david.hopkins@nwh.nhs.uk)

29 October 2003

Ms Helen Fletcher  
Trainee Clinical Psychologist  
Sub-Department of Clinical Health Psychology  
University College London  
1-19 Torrington Place  
London WC1E 6BT

Dear Ms Fletcher,

**BEC 1029 – An investigation of the relationship between previous unresolved losses/trauma and mother's reactions to their child's diagnosis of a learning disability.**

The Brent Medical Ethics Committee considered your application at their meeting on 28 July and reviewed the following documents:

- (a) Complete Harrow LREC Application form
- (b) Adult Attachment Interview Protocol
- (c) Information Sheet
- (d) Consent Form
- (e) Reaction to Diagnosis Interview Sheet

The queries/issues raised by the committee were:

- (1) Question 13 of the application form states that mothers whose ethnicity is not white, UK will be excluded. Whilst the Committee can understand the reason for excluding mothers whose first language is not English, the exclusion of non-white, UK mothers could be considered discriminatory. The Committee would like to know the reason for this proposed exclusion.
- (2) The study titles and study aim details are different on the Patient Information Sheet ("PIS") and application form. In order to give informed consent to participate in the Study, the Committee considered it important that mothers were told the correct and full title and aim of the study.
- (3) In the section of the PIS entitled 'Who has reviewed this study?', the reference to the Harrow Research Ethics Committee should be changed to The Brent Medical Ethics Committee.

- (4) In the PIS under the section entitled 'Why have I been chosen', the Committee would prefer that this be replaced by 'Why have I been invited to participate in this study.' The text in this section should be similarly amended.
- (5) GPs should be informed if any of their patients are participating in the research study. This is to ensure that GPs are able to put in context and appropriately counsel any patients who have participated in the study who seek advice from their GP.
- (6) The Committee noted that you propose to tape interviews (with mothers' consent to this). The Committee would like confirmation on the length of time that these tapes will be stored (this should be for no longer than necessary) and that they will subsequently be securely permanently erased or disposed of.
- (7) The Committee would also like clarification on the recruitment methods and details of how suitable participants will be identified (and by whom) to ensure that this part of the study complies with the Data Protection Act 1998. The Committee would also like confirmation that you have secured the agreement of the Consultant Paediatricians at Northwick Park Hospital and has informed and liaised with the appropriate Primary Care Trust(s) so that they know this study is occurring.
- (8) The Committee would also like clarification on what appropriate support would be offered in the event mothers become distressed during the interview.

I have received your reply and am satisfied that your response has fulfilled the requirements of the committee. Acting under delegated authority from them, I am able to give approval for your research on ethical grounds providing you comply with the conditions set out below.:

**Conditions:**

The members of the Committee present agreed there is no objection on ethical grounds to the proposed study. I am, therefore, pleased to tell you that the committee has approved your study so long as you follow the conditions set out below:

- You do not recruit any research subjects within a research site unless favourable opinion has been obtained from the relevant Research Ethics Committee (REC).
- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained as set out in the Framework for Research Governance in Health and Social Care.
  - North West London Hospitals Trust – Dr. David King; Research and Development Office, Northwick Park Hospital  
(email [david.king@nwlh.nhs.uk](mailto:david.king@nwlh.nhs.uk) Phone 020 8869 2011)
  - Brent PCT – Janet Procter, P/A to Chief Executive  
(email [janet.procter@brentpct.nhs.uk](mailto:janet.procter@brentpct.nhs.uk))
- You do not deviate from, or make changes to, the protocol without prior written approval of the REC, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or

administrative aspects of the research. In such cases the REC should be informed within seven days of the implementation of the change.

- You complete and return the standard progress report form to the REC one-year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to this REC within three months of completion.
- If you decided to terminate this research prematurely you send a report to this REC within 15 days, indicating the reason for the early termination.
- You advise the REC of any unusual or unexpected results that raise questions about the safety of the research.
- NHS Research Ethics Committees are compliant with the International Conference on Harmonisation/Good Clinical Practice/Governance arrangements for NHS Research Ethics Committees (ICH/GCP/GAfREC Guidelines for the conduct of trial involving participation of human subjects.

This project must be started within three years of the date on this letter.

Please quote the reference number on all correspondence with the REC.

Yours sincerely,

**Cathy Vickery**  
Deputy-Chair

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Chair – Dr David Hopkins Vice-Chair Ms Cathy Vickery Administrator Mrs B Frost

An investigation into the relationship between mother's childhood experiences and their experience of parenting a child with a learning disability

CONSENT FORM

Part A: To be completed by the investigator

I confirm that I have explained this research project to the participant in terms which, in my judgement, are suited to the understanding of the participant.

Helen Fletcher

Name of researcher

Signature

Date

Part B: To be completed by the participant

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

YES / NO (please delete as appropriate)

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and that this will not affect any involvement I have with services related to my child's disability.

YES / NO (please delete as appropriate)

3. I understand that my identity will not be disclosed in any published or written data resulting from this study.

YES / NO (please delete as appropriate)

4. I understand the above information and agree to take part in the above research project.

YES / NO (please delete as appropriate)

Name of participant

Signature

Date

## **REACTION TO DIAGNOSIS INTERVIEW**

**Series of questions to elicit feelings and beliefs about diagnosis process, child's condition, and parents' reactions.**

- 1. When did you first realize that your child had a medical problem (probe for details)?**
- 2. What were your feelings at the time of this realization?**
- 3. How have these feelings changed over time?**
- 4. Tell me exactly what happened when you learned of your child's diagnosis. Where were you, who else was there, what were you thinking and feeling at that moment?**
- 5. Parents sometimes wonder or have ideas about why they have a child with special needs. Do you have anything like that that you wonder about?**

**(Prompt if necessary. For example, some parents feel that they might have done something to cause their child's condition; others believe that god must have a reason for giving them this child.)**

**6-10. Repeat questions for spouse/partner reactions.**

**INSTRUCTIONS:**

Below is a list of problems people sometimes have. Please read each one carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Blacken the circle for only one

number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask them now.

|   | NOT AT ALL              | A LITTLE BIT            | MODERATELY              | QUITE A BIT                        | EXTREMELY               |           |
|---|-------------------------|-------------------------|-------------------------|------------------------------------|-------------------------|-----------|
| 1 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input checked="" type="radio"/> 3 | <input type="radio"/> 4 | Bodyaches |

**EXAMPLE**

**HOW MUCH WERE YOU DISTRESSED BY:**

|    | NOT AT ALL              | A LITTLE BIT            | MODERATELY              | QUITE A BIT             | EXTREMELY               |   |
|----|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|---|
| 1  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Headaches   |
| 2  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Nervousness or shakiness inside                           |
| 3  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Repeated unpleasant thoughts that won't leave your mind   |
| 4  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Faintness or dizziness                                    |
| 5  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Loss of sexual interest or pleasure                       |
| 6  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling critical of others                                |
| 7  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | The idea that someone else can control your thoughts      |
| 8  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling others are to blame for most of your troubles     |
| 9  | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Trouble remembering things                                |
| 10 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Worried about sloppiness or carelessness                  |
| 11 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling easily annoyed or irritated                       |
| 12 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Pains in heart or chest                                   |
| 13 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling afraid in open spaces or on the streets           |
| 14 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling low in energy or slowed down                      |
| 15 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Thoughts of ending your life                              |
| 16 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Hearing voices that other people do not hear              |
| 17 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Trembling   |
| 18 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling that most people cannot be trusted                |
| 19 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Poor appetite   |
| 20 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Crying easily   |
| 21 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling shy or uneasy with the opposite sex               |
| 22 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feelings of being trapped or caught                       |
| 23 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Suddenly scared for no reason                             |
| 24 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Temper outbursts that you could not control               |
| 25 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling afraid to go out of your house alone              |
| 26 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Blaming yourself for things                               |
| 27 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Pains in lower back                                       |
| 28 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling blocked in getting things done                    |
| 29 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling lonely  |
| 30 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling blue  |
| 31 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Worrying too much about things                            |
| 32 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling no interest in things                             |
| 33 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling fearful   |
| 34 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Your feelings being easily hurt                           |
| 35 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Other people being aware of your private thoughts         |
| 36 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling others do not understand you or are unsympathetic |
| 37 | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | Feeling that people are unfriendly or dislike you         |

HOW MUCH WERE YOU DISTRESSED BY:

|    | NOT AT ALL | A LITTLE BIT | MODERATELY | QUITE A BIT | EXTREMELY |   |
|----|------------|--------------|------------|-------------|-----------|---|
| 38 | 0          | 1            | 2          | 3           | 4         | Having to do things very slowly to insure correctness                           |
| 39 | 0          | 1            | 2          | 3           | 4         | Heart pounding or racing  |
| 40 | 0          | 1            | 2          | 3           | 4         | Nausea or upset stomach   |
| 41 | 0          | 1            | 2          | 3           | 4         | Feeling inferior to others  |
| 42 | 0          | 1            | 2          | 3           | 4         | Soreness of your muscles  |
| 43 | 0          | 1            | 2          | 3           | 4         | Feeling that you are watched or talked about by others                          |
| 44 | 0          | 1            | 2          | 3           | 4         | Trouble falling asleep  |
| 45 | 0          | 1            | 2          | 3           | 4         | Having to check and double-check what you do                                    |
| 46 | 0          | 1            | 2          | 3           | 4         | Difficulty making decisions   |
| 47 | 0          | 1            | 2          | 3           | 4         | Feeling afraid to travel on buses, subways, or trains                           |
| 48 | 0          | 1            | 2          | 3           | 4         | Trouble getting your breath   |
| 49 | 0          | 1            | 2          | 3           | 4         | Hot or cold spells  |
| 50 | 0          | 1            | 2          | 3           | 4         | Having to avoid certain things, places, or activities because they frighten you |
| 51 | 0          | 1            | 2          | 3           | 4         | Your mind going blank   |
| 52 | 0          | 1            | 2          | 3           | 4         | Numbness or tingling in parts of your body                                      |
| 53 | 0          | 1            | 2          | 3           | 4         | A lump in your throat   |
| 54 | 0          | 1            | 2          | 3           | 4         | Feeling hopeless about the future   |
| 55 | 0          | 1            | 2          | 3           | 4         | Trouble concentrating   |
| 56 | 0          | 1            | 2          | 3           | 4         | Feeling weak in parts of your body  |
| 57 | 0          | 1            | 2          | 3           | 4         | Feeling tense or keyed up   |
| 58 | 0          | 1            | 2          | 3           | 4         | Heavy feelings in your arms or legs   |
| 59 | 0          | 1            | 2          | 3           | 4         | Thoughts of death or dying  |
| 60 | 0          | 1            | 2          | 3           | 4         | Overeating  |
| 61 | 0          | 1            | 2          | 3           | 4         | Feeling uneasy when people are watching or talking about you                    |
| 62 | 0          | 1            | 2          | 3           | 4         | Having thoughts that are not your own   |
| 63 | 0          | 1            | 2          | 3           | 4         | Having urges to beat, injure, or harm someone                                   |
| 64 | 0          | 1            | 2          | 3           | 4         | Awakening in the early morning  |
| 65 | 0          | 1            | 2          | 3           | 4         | Having to repeat the same actions such as touching, counting, or washing        |
| 66 | 0          | 1            | 2          | 3           | 4         | Sleep that is restless or disturbed   |
| 67 | 0          | 1            | 2          | 3           | 4         | Having urges to break or smash things   |
| 68 | 0          | 1            | 2          | 3           | 4         | Having ideas or beliefs that others do not share                                |
| 69 | 0          | 1            | 2          | 3           | 4         | Feeling very self-conscious with others   |
| 70 | 0          | 1            | 2          | 3           | 4         | Feeling uneasy in crowds, such as shopping or at a movie                        |
| 71 | 0          | 1            | 2          | 3           | 4         | Feeling everything is an effort   |
| 72 | 0          | 1            | 2          | 3           | 4         | Spells of terror or panic   |
| 73 | 0          | 1            | 2          | 3           | 4         | Feeling uncomfortable about eating or drinking in public                        |
| 74 | 0          | 1            | 2          | 3           | 4         | Getting into frequent arguments   |
| 75 | 0          | 1            | 2          | 3           | 4         | Feeling nervous when you are left alone   |
| 76 | 0          | 1            | 2          | 3           | 4         | Others not giving you proper credit for your achievements                       |
| 77 | 0          | 1            | 2          | 3           | 4         | Feeling lonely even when you are with people                                    |
| 78 | 0          | 1            | 2          | 3           | 4         | Feeling so restless you couldn't sit still                                      |
| 79 | 0          | 1            | 2          | 3           | 4         | Feelings of worthlessness   |
| 80 | 0          | 1            | 2          | 3           | 4         | The feeling that something bad is going to happen to you                        |
| 81 | 0          | 1            | 2          | 3           | 4         | Shouting or throwing things   |
| 82 | 0          | 1            | 2          | 3           | 4         | Feeling afraid you will faint in public   |
| 83 | 0          | 1            | 2          | 3           | 4         | Feeling that people will take advantage of you if you let them                  |
| 84 | 0          | 1            | 2          | 3           | 4         | Having thoughts about sex that bother you a lot                                 |
| 85 | 0          | 1            | 2          | 3           | 4         | The idea that you should be punished for your sins                              |
| 86 | 0          | 1            | 2          | 3           | 4         | Thoughts and images of a frightening nature                                     |
| 87 | 0          | 1            | 2          | 3           | 4         | The idea that something serious is wrong with your body                         |
| 88 | 0          | 1            | 2          | 3           | 4         | Never feeling close to another person   |
| 89 | 0          | 1            | 2          | 3           | 4         | Feelings of guilt   |
| 90 | 0          | 1            | 2          | 3           | 4         | The idea that something is wrong with your mind                                 |



**Information on Children in Family with a Disability**

Child's Name: \_\_\_\_\_

Gender: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

What disability best describes your child?

\_\_\_\_\_ Developmental Delay

\_\_\_\_\_ Epilepsy

\_\_\_\_\_ Cerebral Palsy

\_\_\_\_\_ Hearing Loss

\_\_\_\_\_ Emotional Disturbance

\_\_\_\_\_ Vision Loss

\_\_\_\_\_ Autism

\_\_\_\_\_ Cognitive Impairment

\_\_\_\_\_ Asperger's Syndrome

\_\_\_\_\_ Pervasive Developmental Delay

\_\_\_\_\_ Physical Disability

\_\_\_\_\_ Down Syndrome

\_\_\_\_\_ Unknown

\_\_\_\_\_ No Confirmation of Diagnosis

\_\_\_\_\_ Other (Please Specify)

\_\_\_\_\_

**In your view:**

**To what extent will this child's disability affect his/her cognitive development?**

Not at all                  Mildly                  Moderately                  Severely                  Unknown

**To what extent will this child's disability affect his/her physical development?**

Not at all                  Mildly                  Moderately                  Severely                  Unknown

**To what extent will ongoing specialized medical attention be required?**

No need                  Some need                  Moderate Need                  Severe Need                  Unknown

**How much assistance will your child require over the years to perform everyday activities like eating, bathing and toileting?**

Very Little                  Moderate Amount                  Frequent Assistance                  Constant                  Unknown



3. Have you been given a diagnosis for your child's learning disability? Yes  No

If yes, please describe: \_\_\_\_\_

When were you given this diagnosis? \_\_\_\_\_

4. How would you describe your child's learning disability?

Mild

Moderate

Severe

5. What kind of school does your child attend? \_\_\_\_\_

6. How many years has your child been in school? \_\_\_\_\_

7. How many siblings does your child have? \_\_\_\_\_

8. What is the birth order of your child?

Youngest

Middle

Oldest