

PARENTAL STRESS, CHILD CHALLENGING BEHAVIOUR AND
RESPITE: AN EXAMINATION OF FACTORS ASSOCIATED WITH
REQUESTING, USING AND ALLOCATING RESPITE SERVICES

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Submitted in part fulfilment towards the degree of Doctorate in Clinical
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August 2005

This thesis is dedicated to the memory of my Grandma, Margaret Delworth, a truly remarkable woman and a continued source of inspiration

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Abstract

Objective: A large body of research has investigated the experience of parental stress in parents of children with learning disabilities with child challenging behaviour being the factor most strongly associated with increased parental stress (e.g. Hastings, 2003 & Quine & Pahl, 1995). The ability of respite to alleviate this stress has also been investigated with studies suggesting that the provision of respite leads to a reduction in stress, (e.g. Botuck & Winsberg, 1991, Mullins et al., 2002). Very few studies have examined the effects of respite care in a UK population and fewer still in a Scottish population. Factors associated with requesting respite have only been studied directly in one UK based study (Chadwick et al. 2002). The present study hypothesised that a correlation would be found between parental stress and child challenging behaviour and that families receiving respite care would experience lower stress than similar families who did not receive respite. In addition, it was hypothesised that families who had requested respite would have children with higher levels of challenging behaviour and would be experiencing more stress than families who had not requested respite services.

Design: A postal questionnaire based method was used to analyse differences between groups in relation to parental stress, child challenging behaviour and respite use.

Method: Seventy three parents of children with learning disabilities participated in the study. Thirty three of these were receiving respite and forty were not. Parents completed four questionnaires relating to: parental stress, child challenging behaviour, respite use and demographic information.

Results: A significant correlation was found between parental stress and child challenging behaviour. In addition, significant differences were found in parental stress and challenging behaviour between those receiving and not receiving respite. Those receiving respite experienced higher levels of stress and had children with higher levels of challenging behaviour. Further analysis revealed that those who had requested respite experienced higher levels of stress and had children who had higher levels of challenging behaviour than those who had not requested respite. Descriptive analysis provided information about the use of respite services in Lothian. The results are discussed in relation to previous research and the clinical implications of the current study. Methodological strengths and difficulties are also discussed and suggestions made for future research.

Chapter 1: INTRODUCTION

1.1. Section 1: Parenting Stress in the General Population

1.1.1. A unique type of stress

The concept of parenting stress, i.e. stress associated with being a parent, has been studied in both general and clinical populations by a number of researchers. Levels of reported parenting stress vary considerably but all parents are thought to experience some degree of parenting stress, (Crnic & Greenberg, 1990). Researchers have sought to explain why it should be that some parents experience extremely high levels of stress and others report very low levels. Models have been proposed to explain this unique type of stress and the relationship between the level of stress and proposed factors which both contribute to it and serve to protect against it. These models are often based on general stress and coping models (e.g. Lazarus, 1999) whereby parenting stress can be thought of as: an external causal event or agent, a cognitive appraisal of the event, coping mechanisms to reduce the negative effects of this event and finally, the effects on the mind and body, i.e. the stress reaction. The presence or absence of a number of environmental, interpersonal and psychological factors are thought to contribute to the experience of parenting stress and the relative influence of these factors is the focus of many studies. Studying the experience of parenting stress is of interest as parenting stress influences parenting behaviour, (Webster-Stratton, 1990), which can in turn lead to dysfunctional family systems and problems with both parent and child mental health. Finding the contributing factors may allow for interventions which can reduce this stress. This is important not only for the psychological health of the parent but also for that of the child. There are potential benefits for the child if parenting stress can be reduced as lower levels may improve

the effectiveness of interventions which are targeting behaviour problems in the child, (Kazdin, 1995).

1.1.2. Factors Associated with Parenting Stress

Various environmental, interpersonal, parent factors and child factors have been studied in relation to parenting stress and the relative influence of these factors is the focus of many studies. The literature relating to the most widely researched factors is outlined below.

1.1.3. Environmental Factors

1.1.3.1 Hassles & Life Events

Crnic & Greenberg (1990) have identified that both negative life events and daily hassles associated with parenting contribute to the experience of parenting stress; with daily hassles being more predictive of level of stress than life events. Their influence has also been found by other researchers, (Deater-Deckard & Scarr, 1996; Krech & Johnston, 1992). Daily hassles have been defined as those low level, but high frequency, tasks and events which occur in the course of everyday life, and are known as caretaking hassles in some areas of the literature. It is proposed that while each individual hassle is unlikely to have an effect on parenting stress, their cumulative effect can be considerable and can have a negative impact on the quality of parenting.

1.1.3.2 Socio-economic Factors

Poverty, unemployment and deprivation have all been studied as ways of highlighting the effect of socio-economic factors on parenting stress. These negative factors pose additional stresses for parents on top of the daily hassles and uncontrollable life events

mentioned above and will reduce parental resources leading to increased stress. Webster-Stratton (1990) found links between negative life events and low socio-economic status suggesting that those of lower socio-economic status are more likely to experience negative life events than those of higher socio-economic status. Given the research discussed in the previous section on the impact of negative life events on parental stress, and Webster-Stratton's findings, it seems reasonable to assume that families of lower-socio economic status are more likely to experience high levels of stress.

1.1.4 Parent Factors

Several studies have looked at the effect of parental mental health on parenting stress but it is not possible to be conclusive in terms of the direction of causality. It may be that parenting stress leads to poor mental health but conversely, it is possible that poor mental health results in parents experiencing a higher level of parenting stress. The main mental health difficulty which has been researched is maternal depression and there would appear to be an association between depression and increased parenting stress, (Abidin, 1986). There would also appear to be association between maternal depression and increased negative life events, (Webster-Stratton, 1990). Given that depression often leads to social withdrawal, it is also likely that parents who are depressed are more likely to have less social support than those who are not and, as will be discussed, social support is thought to have a high level of influence on parenting stress. Belsky (1984) proposes that parental psychological factors are of greatest importance in mediating parenting stress because they will influence the quality and quantity of other sources of social and interpersonal support.

1.1.5. Interpersonal factors

1.1.5.1 Marital Status

As well as being a major life event, divorce or separation generally leads to a reduction in the resources available for parenting. The parent who retains the majority of child care may find they face socio-economic hardships or may have to reduce the amount of time available for child care as a result of having to seek work outside the home. As well as this, the impact of separation on children may result in more externalising behaviour which may in turn increase parenting stress. Forgatch, Patterson, & Skinner (1988) found that recently separated mothers reported an increased level of both daily hassles and life events which, thus increasing the likelihood of parenting stress.

1.1.5.2. Social Support

Availability of social support has been proposed as a factor associated with parenting stress (Crnic & Greenberg, 1990; Östberg & Hagekull, 2000). Again, causality is hard to establish i.e. does a lack of social support result in increased levels of stress or does the presence of social support protect against the effects of other factors that may be contributing to the experience of parenting stress? Findings have varied with some reporting a combination of both direct and protective effects, (Sheldon Cohen & Wills, 1985).

1.1.6. Child factors

Factors such as child temperament and behaviour problems have been identified as contributing to parenting stress, (Bates, 1980). It has been suggested that as child temperament and behaviour are usually measured using parent report or parent

completed questionnaires that this may not be an accurate measure of actual child characteristics since it relies on parental interpretation of the child's behaviour. Whilst this may be the case, and factors such as increased parental stress may lead to an over reporting of difficulties, it remains that a parent who perceives their child as difficult would be more likely to experience greater levels of stress associated with those perceived difficulties than a parent who perceives their child as less difficult, (Krech & Johnston, 1992). Whilst it is possible that taking direct measures of certain child characteristics such as time of waking or time spent sleeping or feeding (Östberg & Hagekull, 2000) may give a more objective measure of child behaviour it still does not allow for individual parent interpretation of, and tolerance to, such behaviours. Belsky (1984) suggest that in an otherwise healthy family system, (i.e. where parents have adequate social support, no personal psychological difficulties and adequate material/financial resources), having a child with a difficult temperament is not in itself sufficient to lead to detrimental levels of parenting stress.

1.1.7. Parenting Stress Specific Models

A study by Östberg & Hagekull, (2000) proposed and tested a multidimensional model of parenting stress which endeavoured to explain the contribution of a number of factors to the experience of parental stress. Their model included the factors outlined above plus a number of demographic factors such as maternal age, education level and level of domestic workload. Some factors were proposed to have a direct effect on parenting stress whereas others were mediated by one or more other factors. Their final model found a direct or indirect effect of all the factors they had identified from the literature with the exception of maternal age and accounted for 48% of variance. Their model predicted that mothers who were older and had high levels of

stress variables (e.g. daily hassles & life events) and low levels of protective variables (e.g. social support) experienced greater stress than mothers with fewer stress variables and more protective variables.

Belsky (1984) proposes a model which illustrates the relative importance of 3 subsystems, in the experience of parental stress and as such parental functioning.

These 3 subsystems are:

- 1) parental personality and psychological well-being
- 2) contextual subsystems of support
- 3) child characteristics

Whilst acknowledging that the experience of stress and the availability of resources is a matter of degree, Belsky proposes a model (see figure 1) which predicts the level of parental functioning when each of the subsystems is either supportive or stressful. This model suggests that different combinations of supportive and stressful subsystems will have different effects on the experience of parenting stress. Difficulties in child characteristics can be mediated by the presence of supportive parental psychological well-being and contextual support. Poor parental psychological well-being and child characteristics in the presence of supportive contextual support are proposed to result in more stressful than poor contextual support and child characteristics in the presence of supportive parental psychological well-being. The worst possible outcome, in terms of stress, is understandably proposed as being a situation in which all 3 subsystems are stressful.

Figure 1: Belsky (1984) Model of Parental Stress

Relative probability of parent functioning competently	Conditions of the parental subsystems		
	Parental personality and psychological well-being	Contextual subsystems of support	Child Characteristics
Highest	+	+	+
	+	+	-
	+	-	+
	-	+	+
	+	-	-
	-	+	-
	-	-	+
Lowest	-	-	-

1.1.8. Summary

Research into parenting stress in the general population highlights a number of parent, child, environmental and interpersonal factors which contribute to the experience of parenting stress. Models which have tried to ascertain the relative contribution of these factors have found a very complex picture in which factors have both mediating and direct effects on the experience of parental stress. As might be expected, families with a high number and level of stressors and few protective/buffering factors are most at risk from stress. The following section will discuss the experience of parenting stress in families with children with learning disabilities and will attempt to relate the factors discussed above to these families.

1.2. Section 2: Parenting Stress in Families of children with Learning Disability

1.2.1. Even More Unique?

The concept of stress in families with children with illness and disability has been well researched. As with the research into stress in the general population, researchers have focussed on a number of factors which have been hypothesised to influence

stress in such families including: family composition, nature of illness or disability, age of child, degree of behavioural disturbance and many more. It is reasonable to assume that the same factors which influence parenting stress in the general population will have an impact on families of children with learning disability. However, the degree of influence of these factors may differ and there may be additional factors which are not relevant to the general population.

The literature in this area will be reviewed in order to try to identify and clarify the factors which contribute to parenting stress in these families and the models which try to explain their impact.

1.2.2. Child Factors

Perhaps the most obvious difference between families of children with a learning disability and families of non-disabled children is the child themselves. Child age, gender of the child, self-care needs, levels of learning disability, the presence of a specific diagnosed disorder and the presence or absence of behavioural problems, have all been examined as possible factors contributed to the variation in stress amongst families of children with learning disabilities. The research into each of these factors will be discussed in terms of the evidence for the relative contribution of each of these factors to the experience of parental stress.

1.2.2.1 Child age

Several studies have looked at the age of the child as a variable when examining parental stress. Some studies have also looked at life stage, which usually has a correlation with age, e.g. starting school, moving to adult services. Most studies have

failed to find a direct link between age of child and parental stress, (Beckman, 1983; Boyce, Behl, Mortensen, & Akers, 1991; Bradshaw & Lawton, 1978; Emerson, Robertson, & Wood, 2004; Flynt & Wood, 1989; Hodapp, Dykens, & Masino, 1997). Other have appeared to find a link, but it may not be the age of the child which is specifically related to parental stress but rather the relationship between child age and other factors, (Floyd & Gallagher, 1997). Such factors include age of symptom onset (Gray & Holden, 1992), issues associated with specific life stages, (Baxter, Cummins, & Yioltis, 2000) and increased behaviour problems, (Stores, Stores, Fellows, & Buckley, 1998).

From the literature, it would appear that there is little evidence for a direct effect of child age on parental stress if all other factors are controlled for. There does however seem to be a link between child age and other factors which may contribute to parental stress, e.g. level of child behaviour difficulties.

1.2.2.2 Child Gender

As with child age, many studies have included the gender of the child with a learning disability in their analysis in order to ascertain any effect that this might have on parental stress. Again, no effect of child gender has been found, (Beckman, 1983; Boyce *et al.*, 1991; Emerson *et al.*, 2004). Some studies have found links between gender and other factors including levels of specific behaviours, (Stores *et al.*, 1998).

The impact of child behaviour difficulties will be discussed below but it would appear that, rather than a direct effect of child gender on parental stress, there may be a tendency for certain behavioural characteristics to be more likely to be associated with one gender as opposed to the other. This may also be the case in terms of specific

diagnosed disorders, (which will also be discussed below), as some disorders with a genetic component may have specific behavioural phenotypes and may be more likely to occur in one gender as opposed to the other.

Gender therefore, seems to be a factor which, like age, is related to other aspects of the child which in turn influence the experience of parental stress.

1.2.2.3 *Level of Care*

The amount of time and level of care some children with learning disabilities require has been identified by some researchers as contributing to parental stress, (Beckman, 1983; Floyd & Gallagher, 1997; Sloper, Knussen, Turner, & Cunningham, 1991; Tomanik, Harris, & Hawkins, 2004). These findings would appear to make sense in relation to the data from the general population which points to the impact of daily hassles on parenting stress. Some of the items identified by Crnic & Greenberg, (1990) in their Parenting Daily Hassles Scale include items relating to care needs which might occur at a higher frequency for parents of children with learning disabilities, (e.g. difficult mealtimes, changing clothing several times a day).

1.2.2.4 *Level of Learning Disability*

Some researchers have hypothesised that the degree of intellectual impairment of a child with learning disabilities may have an influence on parental stress. Some have used IQ measures as an indicator of level of intellectual disability and others have used the category of special educational need as identified by the education system. Some researchers have reported a link between level of intellectual disability and parental stress, (Boyce et al., 1991; Emerson et al., 2004; Hodapp et al., 1997). This

relationship between parental stress and level of learning disability appears to be independent of the presence of behaviour problems, (Floyd & Gallagher, 1997).

Children with increased levels of intellectual disability may contribute to increased parenting stress by having higher associated levels of care needs or behaviour problems and it may be these factors rather than level of intellectual ability per se which is contributing to parental stress. For this reason, it seems that it is possible, but by no means certain, that level of intellectual ability has an effect on parental stress.

1.2.2.5. Communication

Only a few studies have looked specifically at the child's ability to communicate when considering parental stress. Tomanik et al, (2004) found the child's ability to communicate or interact with others had an impact on parental stress with poorer levels of communication being associated with increased stress. They did not however find any link between the child's use of inappropriate speech and parental stress. Frey, Greenberg, & Fewell, (1989) included communication skill in their analysis and found that parents reported more stress if their child's communication skill was relatively low.

1.2.2.6. Specific Diagnoses

Some researchers have investigated the differences in parental stress in families where the child has a specific diagnosed disorder and compared these families to others whose children have a learning disability but no specific disorder. Higher levels of stress have been found in families of children with Prader-Willi Syndrome (Hodapp et

al., 1997) and Smith-Magenis Syndrome (Hodapp, Fidler, & Smith, 1998). Lower levels of stress have been found in families with Down's Syndrome when compared to families of children with learning disabilities but not Down's Syndrome, (Stores et al., 1998). These studies have all identified differences in the behavioural profiles of the children with specific diagnoses with point to a link between behaviour problems and parental stress rather than a direct link between specific diagnoses and parental stress.

Other researchers have compared learning disabled children with a specific diagnosis to children with a diagnosis of chronic illness who are not learning disabled. These studies have also pointed to the link with maladaptive behaviour with the chronically ill children showing lower levels of behaviour difficulties and their families consequently showing lower levels of stress, (Bouma & Schweitzer, 1990; Floyd & Gallagher, 1997; von Gontard *et al.*, 2002).

The presence of specific diagnoses also seems to be related to parental stress via the presence of other factors, namely maladaptive or difficult behaviour. Some diagnoses seem to be associated with increased levels of behaviour difficulties and it seems to be these which lead to differences in parental stress rather than the diagnosis per se.

1.2.2.7. Behaviour Problems

As has been seen above, many of the child factors which have been examined by researchers appear not to have a direct effect on parenting stress but are often associated with the child's level of behavioural problems. An examination of the literature points to behaviour problems, (or maladaptive behaviour), as being the child

factor that best predicts parenting stress. A number of measures have been used and comparisons made both within the learning disabled population, with the chronically ill population, with non-learning disabled children with behaviour problems and with the general population. Most studies have looked at specific aspects of problem behaviour as well as at global behaviour problem scores and have found a number of key factors.

Increased overall levels of disruptive, challenging or maladaptive behaviour have been found to be correlated with increased parental stress by a number of researchers, (Baker et al., 2003; Floyd & Gallagher, 1997; R.P Hastings, 2003; Hodapp et al., 1997; Hodapp et al., 1998; Quine & Pahl, 1985, 1991; Ricci & Hodapp, 2003; Stores et al., 1998; Tomanik et al., 2004; von Gontard et al., 2002). These studies and others have also looked at the subscales of their behaviour measures to identify specific types of behaviour difficulty which relate to parental stress. Those found to have an effect on parental stress include: decreased social responsiveness/“autistic aloofness”, (Beckman, 1983; Emerson *et al.*, 2004; Hodapp *et al.*, 1998; Tomanik *et al.*, 2004), increased repetitive behaviour, (Beckman, 1983), abnormal levels of activity, (Bradshaw & Lawton, 1978; Tomanik *et al.*, 2004), irritability (Tomanik *et al.*, 2004) and sleep problems, (Hodapp *et al.*, 1998; Quine & Pahl, 1985, 1991). Since children may experience more than one of these difficulties and to greater or lesser degrees, this may account for some of the variations in the levels of parental stress found in various studies.

Comparisons with non-learning disabled children with and without behaviour problems highlight that it is the presence of behaviour problems, rather than the

presence of a learning disability per se that causes increases in parental stress, (Donenberg & Baker, 1993; Floyd & Gallagher, 1997).

The number of studies that have found a link either between global or specific behaviour problems and parental stress seems unequivocal. This can be related back to the literature in the general population on daily hassles. The majority of the hassles identified by Crnic & Greenberg, (1990) relate to child behaviour and the need for the parent to respond to such behaviour. As children with a learning disability have been found to have higher levels of such behaviours it seems reasonable that parents of children with learning disabilities who have such behaviour are at greater risk of experiencing increased levels of parental stress.

1.2.2.8. Summary

Of all the child factors examined by researchers the one with most evidence to suggest its impact on parenting stress would appear to be difficult/challenging/maladaptive behaviour. Other factors such as age, gender, level of care, level of learning disability, communication problems and specific diagnosis may play a part but the evidence seems to point to a link between these factors and difficult behaviour in most cases.

1.2.3. Environmental Factors

1.2.3.1. Hassles & Life Events

As has been seen above, parents of children with learning disabilities are at greater risk of experiencing an increased number and frequency of daily hassles as a result of the behaviour difficulties often seen in children with learning disabilities. What is not

clear from the research is whether or not the attribution of such hassles, as a problem or not, differs for parents of children with a learning disability. For the parents of typically-developing children, such hassles may be seen as a greater problem than for parents of children with a learning disability. It may be that some parents of children with learning disabilities see such hassles as part of the daily routine of caring for a child with learning disabilities and as such do not find them so distressing. In terms of life events, Boyce et al., (1991) found an impact on the parental stress on parents of children with learning disability suggesting that they do not differ from the parents of non-learning disabled children in this regard. In fact, it may well be the case that some families of children with learning disabilities experience a higher number of life events since things such as the child being hospitalised for a serious illness may be more likely to occur than in the families of non-learning disabled children.

1.2.3.2. *Socio-economic Factors*

Only a few studies have looked at the socio-economic situation of families of children with learning disabilities. Using data from the 1999 Office for National Statistics survey, (Emerson, 2003) found that families of children with learning disabilities were significantly economically disadvantaged when compared to those who did not have a child with learning disabilities in all of the indicators of socio-economic disadvantage including living in deprived neighbourhoods, living in poverty and living in council accommodation. In the same study, Emerson identified poverty and being in receipt of means tested welfare benefits as being factors which were associated with maternal stress. Bradshaw & Lawton, (1978) also found a trend towards increased parenting stress for families of children with a learning disability who were of lower social class. Boyce et al, (1991) found that higher levels of income were associated with

lower levels of parental stress and Quine & Pahl, (1991) found that lower social class, lower income and financial worries were associated with higher levels of maternal stress. Olsson & Hwang, (2003) looked at the financial strain of having a child with a learning disability in a Swedish sample. They did not find any difference between the learning disabled group and the non-learning disabled group but this is likely to reflect differences in social structure and policy in Sweden.

It would appear that not only do families of children with learning disabilities experience the same increased levels of stress in the presence of socio-economic problems but that they are also significantly more likely to experience such problems than families of children without learning disabilities.

1.2.3.3. Summary

There would appear to be evidence for an effect of the environmental factors discussed above on parental stress. Families of children with learning disabilities appear to be more likely to experience a higher frequency of daily hassles and life events and to be at greater risk of poverty. The general population literature has identified these factors as important in the experience of parental stress.

1.2.4. Parental Factors

1.2.4.1. Mental Health

Several studies have looked at the effects of poor parental mental health on reported levels of parental stress. As with the literature on parental stress in the general population, the difficulty with this area of the literature is one of causality; do parental mental health difficulties result in increased stress or vice versa?

Evidence of a relationship between mental health problems and parental stress in parents of children with learning disabilities, has been found by some researchers (Glidden & Schoolcraft, 2003; R.P Hastings, 2003). Factors which were found to be associated with or predictive of mental health problems included: the mental health of the child's father, (R.P Hastings, 2003) and the presence of the personality characteristic neuroticism, (Glidden & Schoolcraft, 2003).

The nature of the child's disability also seems to be a factor with Olsson & Hwang, (2001) finding higher levels of depression in mothers of children with autism than in mothers of children with learning disabilities but not autism although this study did not look at the link between mental health problems and parental stress.

1.2.4.2. Education Level

A few studies have investigated the effect of parental level of education on the experience of parenting stress and found that educated parents experience less stress than those with fewer years of education or qualifications, (Boyce et al., 1991; Ricci & Hodapp, 2003). However, this did not appear to be the case for fathers of children with Down's syndrome where level of education had no effect on fathers' experience of stress, (Ricci & Hodapp, 2003).

1.2.4.3. Maternal Age

Very few studies have included the age of the mother in their analysis and none of the studies which have included fathers have done this. Boyce et al, (1991) and Flynt & Wood, (1989) found that older mothers experienced less stress than younger mothers,

whereas Bradshaw & Lawson, (1978) found no effect of maternal age. Since studies which have included maternal age in their analysis are so few, it is not possible to draw conclusions about the effect of maternal age on the experience of stress.

1.2.4.4. Summary

Whilst it is hard to be conclusive about the direction of causality between parental stress and other parental mental health problems, it would appear that parental level of education are important in the experience of parental stress. It may be that more educated parents are more confident and more able to both source information and to use this information to alleviate their own stress. They may also be better able to confidently deal with the myriad of professionals and services associated with their child.

1.2.5. Interpersonal Factors

1.2.5.1. Marital Status

Some studies have found lower levels of stress in 2-parent families or in families with more adults living in the family home, (Beckman, 1983; Boyce *et al.*, 1991). Other studies did not find any difference in stress levels between 1 and 2 parent families once other variables were controlled for (Boyce, Miller, White, & Godfrey, 1995), but did find that single parent families made more use of services, (Floyd & Gallagher, 1997). It is therefore possible that single parent families who are not able, for whatever reason, to access services might experience higher levels of stress. There does not seem to be any evidence that children with learning disabilities are more likely to live in single parent families than typically developing children, (Emerson, 2003).

As with the general population, single parents may find that increased demands on their time, in terms of child care, make it being difficult for them to work outside the home and thus may result in socio-economic problems, which, as already noted, have been found to be associated with higher levels of parenting stress.

1.2.5.2. *Social Support*

As in the general population, the direction of causality between parental stress and social support is unclear, i.e. are families less stressed due to higher levels of social support or are families who are less stressed more able to seek out support from family, friends and professionals? The studies which have investigated social support vary as to whether they have looked at family support, friendship support, professional support or a mixture of one or more of these. Some studies do not clearly distinguish between the different types of support.

Duvdevany & Abboud, (2003) found that higher levels of informal social supports were associated with increased levels of well-being in mothers. Similar results were also found by Hassall, Rose, & McDonald, (2005) and Frey et al., (1989) although Hassal et al, (2005) noted that it was likely that it was not the range or number of supporters which was helpful, but rather the perceived effectiveness of this support.

Hodapp et al, (1997) found no link between the levels of child maladaptive behaviour and levels of support families received, or between the level of support and the experience of parental stress in families of children with Prader-Willi Syndrome. However, Hodapp et al, (1998) found that the number of friends identified by families

of children with Smith-Magenis Syndrome accounted for the greatest amount of variation in stress, with those with most friends experiencing the lowest levels of stress. Boyce et al, (1991) also found no effect of family based support on parenting stress.

The effects of social support on parental stress are difficult to untangle as the quantity, quality and source of support varies between studies and the direction of causality is unclear. The effect of a specific support service, respite care, will be examined in a later section.

1.2.6. Coping Styles & Strategies

A number of studies have looked at different parental coping styles as mediators of parental stress, (e.g. Kazak & Marvin, 1984). Some studies have compared problem-focused and emotion-focused coping strategies and evaluated both the relative effectiveness of these two strategies, and also whether parents alternate between them. Kim, Greenberg, Seltzer, & Krauss, (2003) found that an increase in the use of emotion-focused strategies over time led to an increase in stress in mothers. They also found that an increase in the use of problem-focussed strategies led to decreased stress and improvements in their relationships with their child. Hassall et al, (2005) found that parents with a more internal locus of control tended to experience lower levels of stress than those with a more external locus of control.

Studies have found considerable variation in the levels of stress experienced by parents both within and between studies, and even those which have used regression analysis have failed to find one or more factors which explain a large proportion of the variance in parental stress.

Quine & Pahl, (1991) used Folkman, Schaefer, & Lazarus' (1979) transactional model to investigate the experience of stress in mothers of children with learning disabilities. This model proposes that stress is experienced when an individual evaluates that there is a discrepancy between their available resources and the resources required to cope with the situation, i.e. their definition of the situation and their resources. Quine & Pahl found that mothers who had a positive adjustment to and acceptance of their child had lower stress scores and suggested that mother's with more available resources, (personal, social and financial), may be better able to come to such positive appraisals of their child due to the fact that they are less likely to perceive a deficit between what is required and what is available.

Tunali & Power, (1993) used the theory of innate needs as a framework, and mapped on some of the hardships of families with a disabled child which they identified from literature. From here they proposed that a possible reason for stress in families of children with disabilities is the threat to these innate needs being met. They hypothesised that in an inescapable but needs threatening situation, (such as the birth of a disabled child), an individual may redefine what constitutes the fulfilment of a particular need and develop alternative means of achieving it. They proposed that if some families were successful in this strategy, it may explain why they exhibit much lower levels of stress than might be expected. This theory of redefinition is a potential way of explaining the differences in parental stress that seem to remain unexplained by other studies.

Saloviita, Itälina, & Leinonen, (2003) used the Double ABCX model in order to study the variables which contributed to parenting stress in both mothers and fathers

of children with learning disabilities. In the Double ABCX Model, stressors, mediating variables, attributed meaning and adaptation both during and following the crisis situation interact to produce the experience of stress. Adaptation is viewed as a continuum with maladaptation being seen as a continued imbalance in family functioning. In this model, coping is seen as an attempt to restore balance in family functioning. Similar to Quine & Pahl, (1991) and Tunali & Power, (1993), this model proposes that redefinition of the situation, (i.e. having a child with a learning disability), was the factor which explained the greatest amount of variance in parental stress.

Overall, parental coping strategies and appraisal of their situation as parents of a child with a learning disability seem to be of importance in their experience of stress. Many of the other factors discussed above, (e.g. parental age, socio-economic status, and social support) may influence the parents coping style or ability to positively appraise their situation.

1.3. **Section 3: Respite**

This section will focus on descriptions and definitions of respite services which have been reported in the literature. The benefits of respite will be discussed in the next section but, as has been discussed in the previous section, parents of children with learning disabilities are vulnerable to experiencing stress due to the increased demands of caring for a child with a learning disability. One proposed solution to relieving some of the pressures on these families is the provision of respite care.

1.3.1 What is Respite?

Respite has been defined by the Social Services Inspectorate as “an arrangement whereby children or adults who are normally dependent on regular carers for at least some aspect of their personal care and support, are provided with a break from their primary carer for a short period. This may include residential, domiciliary and home supported assistance” (quoted from Robinson, (1994)).

In their Regulations and Guidelines for The Children (Scotland) Act (1995) the Scottish Office (1997) describe the various options for respite as“...provision within the child's home, daytime care, occasional overnight stays and regular periods of care with an approved family or foster carer, or in a residential home and shared care arrangements with foster or other family carers” (p42).

During the 1950s, 1960s and 1970s, when many people with learning disabilities lived in long stay hospitals, respite provision for those who were living in the community was usually provided by these long stay hospitals. However, their gradual closure from the 1970s onwards led to a decrease in respite services at the very time that more people with learning disabilities were starting to remain with their families (Robinson, 1994).

There is a move in the literature and in communities to move away from the term “Respite” towards “Short Breaks” as this further accentuates the break being of benefit to both the person with disabilities and their carers, (SCARE, 2004), as opposed to the traditional notion of the break being purely for the carer. It has been decided to use the term “Respite” throughout this document as that is the terminology used in The Children (Scotland) Act (1995) and it is a term with which parents in Lothian are familiar.

When looking at different types of respite, Salisbury (1986) describes respite as being sub-divided into 2 types: Primary Respite, i.e. services which are specifically to provide relief to caregivers, and Secondary Respite, i.e. services which have another main function but which also serve to provide carers with a break, e.g. educational placements. The respite services discussed in this and later sections will be primary respite where the main purpose of the service is to provide a break to both carers and children with learning disabilities.

1.3.1.1. *Respite in Scotland*

Respite in Scotland is provided under The Children (Scotland) Act (1995), (Regulations and Guidance: Vol. 1. Scottish Office, 1997.) The Same as You? report from the Scottish Executive highlights both the inequity of availability of short break services across Scotland and the difficulty in quantifying this short fall (Scottish Executive, 2000). There do not appear to be any major reviews of services across Scotland, although a Scottish Executive report (Wilson, Hall, Rankin, Davidson, & Schad, 2003) reviewed Sitter services across Scotland. They found a variety of different services catering for a variety of different children and provided by a number of providers. Taken together with the findings from The Same as You? report it seems likely that a similar pattern exists for other respite services in Scotland. In a survey of family-based respite services throughout the UK, Orlik, Robinson, & Russell (1991) found that 9/12 Scottish councils provided a family based scheme, the exceptions being Shetland, Orkney & the Western Isles.

1.3.1.2. Respite in Lothian

As has been seen above, the types of respite placement available vary within and between local authorities and Lothian is no different in this respect. Four separate council authorities make up Lothian, (Midlothian, East Lothian, West Lothian and City of Edinburgh), with the whole area being served by NHS Lothian. A number of different services exist including: Share the Care (where children are cared for in the family home of the carer), after school clubs and playschemes, residential respite centres (local authority & voluntary organisations), babysitting services and outreach carers who take children on outings. Some services are jointly funded by all 4 local authorities and the Health Board, whereas others are provided locally by each local authority. Families' access to these services is usually funded by the local authority and/or health board although the actual service may be provided by a voluntary organisation.

The Lothian Share the Care service was evaluated by Stalker (1988) who found characteristics of both the child and family which were associated with a successful placement in this scheme. These characteristics will be discussed in a later section.

1.3.1.3 Summary

Respite services comprise a range of different provisions all of which aim to provide short breaks to children with learning disabilities and their families. Within Scotland as a whole, and also within Lothian, a range of services exists but there is an overall shortfall in services with inequalities of access found across Scotland.

1.3.2. Cost of Respite Services

There are obvious financial implications for local authorities and health boards in the provision of respite services. Orlik et al., (1991), in their survey of UK family based respite schemes, found that, at the time of their study, the UK wide expenditure on family based respite care alone was £6 million. In a similar study, the mean annual per capita cost of family based short breaks for children was found to be £1767.29 a year (Prewett, 1999). Family based schemes are likely to be significantly less expensive than local authority or voluntary sector provision due to reduced staffing costs; the average staffing cost of 12 hours family based care totalled only £9.94 in Orlik et al.'s (1991) study. The lack of expenditure on premises is also a factor since family based respite takes place in the carers home. The total figure for the provision of all types of respite services is therefore likely to be much significantly higher than this.

Although not the specific focus of their study, McConkey & Adams, (2000) estimated that spending on respite services in one Health and Social Services Board in Northern Ireland, serving a total population of around 700,000, was approximately £1.59 million. The majority of this was being spent on hospital and residential unit services. These services were more expensive per person than leisure, family based or domiciliary services and yet represented the majority of the board's expenditure.

1.3.2.1. Summary

Respite services represent a significant expenditure for Health Boards and Local Authorities. The cheapest services are family based, leisure and domiciliary schemes

but these may be underused due to the majority of budgets being spent on more expensive hospital and residential unit care.

1.3.3. Proportion of Families receiving Respite

The proportion of families of children with learning disabilities receiving respite ranges from 44% - 60%, (Damiani, Rosenbaum, Swinton, & Russell, 2004; McConkey & Adams, 2000). Variations are due to whether the data gathered related to respite of any kind or to a specific service, (e.g. overnight respite).

1.3.4. Factors Restricting Access to Respite Services

A large proportion of the literature on the provision of respite services is from the USA and issues of provision vary considerably to the UK. Funding and legislation also differ in the USA so a direct comparison is neither useful nor helpful and this literature will not be discussed in detail. Despite this, there may be some issues which are relevant in both countries and this literature will be discussed where relevant.

There would appear to be a discrepancy between families' need for respite and their actual receipt of services. As will be seen, those families identified by Cutler, (1986), as most in need of services; i.e. those whose children have increased behaviour or medical problems and who are older, are the very same families who are most likely to experience difficulties when finding a service that can meet the needs of their child and family. The following section describes a range of child and parent factors which may restrict access to respite services for some families.

1.3.4.1. Child Factors

Research from both the USA and the UK suggests that the families who have greatest difficulty in obtaining respite care are those whose children have severe behavioural or medical problems, have a greater degree of learning disability, are older or have multiple disabilities, (Cutler, 1986; Intagliata, 1986; Orlik et al., 1991; Robinson, 1994; Stalker, 1988). Both the American and UK based research, suggests that home based carers are less willing to provide care for older children with more complex needs and behavioural problems, (e.g. Stalker, 1988) and these children will therefore require more specialised, and as has been discussed, costly, services.

Children with Autistic Spectrum Disorders are another group of children who can be hard to place in respite services. They may have some or all of the high level needs identified above, (such as challenging behaviour), as well as difficulties with communication and relating to both adults and other children all of which are likely to have implications for staffing, (Tarleton & Macaulay, (2002). Other factors such as tube feeding and the administration of certain medications can also make certain groups of children hard to place resulting in them being placed in very costly hospital or hospice based services, (Robinson, Jackson, & Townsley, 2001).

1.3.4.2. Parent Factors

Curran & Bongiorno (1986) writing as parents of children with learning disability, highlight a number of factors which might affect parents asking for, and consequently receiving, respite including the “super-mum syndrome” whereby parents, particularly mothers, tend to struggle on alone and have difficulty handing over aspects of their child’s care to others in fear of being seen as a lesser parent. Alongside this, they

discuss the need for parents to see themselves and their children as entitled to care. Wikler, Hanusa & Stoycheff, (1986), conducted two studies where parents were allocated with a non-negotiable number of respite hours in order to circumvent this issue. Another starker finding, which will undoubtedly affect whether parents ask for respite or not, was that 38% of families who were not receiving respite did not know that respite services even existed, (Treneman, Corkery, Dowdney, & Hammond, 1997).

These individual parent factors might affect the likelihood of a parent asking for respite and, as such, affect which families actually receive respite. In light of the finding from Same as You? (Scottish Executive, 2000) that resources in Scotland are scarce, only those families who are actually requesting services are likely to receive them.

1.3.4.3. *Other Factors*

Other factors which have been described in the literature as affecting access to respite services include: transport difficulties, (Cutler, 1986), socio-economic status, (Robinson, 1994) and staffing shortages, (Orlik et al., 1991).

1.3.4.4. *Summary*

Given that respite resources in Scotland are scarce, the factors outlined above may affect whether families are able to access services. They also have implications for the type of service a family may be allocated.

1.3.5. Allocation of Services

The specific services families are able to access also depend on the needs of the child as has been discussed above. Several studies have looked at whether these factors actually dictate which service families are offered and if any other factors are involved.

In a survey of families using respite, McConkey & Adams, (2000) used discriminant analysis to identify the factors which best distinguished between who did and did not receive particular services. Whilst some of these factors appear to identify the most suitable care for particular families, (e.g. those requiring nursing care having hospital based respite), socio-economic factors also seemed to play a role. Families on benefit were more likely to receive hospital based breaks whereas those with incomes greater than £20,000 were more likely to receive family based care and leisure breaks. The factors associated with receiving overnight respite were: no awareness of danger, longstanding emotional problems of carer and difficult behaviour.

Treneman et al. (1997) found that children who were most dependent had the greatest allocation of respite services and had the highest levels of both formal and informal support. In contrast, parents with medium dependency children were more stressed but received less respite.

Chadwick, Beecham, Piroth, Bernard, & Taylor (2002) compared the families in their study who had been allocated services with those who had requested services but had not been allocated them at the time of the study. They found that the factors which determined allocation of services were not the same factors which differentiated the families who had asked from those who had not. Instead, families receiving respite

could be distinguished by having older children, larger families and children with epilepsy rather than by increased stress, increased child behaviour problems and increased child disability, the factors which had led to them seeking respite. These differences between the factors which distinguish families need for respite and the factors which are associated with allocation have not been widely studied.

McConkey, Truesdale, & Conliffe, (2004), highlighted the difficulties of providing services to meet the needs of individual families as being due to families currently accepting whatever service they are offered due to the scarcity of services and also to the lack of a range of services in certain areas.

1.3.5.1. Summary

The allocation of particular services appears to be based, in part, on the needs of the child but there are other factors, such as socio-economic status and demographic factors, which also appear to have an effect on which services families are allocated. The scarcity of services may result in families being offered, and accepting, inappropriate services in order to receive a break of any kind whilst other families, particularly those whose children have behaviour problems will continue to find difficulties in accessing services.

1.3.6. Quantity of Respite received

Few studies have quantified the actual number of respite hours families receive. Stalker & Robinson (1994) surveyed families using a range of respite services and found that those using family based schemes received an average of 20 days per year, those using local authority residential units 37 days and those using Health Authority

units 39 days. Taken together with the finding that those with severe behavioural or medical problems are less likely to fit into in-home services (Cutler, 1986), Stalker & Robinson's findings suggest that those children receiving more days per year are likely to be those with more complex needs. This is only one study however, and other factors which have already been discussed, such as scarcity of resources may also affect the number of respite hours families receive.

1.3.7. Factors Associated with "Good" Respite

The answer to the question, "what is good respite?" is almost impossible to define since, as has been discussed above, the answer will be different for each family, depending on their needs and wants. It is not within the scope of this study to discuss the quality of respite services and their evaluation in specific detail but in order to discuss the effects of respite on parental stress, a summary of the features which have been identified by families as important is necessary.

1.3.7.1. Type of Service

Different researchers have studied family preferences for type of service with a number of different results. Robinson, (1994), found that parents preferred family based and befriending services over local authority or NHS residential services and McGill (1996) found that most parents in her study identified school holidays and after school as the times they needed most help. The value which families place on particular services appears to be influenced, not surprisingly, by the particular needs of their child and family. Families of children who were highly dependent and lacked awareness of dangers valued residential unit respite most highly whereas families of

younger children and where carers suffered from ill health valued family based schemes more highly, (McConkey & Adams, 2000).

1.3.7.2. *Amount of Respite*

The actual number of hours of respite a family require will differ among families, but even taking this into account, many do not feel they get enough support, (McConkey & Adams, 2000). In the same study, only a very small proportion of families, (9%) felt that they did not need respite of any kind. Social workers surveyed by McConkey & Adams, (2000), identified that 69% of the families on their case loads who were receiving respite would benefit from additional services.

1.3.7.3. *Flexibility*

Salisbury, (1986) suggests that unless the respite service provided is tailored to the family, then the outcomes of receiving respite will not be as good. The Same as You? report (Scottish Executive, 2000) identified more flexibility as one of the features most sought after by families. The report also made a specific recommendation in relation to flexibility: “The Scottish Executive and local authorities should review their guidance and procedures to make sure that local authorities and health boards can arrange their short break and shared care arrangements for children and adults flexibly and with as little bureaucracy as possible.” (p70)

Research from the USA & the UK also highlights the importance of flexibility of range of services, duration and frequency, (Levy & Levy, 1986; McGill, 1996; Pollock, Law, King, & Rosenbaum, 2001; Treneman et al., 1997).

1.3.7.4. Staffing

Several studies have found that one of the main concerns for parents is the level of training of the staff caring for their children, (McConkey et al., 2004; McGill, 1996; Stalker, 1988). Parents also like to be able to identify a keyworker for their child, even if this person is not always the one providing direct care, (Treneman et al., 1997). Having friendly and dedicated staff is an important factor for parents, who also have concerns when staff turnover is high, (McConkey et al., 2004).

1.3.7.5. Other Factors

Other factors identified by parents as important in a “good” respite service include: transport to the service, appropriate activities for the child and the mix of children who will be using the service at the same time, (McGill, 1996).

1.3.8. Section Summary

Respite services can take a number of forms. The availability and access to services varies considerably across Scotland and within local authorities. A number of child, parent and operational factors influence individual families’ ability to access what services are available. Families’ opinions of what represents “good” respite also vary. The following section will examine the effects of respite on families and in particular, the research into its effects on parental stress.

1.4. Section 4: Stress and Respite Care

1.4.1. Reasons for asking for respite

Given the scarcity of respite resources discussed in the previous section, it is somewhat unlikely that families will be offered respite services without first requesting them. With this in mind, a number of researchers have investigated both the reasons explicated stated by families for asking for respite and the child, family and demographic factors which distinguish families who have expressed a need for respite services from those who have not.

1.4.1.1. Stated Reasons for Requesting Respite

Stalker (1988) and Stalker & Robinson (1994) found that the reasons given by parents included: relieving the care burden, spending time with other family members, pursuing own interests and increasing the learning disabled child's social and independence skills. The Breaking Point Report (MENCAP, 2003) highlights a number of family crisis situations such as parental illness/injury and family breakdown which had to occur before families were allocated a service.

1.4.1.2. Factors associated with requesting respite

Grant & McGrath (1990) found that families who had expressed a need for minding/babysitting services differed from families who had not expressed such a service in that carers expressed increased loneliness, were younger, had a child with behaviour problems and had financial problems. Similarly, Chadwick, Beecham, Piroth, Bernard, & Taylor, (2002) found that families who had requested respite had children who were more disabled, had behaviour problems and that parents in these families were under greater stress. Those receiving respite, but who felt they needed

more, had children with greater behaviour problems, had smaller families and were experiencing more stress when compared to those who were happy with the amount of respite they received.

Factor, Perry, & Freeman (1990) identified families of autistic children who had requested respite as having children who had lower social, communication and academic skills. These families also experienced greater stress and have lower amounts of social support than families who had not requested respite. Salisbury (1990) also found that mothers who requested respite experienced higher levels of stress at the time they started receiving respite than mothers who had not requested respite. Marc & MacDonald (1988) found that the factors which distinguished those who requested a service were: having more a large family (3 or more children), having a child with a greater degree of learning disability, having a child with more behaviour problems and having more other professionals involved with the child.

Hoare, Harris, Jackson, & Kerley (1998) investigated families with severely disabled children and found that those who received respite were in fact more stressed than those who did not. In the same study, the researchers found that increased stress was associated with emotion focussed coping and low self esteem. Examination of these findings in the context of reduced availability of services discussed in the previous section would suggest that this study has identified stress as a factor which distinguishes families who request respite services from those who do not as opposed to examining the effects of the respite itself.

The Breaking Point Report published by MENCAP (2003) surveyed parents in England about their experiences of obtaining respite services. They identified that many families have to reach “breaking point” before being allocated any sort of respite care and that for some families even these “breaking point” situations are not sufficient for them to be provided with a service. Parents surveyed for the study also reported that minimal support services made little or no difference to their experience of stress.

As has been mentioned in a previous section, Quine & Pahl (1991) highlighted that parental perceptions of an imbalance between available resources and required resources are central to the experience of stress. Parents requesting respite may be seeking to redress this imbalance by requesting respite.

1.4.1.3. *Summary*

Children in families who have requested respite can be distinguished from those who have not in that they are more disabled and have more behaviour problems. Families requesting respite are likely to have more professionals involved in their child’s care. The findings in relation to family size and requests for respite are inconclusive. The carers in families requesting respite can be distinguished from those who have not requested it in that they have lower levels of social support, increased financial problems and perhaps most importantly, will be experiencing greater stress.

As was seen in the previous section, none of the above factors appear to be influential in the allocation of respite services. Given the information in the previous section about the factors which inhibit access to respite, the differences between need and allocation of services may reflect a lack of services which are able to meet the needs

of children who are more disabled and have increased behaviour problems. The presence of child behaviour problems is one of the main contributors to parental stress, so families who have requested, but not been allocated, respite may represent parents of the most challenging, hard to place children; a group most in need of services.

The finding that carers who request respite are experiencing greater stress has implications for studies which seek to examine the effects of respite by comparing families who receive respite with those who do not. If families in these studies have requested respite, but are not receiving any, are used as the control group the finding as to the benefits of respite may be misleading.

1.4.2. Positive Effects of Respite

The positive effects of respite care on parents have been investigated by a number of researchers. Although not all of the studies have looked directly at stress, other positive benefits been identified.

Some of the benefits cited have been of direct benefit to the child's main carer and include: opportunities to relax, (Botuck & Winsberg, 1991; Shirley Cohen, 1982; McConkey et al., 2004; Stalker, 1988; Stalker & Robinson, 1994), improved sleep, (Botuck & Winsberg, 1991; McConkey et al., 2004), ability to spend time at home doing nothing (McConkey et al., 2004; Stalker, 1988), and having a break from the routines of caring, (Botuck & Winsberg, 1991; McConkey et al., 2004).

Family related benefits include: improved marital relationship (Stalker, 1988; Stalker & Robinson, 1994), being able to do activities that would be difficult with the learning disabled child (Botuck & Winsberg, 1991; Joyce, Singer, & Isralowitz, 1983; Marc & MacDonald, 1988; McConkey et al., 2004; Stalker & Robinson, 1994) and being able to spend time with the rest of the family (Joyce et al., 1983; Marc & MacDonald, 1988; McConkey et al., 2004; Stalker, 1988; Stalker & Robinson, 1994),

Some studies have also reported improved relating to the child with learning disabilities (Joyce et al., 1983; Marc & MacDonald, 1988). Some of the above benefits, although not direct measures of stress, could be said to be associated with parental well-being.

Powell & Ogle, (1986) studied the need for, and effects of, respite care on the siblings of children with learning disabilities. They identified a number of functions that respite can serve for siblings including: providing time for renewing their relationships with their parents, providing time for clubs and activities, family holidays without the learning disabled sibling, keeping the family system intact and helping to maintain a positive relationship with their sibling with a learning disability.

1.4.3. Respite & Stress

Even those studies which have explicitly set out to investigate parental stress have used a number of different definitions and ways of gathering this information.

Botuck & Wisnsberg (1991) examined the effects of a 10 day over night respite service for children with severe and multiple disabilities. They found that during respite, mothers scored higher on a measure of well being and lower on depression as

well as changing their daily activities, (see above for other positive effects of respite). The improvements in well-being were still evident 3 or 4 days after the respite ended and although not significant, depression was also lower than prior to respite. However, there was no longer term follow up of the outcomes for these families. Similarly, Mullins, Aniol, Boyd, Page, & Chaney (2002) found that reductions in stress found during respite were still found immediately after respite but this study included a longer term follow up which showed that stress levels had returned to pre-respite levels six months after respite.

Joyce et al. (1983) & Marc & MacDonald (1988) highlighted a number of positive outcomes of respite, some of which have been listed above. They also found that 68%-83% of parents reported feeling less stressed since receiving respite services although they did not use a standardised measure to assess this.

Singer, Irvine, Irvine, Hawkins, & Cooley (1989) demonstrated reduction in levels of depression and anxiety in their experimental group who received respite together with an intensive intervention package consisting of stress management, parenting skills, support groups and additional community respite. Contrary to other studies mentioned here, these gains were maintained at one year follow up. Similar gains were not seen in their control group who received standard respite and case management.

Weiss (1991) identified finding skilled and reliable respite services as being a stressor in families of children with pervasive developmental disorder, (PDD) indicating that the experience of receiving respite may be preceded by a period of increased stress.

Neufeld, Query, & Drummond (2001) looked at the relationship between receiving respite and carers feelings that they were actually getting a break and found that many did not feel that this was the case. They highlighted reasons such as lack of qualified staff, the inflexibility of the timing of respite and the lack of respite during school holiday times as key reasons why they did not feel they were benefiting.

Even those parents using a respite service still expressed some of the same reluctance to use services as parents who had not asked for services, (see previous section). Concerns of putting the burden of care onto strangers, worries about being seen to reject their child, guilt and being judged as unable to cope were all identified by families using the Lothian "Share the Care" scheme, (Stalker, 1988). It may be that in a similar way to the families in the Neufeld et al. (2001) study, these reluctances may have an impact of the benefits parents are able to get from respite care in terms of stress reduction

1.4.3.1. *Summary*

Studies have found links between respite and reduced psychological distress, although the variety of measures used make direct comparisons difficult. However, regardless of the methods used, it would appear that respite is able to reduce parental stress both as measured by standardised instruments and by parental report. Some studies have looked at the long term gains of a single period of respite and found that the effects are not long lasting. However, none of the studies has looked at the long term effects of regular, scheduled respite. These findings have clinical implications for the provision of services to families of children with special needs as they suggest that single episodes of basic respite alone will not be sufficient to reduce psychological

distress in the long term. The Singer et al. (1989) study suggests that in order to see long term benefits the provision of additional services is necessary. Flexibility and access to respite care also need to be addressed so as not to add an additional stressor to already stressed families.

1.4.4. Are some types of respite better more beneficial than others?

McConkey & Adams (2000) found that home-based care in particular was viewed by families and social workers as being beneficial to both the family and the child with a learning disability. They also found that hospital based care was only thought to be beneficial in 50% of cases. Mullins et al. (2002) compared 30 day hospital stays with 3-7 days respite in a respite centre. They found that there was no difference in the level of stress reduction between these two breaks despite the difference in duration. It may be that the benefits from respite care are found after a few nights and that further nights do not add any further benefit.

The findings of Singer et al. (1989) that an intensive intervention package including stress management, parenting skills, support groups and additional community based respite led to long term gains has clinical implications as discussed above. Although both the control and the experimental groups in their study were satisfied with the service they received only the experimental group showed a reduction on measures of distress showing that this package was more beneficial.

1.4.5. Section Summary

Factors associated with requesting respite have been identified from the literature but have not been found to be the same factors, identified in the previous section, by

which respite services are allocated. Families coming into respite services are likely to be under great stress, (since stress was one of the factors associated with requesting respite), and families who have requested, but have not yet been allocated, respite may be under even greater stress. Single episodes of respite do not seem to be sufficient to bring about long term improvements in parental stress which is perhaps not surprising given that parents are often extremely stressed before even requesting services. More intensive, regular, multi-faceted packages involving stress management and coping strategies seem to be necessary to bring about long term improvements.

1.5. Section 5: Thesis Rationale

It would appear that there is a gap in the literature in terms of investigating the relationship between challenging behaviour, parental stress and scheduled respite. Previous experimental studies have often looked at single episode respite care, (which is not the usual model of service delivery) and have often failed to highlight the contribution of challenging behaviour to parental stress. There are a limited number of studies which have investigated a UK population in relation to the effects of respite on parental stress and as the model of service delivery in the USA appears to differ to that in the UK, it is necessary to investigate a UK, and more specifically a Scottish, population.

The reduction of parental stress is of clinical relevance to psychology as high levels of parental stress have been found to be associated with poor mental health and increased behaviour problems in children. As has been discussed previously, the direction of

this relationship is not clear but is likely to be bi-directional. Ascertaining the association between challenging behaviour to parental stress and the effects of respite on the reduction of this stress will allow clinical psychologists to better target their interventions, perhaps in conjunction with respite providers using a model similar to that proposed by Singer, Irvine, Irvine, Hawkins, & Cooley, (1989).

The present study will differ from previous research as it will use well researched and standardised measures of both challenging behaviour and parental stress. This will allow the research to be replicated in future and will also allow comparisons with other populations.

1.5.1. Limitations of Previous Studies

As has already been stated, many of the previous studies have failed to use a standardised measure for gathering information about parental stress. Other studies have used a variety of measures of parental mental health problems and general psychological well-being as opposed to measuring stress itself. Some of the studies which have used a measure of parental stress have used one which is not specifically designed for the parents of children with disabilities. As was discussed in section 2 there are factors relevant to the experience of stress in families of children with learning disabilities which are not relevant to the general population, (e.g. challenging behaviour, level of dependency and communication difficulties).

Studies which have included challenging behaviour in their studies of the effects of respite on parental stress have used a variety of measures to assess this; some standardised and some not. The use of a standardised measure, again specifically



designed for individuals with learning disabilities, not only ensures an accurate measure of the sorts of behaviour difficulties specific to those with learning disabilities but it also allows for the levels of challenging behaviour in the studied population to be compared with the levels of those in previous and future studies.

Only one UK based study (Chadwick et al., 2002) has specifically set out to compare families who have asked for respite with those who have not. Two other studies have also looked at this during the course of their study, (Grant & McGrath, 1990; Hoare et al., 1998) but this was not the specific focus. As has been highlighted in section 3 respite services in Scotland are in short supply so it seems likely that there will be a significant number of families who have requested respite services but are not currently receiving any. This group are equally, if not more important, than the group receiving respites since, as has been pointed out by Chadwick, Beecham, Piroth, Bernard, & Taylor (2002), they are families who are likely to be experiencing increased stress, increased behaviour problems and be coping with a more disabled child. This group is of clinical interest as they are almost certainly a group who are in need of psychological input, particularly if they are likely to face a long wait for respite services.

1.6. Section 6: Aims & Hypotheses

1.6.1. Aims

The main aim of this study was to provide an account of the occurrence of challenging behaviour and parental stress and their relationship to respite care in families of children with learning disabilities. A secondary aim was to investigate the factors

associated with requesting respite care and to investigate the factors which differentiated the families who received such care from those who did not. Finally, the study aimed to investigate the effects of satisfaction with respite services on parental stress for those families receiving respite.

1.6.2. Hypotheses

1. **There will be a correlation between the presence of challenging behaviour and increased parental stress in all parents surveyed.** This is based on findings from a number of previous studies, (Floyd & Gallagher, 1997; R.P Hastings, 2003; Hodapp et al., 1997; Hodapp et al., 1998; Quine & Pahl, 1985, 1991; Ricci & Hodapp, 2003; Stores et al., 1998; Tomanik et al., 2004; von Gontard et al., 2002).
2. **Parents who receive respite will experience less stress than parents of children with similar levels of challenging behaviour who do not receive respite.** According to the literature on parental stress and respite, parental stress has been found to be reduced in families receiving respite, (Botuck & Winsberg, 1991; Joyce et al., 1983; Marc & MacDonald, 1988; Mullins et al., 2002). Since child challenging behaviour is thought to be one of the largest contributors to parental stress, once this is controlled for the benefits of respite on parental stress should be evident.
3. **Parents who have requested respite, (regardless of whether or not they are currently receiving any), will experience higher levels of stress than those parents who have not requested respite.** This is based on the findings of the UK & USA studies who found higher rates of stress in those families

who had requested respite services than in those who had not, (Chadwick et al., 2002; Factor et al., 1990; Hoare et al., 1998; Salisbury, 1990).

- 4. Parents who have requested respite, (regardless of whether or not they are currently receiving any), will have children with a greater degree of behaviour problems than those parents who have not requested respite.**

This is again based on UK and USA studies that have found differences in the children of families who have requested respite as opposed to those who have not, (Chadwick et al., 2002; Factor et al., 1990; Grant & McGrath, 1990; Marc & MacDonald, 1988).

- 5. Parents who have requested respite, (regardless of whether or not they are currently receiving any), will differ from those parents who have not requested respite in relation to demographic variables.**

This is based on the UK and USA studies that have identified differences in various demographic variables for families who have requested respite as opposed to those who have not, (Chadwick et al., 2002; Factor et al., 1990; Grant & McGrath, 1990; Marc & MacDonald, 1988).

- 6. Families who have requested respite and have been allocated a service will differ from families who have requested respite and not been allocated a service in relation to demographic variables.** The number of studies which have examined this issue are few (Chadwick et al., 2002; Treneman et al., 1997), so a number of child, carer and demographic variables will be investigated.

- 7. Families who are satisfied with the respite they are receiving will experience less stress than those who are not satisfied with the service they are receiving.** Neufeld, Query, & Drummond, (2001) highlighted that

carers concerns about the appropriateness of services available to them prevented carers from feeling the benefit of the respite they received. It is therefore hypothesised that families who are satisfied with the service they receive will benefit more than those who are less satisfied.

Chapter 2: METHODOLOGY

2.1. Section 1: Design

A questionnaire method was used to analyse levels of, and relationships between, challenging behaviour, parental stress and respite use in families of children with learning disabilities attending special schools in Lothian, Scotland. The study used a between subjects design, first, to compare families who were receiving respite with those who were not, and second, to compare those who had asked for respite (regardless of whether they were receiving a service), with those who had not. A within-subjects design was used to examine the effects of satisfaction in those families receiving respite.

2.2 Section 2: Procedure

2.2.1. Recruitment of Participants

Permission to distribute questionnaires to families of children attending special schools was sought by the researcher from the four local authorities served by NHS Lothian, (West Lothian, East Lothian, Midlothian and Edinburgh City). The appropriate council official for each council was contacted and sent a copy of the research proposal, together with a copy of the participant information sheet and all measures which were to be used. Once approval had been given, the researcher contacted 6 special schools across the 4 areas, (1 in Midlothian, 1 in East Lothian, 2 in Edinburgh City and 3 in West Lothian). The schools were chosen in order to ensure a range in the level of learning disability and also bearing in mind that some other schools, particularly in the Edinburgh area, had recently taken part in other research. The head teachers of all 6 schools were happy to take part in the study by distributing

questionnaire packs. The schools catered for children with mild-severe learning disability who may or may not have additional physical or sensory disabilities.

Participant packs contained 4 questionnaires: The Aberrant Behaviour Checklist-Community (ABC-C), The Questionnaire on Resources and Stress-F (QRS-F), a Respite Questionnaire and an Information Questionnaire) and a participant information sheet. These were distributed to the parents/carers of 350 children attending the 6 selected special schools across the 4 local authorities. Participants were provided with a stamped, addressed envelope to use to return the questionnaires to the researcher. By recruiting participants in this way, the study was entirely anonymous and it was hoped that this would encourage parents to participate. Questionnaires were distributed via the schools which had agreed to participate by teachers putting a questionnaire pack into the school bag of each child aged 5-16.

2.2.2. Inclusion and Exclusion Criteria

The inclusion criterion was that all questionnaires completed by the main carer of children, aged 5-16, who attended one of the 6 special schools which had agreed to take part would be included in the study. The exclusion criteria were: questionnaires returned by carers of children under 5 or over 16 and questionnaires completed by those who were not the main carer of the child with a learning disability.

2.3 Section 3: Measures

Each participant completed 4 questionnaires/measures. These consisted of: The Aberrant Behaviour Checklist- Community (ABC-C), The Questionnaire on

Resources and Stress-F (QRS-F), a Respite Questionnaire and an Information Questionnaire.

2.3.1. Aberrant Behaviour Checklist – Community (ABC-C)

The Aberrant Behaviour Checklist – Community (ABC-C, Aman & Singh, 1994) was used to measure the level of behavioural difficulty of the children of participants. The original Aberrant Behaviour Checklist (ABC, Aman & Singh, 1985) was designed for use with those living in institutions. The community version of the scale was developed subsequently for use with individuals with learning disabilities living in the community. The wording of the manual and some of the individual items have been changed by the authors to make it more relevant to a community population.

The original ABC is a well standardised measure which has been shown to have satisfactory test-retest reliability and has been validated against other measures including direct observations, (Aman, Singh, Stewart, & Field, 1985). Factor analysis of the measure results in 5 factors each comprising a number of items from the measure: Irritability (15 items), Lethargy (16 items), Stereotypies (7 items), Hyperactivity (16 items) and Inappropriate Speech (4 items). The structure and validity of the measure have been confirmed by both USA (Aman & Singh, 1986) and UK based studies (Newton & Sturmey, 1988).

In a study in which special education teachers rated their pupils' behaviour, the ABC-C was found to have a factor structure which so closely resembled that of the original instrument that the scoring method of the original ABC was deemed to be appropriate for the ABC-C, (Marshburn & Aman, 1992). A further study by (Brown, Aman, &

Havercamp (2002) confirmed the factor structure to be robust when the scale was completed by parents. The study from which this conclusion was derived was conducted with children attending special schools in the USA and yielded co-efficient alpha ranging from .76 to .96.

There are no formal clinical cut-offs for the ABC-C but Aman & Singh (1994) recommend that an individual's score can be regarded as clinically significant if it exceeds the 85th percentile for the individual's normative group; in this case children in special educational placements.

The measure itself consists of 58 items which the respondent rates on a scale from 0 to 3, where 0 indicates the behaviour is "not at all a problem", 1 indicates "the behaviour is a problem but slight in degree", 2 indicates "the problem is moderately serious" and 3 indicates "the problem is severe in degree". The totals are then summed to give the 5 subscale scores of Irritability, Lethargy, Stereotypy, Hyperactivity and Inappropriate Speech. All 5 subscales were used in the analyses.

The ABC and ABC-C have been widely used by researchers in the UK studying challenging behaviour in children with learning disabilities, (Chadwick, Piroth, walker, Bernard, & Taylor, 2000; Murphy, Hall, Oliver, & Kissi-Debra, 1999; Stores et al., 1998; Tomanik et al., 2004)

2.3.2. Questionnaire on Resources and Stress- Friedrich Short Form (QRS-F)

The Friedrich Short Form of the Questionnaire on Resources and Stress (QRS-F, Friedrich, Greenberg, & Crnic, 1983) was used to measure parental stress. This scale

was derived from the original Questionnaire on Resources and Stress, (Holroyd, 1974). The original scale consisted of 285 true-false items but only 222 of these are actually scored. The scale was developed in order to measure the impact that a learning disabled or chronically ill child had on other members of the family. The original questionnaire consists of 15 scales which are reported to measure the three broad dimensions of: parent problems, problems in family functioning and problems the parent sees in or for the child. It has been found to distinguish between learning disabled and non-learning disabled children (Holroyd, Brown, Wikler, & Simmons, 1975) and children with learning disabilities but with different diagnoses, (Friedrich & Friedrich, 1981).

Despite the ability of the original QRS to accurately assess stress in families of children with learning disabilities, its utility has been limited due to the number of items and the lack of internal reliability and validity. In order to address these issues, Friedrich et al. (1983) combined the data from a large number of completed QRS forms from a number of different studies in order to develop a shortened and more psychometrically robust measure.

Using correlations, the authors reduced the initial 222 scored items from the QRS to 52 items which were found to differentiate between matched samples of families of "handicapped" and "non-handicapped" children. The reliability co-efficient for the resulting short form was found to be .951 and the short form total was found to correlate extremely highly with the original QRS. Factor analysis of the short form items yielded 4 factors: Parent and Family Problems (20 items), Pessimism (11 items), Child Characteristics (15 items) and Physical Incapacitation (6 items).

Friedrich et al. (1983) then conducted a validation study in which the reliability coefficient was found to be .93. In order to assess the validity of the short form, they also correlated each of the four factors with measures of depression, social desirability and child behaviour and found that the pattern of correlations differentiated between the four factors.

A subsequent study by Glidden & Floyd (1997) sought to disaggregate depression from Factor I of the QRS-F (Parent and Family Problems). They pointed out that five of the items which make up this factor tap symptoms of depression commonly measured by various self-report measures of depression and which are diagnostic features of depression in the Diagnostic and Statistics Manual – IV (DSM-IV). They highlighted that these 5 items (which they called DEP5) related to general aspects of depression or low mood as opposed to those specifically related to having a child with a learning disability. Using factor analysis they found that their 5 factor model (i.e. DEP5, reduced Parent and Family Problems, Pessimism, Child Characteristics and Physical Incapacitation) provided a better fit than Friedrich et al (1983) original 4 factor model. Cronbach alpha coefficients for DEP5 calculated from a number of samples ranged from .67 to .74. Correlations of DEP5 with 2 self-report measures of depression suggested good concurrent validity.

For the current study, the QRS-F was used and scores calculated based on the 5 factor model discussed by Glidden & Floyd (1997). This removed the need to use an additional measure of depression in the current study. A number of other studies in the UK examining stress in families of children with learning disabilities have used both the QRS-F and the DEP5 factor indicating that this measure is well researched

with this population, (e.g. Hastings, 2003; Hastings & Johnson, 2001; Hoare, Harris, Jackson, & Kerley, 1998). (R.P Hastings, 2003; Richard P. Hastings & Johnson, 2001)

2.3.3. Information Questionnaire

This was devised by the researcher and consisted of questions regarding demographic factors identified in the literature as being associated with parental stress. Questions relating to the child, the family unit, the parent completing the questionnaire, support services the family received and a rating of the main carer's level of stress both overall and in relation to their child with a learning disability were included.

Questions about the child included: age, presence of sensory problems, diagnoses in addition to, or which explained, the child's learning disability and what the parents considered their child's main difficulty/difficulties to be, (physical, behavioural, communication).

In relation to the family unit, respondents were asked to indicate: the number of adults living in the house and their relationship to the child, the number of siblings the child had and how many of those siblings were living in the family home.

The respondent was asked to state their relationship to the child and to indicate whether they worked outside the home on either a full or part-time basis. They were also asked to list their top three stressors at the time of filling out the questionnaire regardless of whether or not these were related to caring for the child with a learning

disability. Finally they were asked to rate their overall stress and their stress relating to their child with a learning disability using a five point Likert scale.

The final section of the information questionnaire asked respondents to indicate whether or not they had received services from a number of relevant professionals either currently, previously or never. Professionals included: clinical psychologist, community learning disability nurse, occupational therapist and social worker.

2.3.4. Respite Questionnaire

A Respite questionnaire was devised by the researcher in order to gather information about the respite services families were receiving (if any), their level of satisfaction with these services, what dimensions they considered to be most important when considering a respite service for their child/family and their overall level of satisfaction with the service they were receiving. Participants were asked to indicate what respite (if any) they currently received, how often they received it, how it was funded and by whom care was provided.

Those receiving respite were asked to rate their current respite provision in terms of their level of satisfaction on 14 separate dimensions and to provide an overall rating of satisfaction using a 5 point scale. The individual dimensions were derived from the literature and represented dimensions which parents had identified as being important to them when considering a “good” respite service. These included: location of service, (e.g. (McConkey & Adams, 2000)), qualified staff, (e.g. McConkey, Truesdale, & Conliffe, 2004), same carer each time, (e.g. (Treneman et al., 1997)), transport, appropriate activities and suitable peer group (McGill, 1996). They were

also asked to rate how much they believed their child enjoyed their respite using the same 5 point scale.

All participants, including those not currently receiving respite were asked to rank the 14 dimensions in order from most to least important when considering their “ideal” respite provision.

Those not currently receiving respite but who had been offered a service in the past were asked to indicate why they were not currently receiving respite. If they indicated that did not consider the service offered to be suitable they were asked to indicate which (if any) of the 14 dimensions, which those receiving respite had rated for satisfaction, they believed made the service offered unsuitable for their child/family.

2.4. Section 4: Participants

2.4.1. Response Rate

A large number of questionnaires were distributed in order to ensure a sufficient number of respondents to reach statistical power for the study. The response rate for postal, questionnaire based studies is expected to be relatively low, (Oppenheim, 1992). 350 questionnaires were distributed via the 6 special schools and a total of 82 were returned. This resulted in a response rate of 23%. 9 questionnaires were excluded from the analysis. Of these, 8 had failed to complete all 4 questionnaires and 1 was completed by an adult who was not the main carer of the child with a learning disability.

Of the 73 participants who were included in the study 33 families reported that they were receiving a respite service of some kind (45.2%) and 40 reported that they were not (54.8%).

2.4.2. Respondents

Of the respondents, 67 were mothers of the child (91.8%), 4 were fathers (5.5%), 1 was a grandmother (1.4%) and 1 a female foster carer (1.4%). Previous studies have focussed on the stress of female caregivers due to the tendency of women to be the main carers of children with disabilities. However, since this study aimed to assess stress of the primary carer regardless of gender, fathers were included in the study.

In terms of employment, 63% of respondents did not work outside the home, 27.4% worked part-time and 9.6% worked full time.

2.4.3. Families

The majority of children lived in households with 2 or more adults, (79.4%). In most cases 2 of the adults in the house were the parents or step-parents of the child although in 1 case the second adult was a grandparent. Additional adults were adult siblings still living in the family home. The proportion of children in the respite and no respite groups living in single parent families was 27.5% and 12.1% respectively.

The children with learning disabilities had a mean number of 1.05 (range 0-8, S.D. = 1.13), siblings under 16 living in the family home. As mentioned above, siblings over 16 living in the family home were included in the number of adults in the household.

2.4.4. Children

The mean age of the children of participants was 10.7 years (range 5-16 years, S.D. = 3.33).

In terms of diagnosis, 15 (20.55%) had no diagnosis explaining or in addition to their learning disability. Table 1 shows the diagnoses for both the respite and no respite groups. The total numbers of diagnoses totals more than 73 as some children had more than one diagnosis in addition to learning disability. The most common diagnoses were autism (24.66%) and Down's Syndrome (19.18%).

Respondents were asked whether or not their child experienced any sensory difficulties. The severity of these was not specified so the information below does not necessarily refer to significant loss of either sight or hearing. 72.6% of children were reported to have no sensory impairments, 16.44% were reported to have sight impairment, 6.85% had hearing loss and 4.11% had both sight and hearing impairments.

Respondents were also asked what they considered their child's main difficulty to be, (communication, behaviour or physical) and were also given the option of indicating whether or not they felt their child had an equal mix of 2 or more difficulties. 2 respondents failed to indicate what their child's main difficulty was. The majority of respondents, (69.87) reported that their child had 2 or more difficulties.

Table 1: Diagnoses explaining/in addition to Learning Disability

Diagnosis	All n=73	
	Count	%
No Additional Diagnosis	15	20.55%
ADHD	4	5.48%
Dyspraxia	3	4.11%
Autism	18	24.66%
Down's Syndrome	14	19.18%
Lujan-Fryns syndrome	1	1.37%
Epilepsy	3	4.11%
Angelman's Syndrome	3	4.11%
Dubowitz Syndrome	1	1.37%
Cerebral Palsy	5	6.85%
CHARGE Association	1	1.37%
Hemiplegia	1	1.37%
Nicolaides Baraitser Syndrome	1	1.37%
Hirschprungs Disease	1	1.37%
Cerebellar Hypoplasia	2	2.74%
Chromosomal Disorder	1	1.37%
Lennox Gastaut Syndrome	1	1.37%
Tuberous Sclerosis	1	1.37%
Duchennes Muscular Dystrophy	1	1.37%
Sotos Syndrome	1	1.37%
Hydrocephalus	1	1.37%
TOTAL	79	

2.5 Section 5: Statistical Analysis

All analyses were carried out using the Statistical Package for the Social Sciences, version 12, (SPSS-12). The statistical tests used were: Mann Whitney Tests, Cross-tabulations, Pearson (r) correlations, Spearman correlations, t-tests and Analysis of variance (ANOVA), (Clark-Carter, 2004; Coolican, 1994; Kinnear & Gray, 2004).

Both parametric and non parametric analyses were used in the analysis of the data. Parametric tests were used when the data was normally distributed, was either interval or ratio and where there was homogeneity of variance. Non parametric tests were used when these criteria were not met.

This study assumed a large effect size as previous studies had found large effect sizes when looking at the effect of respite on parental stress (Mullins et al., 2002; Singer et al., 1989) and the association between parental stress and child challenging behaviour (Floyd & Gallagher, 1997; Tomanik et al., 2004). Assuming a large effect size with a power of 0.8 and an alpha level of 0.05, an N of 28 was the minimum number of participants required in each group (Respite and No Respite) for correlations. Other tests required fewer participants. This calculation is based on Cohen's estimate of the number of participants required under his definition of a large effect size (J. Cohen, 1992).

Chapter 3: RESULTS

3.1 Section 1: Descriptive Statistics

Descriptive statistics will be given in relation to demographic variables, child behaviour, parental stress and respite use. All analyses were one-tailed (with the exception of chi-squares), unless otherwise stated.

3.1.1. Demographic Variables and Respite Group Membership

Demographic information for all respondents has been given in the method section. This section will focus on the differences in the demographic variables between those who receive respite and those who do not. Support that families receive from professionals will also be examined.

3.1.1.1. Respondents

In the Respite group ($n = 33$), 23 (69.70%) of parents did not work outside the home, 7 (21.21%) worked part time and 3 (9.09%) worked full time. In the No Respite group ($n = 40$), 23 (57.50%) did not work outside the home, 13 (32.50%) worked part time and 4 (10.00%) worked full time.

3.1.1.2. Children

The mean age of children in the Respite group was 11.03 (range 5-16, S.D. = 3.26) and 10.42 (range 5-16, S.D. = 3.40) for the No Respite Group. There was no significant difference between the two groups, ($t = 0.771$, $df = 71$, $p = 0.443$, two tailed).

Table 2 below, shows the distribution of diagnoses for the Respite and No Respite groups. As in the method section, the total number of diagnoses for each group is greater than the number of participants in each group due to some children having more than one diagnosis in addition to having a Learning Disability. Autism and Down's Syndrome were the two most common diagnoses and, although the proportion of children with Autism in each group was similar, there was a significant difference, ($\chi^2 = 3.95$, $df = 1$, $p < 0.05$), between the proportion of children with Down's Syndrome in the Respite group (9.09%) when compared with the No Respite group, (27.50%).

Table 2: Diagnoses by Group

Diagnosis	Respite n=33		No Respite n=40	
	Count	Percentage	Count	Percentage
No Additional Diagnosis	5	15.15%	10	25.00%
ADHD	3	9.09%	1	2.50%
Dyspraxia	1	3.03%	2	5.00%
Autism	9	27.27%	9	22.50%
Down's Syndrome	3	9.09%	11	27.50%
Lujan-Fryns syndrome	0	0.00%	1	2.50%
Epilepsy	2	6.06%	1	2.50%
Angelman's Syndrome	2	6.06%	1	2.50%
Dubowitz Syndrome	0	0.00%	1	2.50%
Cerebral Palsy	4	12.12%	1	2.50%
CHARGE Association	0	0.00%	1	2.50%
Hemiplegia	0	0.00%	1	2.50%
Nicolaides Baraitser Syndrome	0	0.00%	1	2.50%
Hirschprungs Disease	1	3.03%	0	0.00%
Cerebellar Hypoplasia	2	6.06%	0	0.00%
Chromosomal Disorder	1	3.03%	0	0.00%
Lennox Gastaut Syndrome	1	3.03%	0	0.00%
Tuberous Sclerosis	1	3.03%	0	0.00%
Duchennes Muscular Dystrophy	1	3.03%	0	0.00%
Sotos Syndrome	1	3.03%	0	0.00%
Hydrocephalus	1	3.03%	0	0.00%
TOTAL	38		41	

Table 3 shows the child's main difficulty as reported by parents. Analysis of the differences between the groups in relation to the child's difficulties showed that carers in the Respite group reported a significantly higher number of difficulties than parents in the No Respite group, ($\chi^2 = 8.90$, $df = 2$, $p = 0.012$).

Table 3: Main Difficulty by Group

Main Difficulty	Respite n=33		No Respite n=40	
	Count	Percentage	Count	Percentage
None Stated	1	3.03%	1	2.50%
Physical	1	3.03%	1	2.50%
Behavioural	2	6.06%	4	10.00%
Communication	3	9.09%	9	22.50%
Behavioural & Communication	14	42.42%	20	50.00%
Physical & Communication	3	9.09%	2	5.00%
Physical & Behavioural	1	3.03%	2	5.00%
All 3	8	24.24%	1	2.50%

In terms of sensory difficulties, the majority of children in both groups had no sensory difficulties, (Respite Group = 78.79%, No Respite Group = 67.50%).

3.1.1.3. *Family*

The majority of children in both groups live with 2 or more adults, (Respite Group = 87.88%, No Respite Group = 72.5%). There was no difference between the groups of the number of children living in single parent families, ($\chi^2 = 2.62$, $df = 1$, $p = 0.11$).

The number of children with learning disabilities who had no siblings under 16 living in the family home was 11 (33.33%) for the Respite group and 10 (25.00%) for the No Respite group. In the Respite group 16 (48.48%) of children had 1 sibling under 16 living at home and 6 (18.18%) had 2 or more siblings under 16 living at home. In the No Respite group these figures were 19 (57.50%) and 11 (27.50%) respectively.

There was no difference between the two groups in terms of the number of siblings under 16 living in the family home, ($\chi^2 = 1.11$, $df = 2$, $p = 0.57$)

3.1.1.4. Professional Support

The mean number of professionals involved with the families in the Respite group at the time of the study was 4.3 (range 1-10, S.D. = 1.70). The figure for families in the No Respite group was 2.8 (range 0-7, S.D. = 1.47). Comparison of the numbers of professionals revealed a significant difference between the number of professionals supporting each group, ($U = 315.50$, $Z = -3.89$, $p < 0.01$). Previous professional involvement was also investigated, with families in the Respite group having previous involvement of a mean number of 2.47 professionals (range 0-6, S.D. = 1.39) and those in the No Respite group had a mean number of 2.75 (range 0-7, S.D. = 1.85) professionals involved with their families. There was no significant difference between the groups in terms of previous professional involvement, ($U = 602.00$, $Z = -0.65$, $p = 0.51$).

31.51% of families had had involvement from a clinical psychologist at some point and 20.55% had had involvement from a child psychiatrist.

3.1.2. Child Behaviour

The mean total ABC-C score for the Respite group was 54.88 (range 4-112, S.D. = 33.64) and for the No Respite group 42.43 (range 0-140, S.D. = 32.98). As would be predicted from the literature, children in the Respite group had significantly higher total ABC-C scores, ($U = 504.00$, $Z = -1.73$, one-tailed, $p < 0.05$).

On examination of the individual factors of the ABC-C, children in the Respite group scored significantly higher on Irritability, ($U = 506.50$, $Z = -1.70$, one-tailed $p < 0.05$), Stereotypies, ($U = 459.50$, $Z = -2.25$, one-tailed $p < 0.05$) and Hyperactivity, ($U = 502.00$, $Z = -1.75$, one-tailed $p < 0.05$). The two groups did not differ in terms of their scores on either Lethargy, ($U = 591.50$, $Z = -0.76$, one-tailed $p = 0.23$) and Inappropriate Speech, ($U = 642.50$, $Z = -0.20$, one-tailed $p = 0.42$).

In terms of clinical significance, Table 4 shows the number of children in each group who meet the Aman & Singh (1994) recommendation for clinically significant scores, (i.e. they score about the 85th percentile for their normative group).

Table 4: Children Scoring above 85th Percentile for each ABC-C Subscale

ABC-C Subscale	Respite n=33		No Respite n=40	
	Count	Percentage	Count	Percentage
Irritability	13	39.39%	12	30.00%
Lethargy	10	30.30%	8	20.00%
Stereotypy	19	57.58%	12	30.00%
Hyperactivity	11	33.33%	8	20.00%
Inappropriate Speech	11	33.33%	17	42.50%
Total ABC-C score	12	36.36%	6	17.50%

As can be seen from table 4, the Respite group had a higher proportion of children scoring above the 85th percentile for all subscales except Inappropriate Speech. The only subscale in which the numbers of children scoring above the 85th percentile differed between the two groups was Stereotypic Behaviour, ($\chi^2 = 5.63$, $df = 1$, $p < 0.05$). Significantly more children in the Respite group had a total ABC-C score above the 85th percentile, ($\chi^2 = 4.44$, $df = 1$, $p < 0.05$).

3.1.3. Parental Stress

Parents were asked to rate their stress in relation to their child with a learning disability using a 5 point Likert scale. No difference was found between the Respite and No Respite group on this item, ($U = 538.00$, $Z = -1.27$, $p=0.11$). Neither was there a difference between the groups on carers rating of overall stress on a 5 point Likert scale, ($U = 631.30$, $Z = -0.15$, $p = 0.44$).

Data from the QRS-F were analysed for both groups. The mean QRS-F total score for the Respite group was 33.48 (range 17-49, S.D. = 9.77) and 26.90 (range 8-43, S.D. = 9.73) for the No Respite group. Analysis showed that this difference was significant, ($U = 419.50$, $Z = -2.67$, one-tailed $p < 0.01$). Parents in the Respite group also scored significantly higher on the factors of Parent and Family Problems ($U = 498.00$, $Z = -1.80$, one-tailed $p < 0.05$), Child Characteristics, ($U = 435.50$, $Z = -2.50$, one-tailed $p < 0.01$) and Physical Incapacitation, ($U = 380.50$, $Z = -3.17$, one-tailed $p < 0.01$). The difference between groups on the DEP5 factor was approaching significance, ($U = 516.00$, $Z = -1.65$, $p = 0.051$). The two groups did not differ significantly on the Pessimism sub-score ($U = 544.50$, $Z = -1.30$, one-tailed $p = 0.10$).

In addition to completing the QRS-F, parents were asked to rate their top 3 stressors at the time of completing the questionnaires. This was in order to gather data about stresses which may be not directly related to having a child with a learning disability. Significantly more parents in the Respite group ($n = 14$, 50.00%) compared to the No Respite group ($n = 9$, 24.32%) reported that their first source of stress was in relation to their child with a learning disability, ($\chi^2 = 6.79$, $df = 2$, $p \leq 0.05$).

3.1.4. Respite

As has been stated previously, 33 (45.2%) of participants were receiving a respite service of some kind at the time of the study and 40 (54.8%) were not. Of the Respite group families, the 28 (84.85%) had had to request a service. In the No Respite group, 17 (42.50%) families had requested a service but were not currently receiving one.

Table 5 shows which services families were receiving. The majority of families received two or more services, (69.69%). The most commonly received service was a Playscheme and the least common was care provided in the family home during the night. 51.52% of parents received an overnight break with the mean number of nights per month being 2.71, (range 1-6, S.D. = 1.46). The mean number of hours of daytime respite per week was 4.29 (range, 1-12, S.D. = 3.40). One parent received a break only during the school holidays in the form of a playscheme.

Table 5: Respite Services received by families

Type of Service	Count	Percentage
Own Home Care (Day)	4	12.12%
Own Home Care (Night)	1	3.03%
Outing	15	45.45%
Respite Carers Home (Day)	7	21.21%
Respite Carers Home (Night)	9	27.27%
Respite Centre (Day)	6	18.18%
Respite Centre (Night)	9	27.27%
After School Club	7	21.21%
Playscheme	22	66.67%
Other	4	12.12%

Care was usually funded by the families' Social Work Department but was delivered by other agencies (e.g. voluntary organisations) in 45.45% of cases. For the majority of children, care was provided by familiar staff either due to the child having the same

1:1 carer each time, (42.42%), by a team of familiar carers, (24.24%) or by the child having a key-worker within the care team (15.15%).

Thirty one parents rated their satisfaction with the respite they were receiving on a 5 point Likert Scale. The majority of parents were either “Satisfied” or “Very Satisfied” (80.66%). 6 parents said they were neither satisfied nor unsatisfied. No parents expressed an overall lack of satisfaction with their current service(s). Some parents found certain aspects of their current service unsatisfactory. These were: communication between home and respite (3.03%), consistency between home, school and respite (3.13%), transport to and from respite (9.38%), communication systems used (9.09%), ability to meet health needs (3.13%), suitability of peer group (9.38%), staffing ratio (6.06%) and consistency of carers (3.03%). The majority of children were thought to enjoy their respite (84.38%).

Ten families had asked for, and been offered, respite but were not currently receiving a service. Of these families, 5 felt that the service offered to them was inappropriate. 4 had had their service withdrawn and 1 child had become too old for the service they had been receiving. Of those who felt the service would have been inappropriate, 4 had concerns about some aspect of staffing (staff knowledge, staffing ratio and the physical ability of staff) and 2 had concerns about the service’s ability to meet their child’s needs (health needs, activities, safety and communication methods).

All respondents, even those not receiving respite, were asked to rank the 14 respite attributes in order of importance when considering their ideal respite service. 52 respondents (71.23%) provided this information. “Knowledge & Skills of

staff/carers” was ranked in the top three most important attributes by 71.15% of parents. The next two most important attributes were “Good communication between respite & home” and “Same Carer(s) each time”; both being ranked in the top 3 by 38.47% of parents.

3.2 Section 2: Results of Hypotheses

Results will be presented for each of the six hypotheses in the order in which they were presented in the introduction.

3.2.1. Hypothesis 1: There will be a correlation between the presence of challenging behaviour and increased parental stress in all parents surveyed

The total score for both the ABC-C and the QRS-F were examined for normality in order to see if parametric tests were appropriate. A departure from normality and two outliers in the No Respite group were removed using a square root transform.

A Pearson’s r parametric correlation revealed a significant positive correlation between parental stress (QRS-F total) and child challenging behaviour (ABC-C total), ($r = 0.60$, $n = 73$, $p < 0.01$). In addition, correlations were found between ABC-C total and four of the five QRS-F subscales, (Parent and Family Problems, Pessimism, Child Characteristics and DEP5). The only subscale not to correlate was Physical Incapacitation which is the only subscale in which all items relate to purely factual information. All other subscales include items in which the parent’s opinions or reactions to particular situations or aspects of their child and family are measured.

In order to ensure that this correlation was not biased by one or other group, separate Pearson's correlations were carried out for the ABC-C and QRS-F total scores for the Respite and No Respite groups. A significant positive correlation was found for the Respite group ($r = 0.42$, $n = 33$, $p < 0.05$) and the No Respite group, ($r = 0.71$, $n = 40$, $p < 0.01$). As can be seen the significance level for the Respite group was $p < 0.05$ compared to $p < 0.01$ for the No Respite group.

Due to the departure from normality of the ABC-C subscale scores, a non-parametric Spearman's correlation was carried out between the ABC-C and QRS-F subscales. Correlations were found between all ABC-C subscales and the QRS-F subscales with the exceptions of Inappropriate Speech and Physical Incapacitation which only correlated with each other.

Hypothesis 1 was accepted.

3.2.2. Hypothesis 2: Parents who receive respite will experience less stress than parents of children with similar levels of challenging behaviour who do not receive respite.

An analysis of variance was carried out in order to determine whether or not parents who received respite experienced less stress (as measured by the QRS-F Total) than those who did not. Child behaviour problems were found to correlate with parental stress so, in order to remove this effect, child behaviour was included as a covariate in the analysis of variance. A significant difference was found between the Respite and

No Respite groups in terms of parental stress ($F(1, 70) = 5.27, p < 0.05$), with the Respite groups having significantly higher stress scores than the No Respite group.

Hypothesis 2 was rejected since the direction of the results was the opposite of that predicted by the hypothesis.

3.2.3. Hypothesis 3: Parents who have requested respite, (regardless of whether or not they are currently receiving any), will experience higher levels of stress than those parents who have not requested respite

QRS-F scores for families who had requested respite were compared with those who were not, regardless of whether or not they were receiving respite. 45 families had requested respite and 28 families had not. Comparisons of the QRS-F scores showed that those who had requested respite had significantly higher total QRS-F scores ($U = 340.500, Z = -3.29, \text{one-tailed } p < 0.01$). They also had higher scores on Parent and Family Problems ($U = 337.00, Z = -3.34, \text{one-tailed } p < 0.01$), Pessimism ($U = 442.50, Z = -2.15, \text{one-tailed } p < 0.05$), Child Characteristics ($U = 446.50, Z = -2.09, \text{one-tailed } p < 0.01$), Physical Incapacitation ($U = 416.00, Z = -2.48, \text{one-tailed } p < 0.05$) and DEP5 ($U = 388.00, Z = -2.83, \text{one-tailed } p < 0.01$).

Exploratory analysis was then carried out in order to compare those families in each group who had asked for respite with those who had not. Five families in the respite group had been offered, and were receiving, a respite service without having had to ask for one. Two tailed tests were used in this analysis due to the lack of literature which would suggest the direction of any differences between this subgroup and the

rest of the Respite group. There were no significant differences between the two groups on total QRS-F score or on four of the five subscales although those who had not requested respite had lower mean scores on all subscales and on the QRS-F total score. However, respondents who had not requested respite had significantly lower scores on the DEP5 subscale than those who had had to request respite, ($U = 19.50$, $Z = -2.66$, two-tailed $p < 0.01$).

Families in the No Respite group who had asked for respite were then compared with those who had not. One tailed tests were used in this analysis since much of the literature which has compared those who have requested respite with those who have not is from the USA. As such it has not had to consider resource issues which might mean that families are unable to be allocated a service once they request it, (Factor et al., 1990; Marc & MacDonald, 1988). It is therefore assumed that those who have requested respite but have not been allocated will experience more stress than those who have not requested a service. Those who had requested respite had significantly higher scores on the Parent and Family Problems subscale ($U = 114.50$, $Z = -2.22$, one-tailed $p < 0.05$), Pessimism (131.50 , $Z = -1.78$, one-tailed $p < 0.05$), Physical Incapacitation ($U = 128.50$, $Z = -1.95$, one-tailed $p < 0.05$) and also had significantly higher QRS-F total scores ($U = 119.00$, $Z = -2.09$, $p < 0.05$). They did not differ significantly in terms of their scores on the Child Characteristic ($U = 156.50$, $Z = -1.07$, one-tailed $p = 0.14$) or DEP5 ($U = 156.50$, $Z = -1.09$, one-tailed $p = 0.14$) subscales but their mean scores on these subscales were higher than those who had not requested respite.

The final exploratory analysis compared the stress scores of those in the Respite and No Respite groups who had not requested respite. No differences were found between the two groups on any of the subscales or on the QRS-F total scores ($U = 45.50, Z = -0.72, p = 0.471$).

The significant differences between the Requested and Not Requested groups (regardless of respite status) and the lack of significant difference within the Requested and Not Requested groups (again regardless of respite status) suggest that it is requesting status which dictates stress level as opposed to respite status.

Based on the above results, hypothesis 3 was accepted.

3.2.4. Hypothesis 4: Parents who have requested respite, (regardless of whether or not they are currently receiving any), will have children with a greater degree of behaviour problems than those parents who have not requested respite.

Comparisons of the ABC-C total and subscale scores for those who had requested and not requested respite showed that those who had requested respite had children who scored significantly higher on the Irritability ($U = 341.50, Z = -2.28, \text{one-tailed } p < 0.05$), Stereotypic Behaviour ($U = 340.00, Z = -2.33, \text{one-tailed } p < 0.05$) and Hyperactivity, ($U = 348.00, Z = -2.20, \text{one-tailed } p < 0.05$) subscales. They also had higher total ABC-C scores, ($U = 352.00, Z = -2.15, \text{one-tailed } p < 0.05$). Those who had requested respite had higher scores on the other two subscales, Lethargy and Inappropriate Speech although these did not differ significantly.

Again, exploratory analysis was carried out in order to compare those families in each group who had asked for respite with those who had not. The five families in the Respite group who had not requested respite were first compared to the rest of the respite group. As was the case for the comparisons of stress scores, two-tailed tests were used in this analysis. No differences were found on any of the ABC-C subscales or on the total ABC-C score ($U = 56.00$, $Z = -0.70$, two-tailed $p = 0.48$).

Those in the No Respite group who had requested respite were then compared with those in the same group who had not requested respite. As for the previous hypothesis, one tailed tests were used to compare these subgroups. No differences were found between the groups on four out of five of ABC-C subscales or the total ABC-C score ($U = 146.00$, $Z = -1.36$, one-tailed $p = 0.09$). The only exception was the Hyperactivity sub-score ($U = 136.00$, $Z = -1.63$, one-tailed $p = 0.05$).

The finally exploratory analysis compared the ABC-C scores of those in the Respite and No Respite groups who had not requested respite. No differences were found in either the ABC-C total or subscale scores.

In terms of clinical significance, Table 6 shows the number of children in each group who meet the Aman & Singh (1994) recommendation for clinically significant scores, (i.e. they score about the 85th percentile for their normative group).

Table 6: Children Scoring above 85th Percentile for each ABC-C Subscale

ABC-C Subscale	Requested n=45		Not Requested n=28	
	Count	Percentage	Count	Percentage
Irritability	18	40.00%	7	25.00%
Lethargy	15	33.33%	3	10.71%
Stereotypy	24	53.33%	7	25.00%
Hyperactivity	14	31.11%	5	17.86%
Inappropriate Speech	19	42.22%	9	32.14%
Total ABC-C score	14	31.11%	5	17.86%

As can be seen from Table 6, those who had requested respite had a higher proportion of children scoring above the 85th percentile for all subscales. The subscales in which the numbers of children scoring above the 85th percentile differed between the two groups were Lethargy ($\chi^2 = 4.75$, $df = 1$, $p < 0.05$) and Stereotypic Behaviour ($\chi^2 = 5.67$, $df = 1$, $p < 0.05$). There was no significant difference between those who had requested respite and those who had not in term of total ABC-C score ($\chi^2 = 1.58$, $df = 1$, $p = 0.21$).

The groups differed in relation to three out of five of the ABC-C subscale scores and also the total ABC-C score. They also differed in terms of the number of children who had clinically significant scores on two of the five ABC-C subscales, (Lethargy and Stereotypic Behaviour).

Based on the above findings, Hypothesis 4 was accepted.

3.2.5. Hypothesis 5: Parents who have requested respite, (regardless of whether or not they are currently receiving any), will differ from those parents who have not requested respite in relation to demographic variables.

The 45 families who had requested respite were compared with the 28 families who had not requested any.

3.2.5.1 Respondents

68.89% of respondents who had requested respite did not work outside the home. This figure was 53.57% for those who had not requested respite. The difference between the two groups was not significant ($\chi^2 = 1.74$, $df = 1$, $p = 0.19$). 24.44% of those who had requested respite worked part-time and 6.67% worked full time. These figures were 32.14% and 14.29% for those who had not requested respite.

3.2.5.2. Children

The mean age of children in the Requested group was 10.93 (range 5-16, S.D. = 3.20) and 10.32 (range 6-15, S.D. = 3.55) for the Not Requested group. There was no significant difference between the two groups, ($t = 0.76$, $df = 71$, $p = 0.45$, two tailed).

Table 7: Main Difficulty by Group

Main Difficulty	Requested n=45		Not Requested n=28	
	Count	Percentage	Count	Percentage
None Stated	1	2.22%	1	3.57%
Physical	2	4.44%	0	0.00%
Behavioural	3	6.67%	3	10.71%
Communication	5	11.11%	7	25.00%
Behavioural & Communication	22	48.89%	12	42.86%
Physical & Communication	2	4.44%	3	10.71%
Physical & Behavioural	3	6.67%	0	0.00%
All 3	7	15.56%	2	7.14%

Table 7 shows the child's main difficulty as reported by parents. Analysis of the differences between the groups in relation to the child's difficulties showed that carers who had requested respite did not report significantly higher numbers of difficulties than parents who had not requested respite, ($\chi^2 = 2.27$, $df = 2$, $p = 0.32$).

Table 8 shows the diagnoses, in addition to learning disability, of children in families who have requested and not requested respite. None of the children in the Not Requested group had more than one diagnosis. The most common diagnosis of those in the Not Requested group was Down's Syndrome with 28.57% of children having this diagnosis. The figure for the Requested group was 13.33%. There was no significant difference between the groups in terms of the number of children diagnosed with Down's Syndrome ($\chi^2 = 2.59$, $df = 1$, two tailed $p = 0.11$).

6 children of families in the Requested group had 2 diagnoses in addition to the diagnosis of learning disability. The most common diagnosis in the Requested group was Autism with 31.11% of children having this diagnosis. The figure for the Not Requested group was 14.29%. There was no significant difference between the two groups in relation to a diagnosis of Autism, ($\chi^2 = 2.63$, $df = 1$, two tailed $p = 0.11$).

The majority of children in both groups did not have any sensory impairment, (Requested = 73.33 % and Not Requested = 71.43%).

3.2.5.3 *Family*

The majority of children in both the Requested (82.22%) and Not Requested groups (75.00%) lived with 2 or more adults. There was no difference between the groups of the number of children in single parent families, ($\chi^2 = 0.55$, $df = 1$, $p = 0.46$).

The number of children with no siblings under 16 at home was 12 (26.67%) for the Requested group and 9 (32.14%) for the Not Requested group. This difference was not significant, ($\chi^2 = 0.25$, $df = 1$, $p = 0.62$). In the Requested group, 24 (53.33%) had 1 sibling under 16 living at home and 9 (20.00%) had two or more siblings under 16 living at home. These figures were 11 (39.29%) and 8 (28.57%) respectively for the Not Allocated group.

Table 8: Diagnoses by Group

Diagnosis	Requested n = 45		Not Requested n = 28	
	Count	percentage	Count	percentage
No Additional Diagnosis	8	17.78%	7	25.00%
ADHD	2	4.44%	2	7.14%
Dyspraxia	1	2.22%	2	7.14%
Autism	14	31.11%	4	14.29%
Down's Syndrome	6	13.33%	8	28.57%
Lujan-Fryns syndrome	0	0.00%	1	3.57%
Epilepsy	2	4.44%	1	3.57%
Angelmans Syndrome	2	4.44%	1	3.57%
Dubowitz Syndrome	1	2.22%	0	0.00%
Cerebral Palsy	4	8.89%	1	3.57%
CHARGE Association	1	2.22%	0	0.00%
Hemiplegia	1	2.22%	0	0.00%
Nicolaides Baraitser Syndrome	0	0.00%	1	3.57%
Hirschprungs Disease	1	2.22%	0	0.00%
Cerebellar Hypoplasia	2	4.44%	0	0.00%
Chromosomal Disorder	1	2.22%	0	0.00%
Lennox Gastaut syndrome	1	2.22%	0	0.00%
Tuberous Sclerosis	1	2.22%	0	0.00%
Duchennes Muscular Dystrophy	1	2.22%	0	0.00%
Sotos Syndrome	1	2.22%	0	0.00%
Hydrocephalus	1	2.22%	0	0.00%
Total	51		28	

3.2.5.4 Professional Support

The mean number of professionals currently involved with families who had requested respite was 3.96 (range 1-10, S.D. = 1.71). The figure for the Not Requested group was 2.71 (range 0-6, S.D. = 1.54). Comparison of the number of professionals involved with each group at the time of the study revealed a significant difference between the number of professionals involved with each group ($U = 382.50$, $Z = -2.86$, two tailed $p < 0.01$). Previous professional involvement was also investigated with families who had requested respite having a mean number of 2.64 (range 0-6, S.D. 1.61) professionals previously involved in their care and those who had not requested respite having 2.57 (range 0-6, S.D. = 1.61) professionals previously involved. There was no significant difference between the two groups, ($U = 597.50$, $Z = -0.36$, two tailed $p = 0.71$).

40.00% of families who had asked for respite had had involvement from a clinical psychologist and 20.00% had had input from a child psychiatrist. The figures for the Not Requested group were 17.86% and 21.43% respectively. There was a difference between the groups in terms of clinical psychology involvement ($\chi^2 = 3.92$, $df = 1$, $p < 0.05$) but not in terms of child psychiatry involvement ($\chi^2 = 0.02$, $df = 1$, $p = 0.88$).

3.2.5.5. Summary

The above analysis found only one significant difference between those who had requested respite and those who had not with those in the Requested group having a significantly higher number of professionals involved in their care at the time of the study. Although only one difference was found hypothesis 5 was still accepted as the nature or number of differing factors was not specified in the hypothesis.

3.2.6. Hypothesis 6: Families who have been allocated a service will differ from families who have requested respite and not been allocated a service in relation to child challenging behaviour, parental stress and demographic variables

For the purpose of this analysis, those who had been allocated a respite service without requesting one have been included in the Allocated group since the purpose of this analysis is to look at the factors which differentiate between those who have been allocated a service and those who have not rather than to examine differences between families who had requested respite.

3.2.6.1 Respondents

The majority of respondents in both the Allocated and Not Allocated groups did not work outside the home, (69.70% and 70.59% respectively). 21.21% of those who had been allocated respite worked part time and 9.09% worked full time. None of the respondents who had not been allocated respite worked full time and 29.41% worked part time.

3.2.6.2 Children

The mean age of children in the Allocated group was 11.03 (range 5-16, S.D. = 3.26) and 10.53 (range 6-15, S.D. = 2.92) for the Not Allocated Group. There was no significant difference between the two groups, ($t = 0.532$, $df = 48$, $p = 0.597$, two tailed).

Table 8 shows the diagnoses, in addition to learning disability, of children who have been allocated and not allocated respite. The most common diagnosis in both groups is Autism. Cerebral Palsy was the second most common diagnosis in those in the Allocated group (12.12%), with 5.88% of those in the Not Allocated group having this diagnosis. Down's syndrome was the second most common diagnosis in the Not Allocated group (17.65%), with 9.09% of those in the Allocated group having this diagnosis. Comparisons could not be made between the groups in relation to these two diagnoses due to low expected frequencies.

The majority of children in both groups did not have any sensory impairment, (Allocated = 78.79% and Not Allocated = 64.71%).

3.2.6.3 *Family*

The majority of children in both the Allocated (87.88%) and Not Allocated groups (76.47%) lived with 2 or more adults with additional adults being siblings over the age of 16. There was no difference between the groups of the number of children in single parent families, ($\chi^2 = 1.09$, $df = 1$, $p = 0.30$).

The number of children with no siblings under 16 at home was 11 (33.33%) for the Allocated group and 3 (17.65%) for the Not Allocated group. This difference was not significant, ($\chi^2 = 1.37$, $df = 1$, $p = 0.24$). In the Allocated group, 16 (48.48%) had 1 sibling under 16 living at home and 6 (18.18%) had two or more siblings under 16 living at home. These figures were 10 (58.82%) and 4 (23.53%) respectively for the Not Allocated group.

Table 8: Diagnoses according to whether a service has been allocated or not

Diagnosis	Allocated n = 33		Not Allocated n = 17	
	Count	percentage	Count	percentage
No Additional Diagnosis	5	15.15%	3	17.65%
ADHD	3	9.09%	1	5.88%
Dyspraxia	1	3.03%	0	0.00%
Autism	9	27.27%	5	29.41%
Down's Syndrome	3	9.09%	3	17.65%
Epilepsy	2	6.06%	1	5.88%
Angelman's Syndrome	2	6.06%	1	5.88%
Dubowitz Syndrome	0	0.00%	1	5.88%
Cerebral Palsy	4	12.12%	1	5.88%
CHARGE Association	0	0.00%	1	5.88%
Hemiplegia	0	0.00%	1	5.88%
Hirschprungs Disease	1	3.03%	0	0.00%
Cerebellar Hypoplasia	2	6.06%	0	0.00%
Chromosomal Disorder	1	3.03%	0	0.00%
Lennox Gastaut Syndrome	1	3.03%	0	0.00%
Tuberous Sclerosis	1	3.03%	0	0.00%
Duchennes Muscular Dystrophy	1	3.03%	0	0.00%
Sotos Syndrome	1	3.03%	0	0.00%
Hydrocephalus	1	3.03%	0	0.00%
TOTAL	38		18	

3.2.6.4 *Professional Support*

The mean number of professionals currently involved with families who had been allocated respite was 4.3 (range 1-10, S.D. = 1.70). The figure for the Not Allocated group was 3.29 (range 1-7, S.D. = 1.53). The difference between the two groups was found to be significant ($U = 1.73$, $Z = -2.25$, two-tailed $p < 0.05$). Previous professional involvement was also investigated with families who had been allocated respite having a mean number of 2.45 (range 0-6, S.D. 1.39) professionals previously involved in their care and those who had not been allocated respite having 2.82 (range 0-5, S.D. = 1.88) professionals previously involved. There was no significant difference between the two groups in terms of previous professional involvement ($U = 240.50$, $Z = -0.83$, two-tailed $p = 0.41$).

Of those who had been allocated respite, 36.36% had had involvement from a clinical psychologist with 21.21% having had involvement from a child psychiatrist. The figures for those who had not been allocated respite were 47.06% and 23.53% respectively. The differences between the two groups in term of clinical psychology involvement ($\chi^2 = 0.54$, $df = 1$, $p = 0.47$) and child psychiatry involvement ($\chi^2 = 0.04$, $df = 1$, $p = 0.85$) were not significant.

3.2.6.5. Child Behaviour

ABC-C total and subscale scores were analysed for both the Allocated and Not Allocated groups. The total and subscale scores were all higher for the Allocated group with the exception of Inappropriate Speech which was higher for the Not Allocated group. However, none of the differences between the groups were significant.

Table 9 shows the numbers and percentages of children who met the 85th percentile cut-off suggested by Aman & Singh (1994) as necessary for clinical significance. As can be seen in table 9, the proportions of children who meet the cut off for clinical significance is higher in the Allocated group for total ABC-C score and all subscales except Inappropriate Speech. Once more, none of these differences were significant.

Table 9: Children Scoring above 85th Percentile for each ABC-C Subscale

ABC-C Subscale	Allocated n=33		Not Allocated n=17	
	Count	Percentage	Count	Percentage
Irritability	13	39.39%	6	35.29%
Lethargy	10	30.30%	5	29.41%
Stereotypy	19	57.58%	7	41.18%
Hyperactivity	11	33.33%	4	23.53%
Inappropriate Speech	11	33.33%	8	47.06%
Total ABC-C score	12	36.36%	3	17.65%

3.2.6.6. *Parental Stress*

Total and subscale scores for the QRS-F were compared for the Allocated and Not Allocated groups. Although the subscale and total scores were higher for those who had been allocated respite, none of the differences were significant. The biggest difference was in relation to the Physical Incapacitation score with the significance approaching the 0.05 level ($U = 192.00$, $Z = -1.84$, $p = 0.07$).

The top three stresses given by parents were also analysed for the two groups. The main source of stress for 50.00% of the Allocated group and 31.25% of the Not Allocated group was the child with learning disabilities. The two groups did not differ significantly in relation to their main source of worry. The groups also did not differ in relation to their overall stress as rated on the Likert scale ($U = 242.50$, $Z = -0.84$, $p = 0.40$) or their stress in relation to their child with learning disability ($U = 253.00$, $Z = -0.60$, $p = 0.55$).

3.2.6.7. *Summary*

Data for those parents who had been allocated respite and those who had requested respite but had not been allocated any were compared to see if there were any differences between the two groups. The two groups did not differ significantly in relation to child or family demographic variables with the exception of current level of professional support. Families who had been allocated respite had significantly more professionals involved in their child's care at the time of the current study. There was also no significant difference between the groups in relation to the ABC-C data although there was a trend for more of those in the Allocated group to meet the criteria for clinical significance. The groups also did not differ in relation to stress as

measured by the QRS-F although there was a trend for those in the Allocated group to score higher on all subscales with the Physical Incapacitation score approaching significance.

Although only one difference was found hypothesis 6 was still accepted as the nature or number of differing factors was not specified in the hypothesis

3.2.7. Hypothesis 7: Families who are satisfied with the respite they are receiving will experience less stress than those who are not satisfied with the service they are receiving.

Since no respondents indicated that they were not satisfied with their current respite provision it was not possible to investigate this hypothesis.

3.3. Section 3: Summary of Results

- A correlation was found between parental stress and child challenging behaviour in terms of both total and subscale scores for all parents.
- Parents who received respite experienced significantly higher levels of stress than those who did not when child behaviour problems were controlled for.
- Parents who had requested respite (regardless of whether they were receiving a service or not) experienced significantly higher levels of stress than those who had not requested a service.
- Parents who had requested respite (regardless of whether they were receiving a service or not) had children who scored significantly higher on measures on challenging behaviour.

- Parents who had requested respite (regardless of whether they were receiving a service or not) had significantly more professionals involved in their child's care.
- Parents who had requested respite (regardless of whether they were receiving a service or not) were significantly more likely to have had input from a clinical psychologist for their child.
- There were no significant differences between those who had requested and been allocated respite and those who had requested respite but had not been allocated a service.
- More children who had been allocated respite had clinically significant behaviour scores than those who were not allocated respite although this difference was not significant.
- Parents who had been allocated respite had higher parental stress scores although these were not significantly higher than those of parents who had not been allocated respite.
- Families who had been allocated respite had significantly more professionals involved in their child's care than families who had requested respite but had not been allocated any.
- It was not possible to compare stress scores of parents who were satisfied with their respite with those who were not due to no parents expressing dissatisfaction with their respite provision.

Chapter 4: DISCUSSION

The main aim of this study was to provide an account of the occurrence of challenging behaviour and parental stress and their relationship to respite care in families of children with learning disabilities. A secondary aim was to investigate the factors associated with requesting respite care and those which differentiated the families who received such care from those who did not. Finally, the study aimed to investigate the effects of satisfaction with respite services on parental stress for those families receiving respite.

Previous studies have found a relationship between parental stress and child behaviour problems (Floyd & Gallagher, 1997; R.P Hastings, 2003; Hodapp et al., 1997; Hodapp et al., 1998; Quine & Pahl, 1985, 1991; Ricci & Hodapp, 2003; Stores et al., 1998; Tomanik et al., 2004; von Gontard et al., 2002). Other studies which have examined the effects of respite on parental stress (Botuck & Winsberg, 1991; Joyce et al., 1983; Marc & MacDonald, 1988; Mullins et al., 2002; Singer et al., 1989) have found that the provision of respite results in lower levels of parental stress. The studies have varied in their findings in relation to the degree and sustainability of these improvements. Previous studies have rarely looked at the associations between parental stress, child challenging behaviour and respite care. In addition, many of the studies examining the effects of respite have been based outside the UK and as such a number of resource issues which are specific to the UK (and particularly Scottish) provision of respite services have not been investigated. In order to address some of these issues, factors associated with requesting and allocating respite services were also examined.

The findings of the current study suggest that the relationship, found in previous studies, between parental stress and child challenging behaviour can be seen in a Scottish population of families of children with learning disability. The finding that respite care leads to lower parental stress does not appear to hold in the studied population, but resource and methodological issues may explain this. The findings of the current study will be discussed in relation to previous research. Methodological and clinical implications will also be discussed, as will possible directions for future research.

4.1 Section 1: Discussion of Results

4.1.1 Respite Services in Lothian

The proportion of families in the present study receiving respite (45.20%) is in keeping with the findings from the literature indicating a figure of 44%-60% (Damiani et al., 2004; McConkey & Adams, 2000). In order to meet the demand for respite services, provision would have to increase significantly since 61.64% of families had requested a service.

Families in the current study received a mean equivalent of 9.30 days per year worth of daytime respite, and those receiving overnight care received a mean number of 35.52 overnight stays per year. The amount of respite per year quoted by Stalker & Robinson (1994) is given as an equivalent number of days per year which in turn is composed of 12 hour sessions. Based on these figures, it is difficult to make a direct comparison between the present study and that of Stalker & Robinson (1994) since the duration of respite for the families in the present study varied considerably, and overnight stays could reasonably consist of anything from 12 to 24 hours.

The literature points to carer factors as being of central importance to families when considering respite (McConkey et al., 2004; McGill, 1996; Stalker, 1988; Treneman et al., 1997). Similarly, parents in Lothian rated carer factors as being of high importance when considering their ideal respite service. Children in Lothian were in fact usually cared for by familiar staff/carers; one of the carer factors rated as important by parents.

It is encouraging to note that the majority of parents (80.66%) indicated that they were either “satisfied” or “very satisfied” with the quality of service they were receiving. However, the present study did not seek parents’ views as to their satisfaction with the number of hours respite they received or the flexibility of the service, and these issues will be discussed in relation to the methodology in a later section.

The 10 families who had been offered a respite service but were not currently receiving one are worthy of further discussion. Five of these families had declined the service offered to them on the grounds that they did not feel it was appropriate, with the majority indicating concerns about staffing. This is in keeping with the literature discussed above and with the findings from the current study, which indicate that parents consider staffing factors of great importance when considering respite care for their child. Another relevant finding in relation to this group of families was regarding to the ongoing provision of respite services. Four families had had their service withdrawn although reasons as to why this occurred were not given. Respite for one family had stopped due to the child becoming too old. The child in this case was only 10 years old so it may be that some of the other families who had had their services withdrawn had experienced similar difficulties with age related services.

Whilst this is only a hypothesis, studies from the UK and USA (Cutler, 1986; Intagliata, 1986; Orlik et al., 1991; Robinson, 1994; Stalker, 1988) have found age to be a restricting factor in the provision of respite care and this may be the case for more families in Lothian.

To summarise, the number of families receiving a respite service in Lothian is similar to that found in other UK based studies. However, there remain a relatively large number of families (23.29% of all participants) who have requested a service but are not currently receiving one, presumably due to a lack of resources. Factors which differentiate those families who have been allocated a service from those who have not will be discussed in a later section. Parents in the current study were generally satisfied with the quality and appropriateness of the respite they were receiving.

4.1.2 Association between child challenging behaviour and parental stress

The findings of the present study support those of previous studies which have found that the presence of child challenging behaviour is associated with parental stress (Baker et al., 2003; Floyd & Gallagher, 1997; R.P Hastings, 2003; Hodapp et al., 1997; Hodapp et al., 1998; Quine & Pahl, 1985, 1991; Ricci & Hodapp, 2003; Stores et al., 1998; Tomanik et al., 2004; von Gontard et al., 2002).

Children in the present study displayed varying degrees of challenging behaviour and parents experienced varying degrees of stress. Despite these variations, a significant positive correlation was found between challenging behaviour and parental stress. This correlation was also found when the participants were split into those who were

receiving respite and those who were not receiving respite, indicating that the correlation was not confined to one or other group.

This finding can, at least in part, be explained by a possible association between challenging behaviour and daily hassles. In the general population, these hassles have been found to be one of the main predictors of parental stress (Deater-Deckard & Scarr, 1996; Krech & Johnston, 1992). Responding to child behaviour accounts for a large number of the hassles identified by Crnic & Greenberg, (1990) so, together with the findings from Deater-Deckard & Scarr (1996) and Krech & Johnston (1992), it seems reasonable that this association between challenging behaviour and parental stress should be found in parents of children with a learning disability.

Another possible explanation relates to the various coping models discussed in chapter 1. All of these models (Quine & Pahl, 1991; Saloviita et al., 2003; Tunali & Power, 1993) have proposed that parents' evaluations and attributions about their child with a learning disability will contribute to the experience of stress, with those who manage to appraise their situation positively experiencing less stress. It is possible that parents of children with increased levels of challenging behaviour may struggle to appraise their situation positively, and as such will experience greater stress.

In addition, Baker et al. (2003) have found that increased parental stress leads to increased challenging behaviour in children, which in turn leads to a further increase in parental stress. The families experiencing most stress and who have children with

higher levels of challenging behaviour may have found themselves caught in this cycle. The possible clinical implications of this will be discussed in a later section.

4.1.3 Effect of Respite on Parental Stress

The findings in relation to the effect of respite on parental stress were not in keeping with those of previous research which indicated that being in receipt of respite resulted in lower levels of parental stress. In fact, in this study the opposite appeared to be true, with those who were receiving respite experiencing higher levels of stress than those who were not. A number of possible explanations as to why this might be were considered and will be discussed below.

4.1.3.1 Respite group parents experienced higher initial stress prior to receiving respite

One possible explanation which was considered in order to explain why those parents who were receiving respite appeared to be more stressed than those who were not was that they had been experiencing even higher levels of stress prior to receiving respite.

The Breaking Point Report (MENCAP, 2003) reported that the majority of parents surveyed for the report had to reach “breaking point” before they were allocated a respite service. The higher levels of stress in the Respite group might represent the increased level of stress associated with this “breaking point” which had to be reached before services were allocated. The influence of parental stress on respite allocation will be discussed further below.

It was not the focus of the current study to investigate the changes in parental stress as a result of receiving respite care and as such, the current study measured parental stress at one point in time. Although the levels of stress measured in the current study were higher for those receiving respite than for those who were not receiving respite, it is not possible to say whether or not respite has resulted in a reduction, or indeed an increase, in stress. It is possible that the levels of stress reported by families in the Respite group in the current study were lower than those experienced prior to respite services being allocated.

Previous studies have often failed to find sustained reductions in parental stress and this is another possible explanation of the higher stress scores reported by those in the Respite group. Hypothesis 2 of the present study, which stated that “Parents who receive respite will experience less stress than parents of children with similar levels of challenging behaviour who do not receive respite”, was based on studies which have all measured parental stress before, during and after receiving respite, although not all have included long term follow up measures (Botuck & Winsberg, 1991; Mullins et al., 2002). It may be that studies which have concluded that respite has positive effects on parental stress may have drawn different conclusions had they conducted long term follow up. Other studies which have reported improvements in parental stress have not used standardised measures so it may be the case that use of a standardised measure of stress (as was the case in the current study) may have resulted in different outcomes. The only study to include long term follow up in its design was that of Singer et al. (1989), and failed to find long term gains in parental stress for families receiving a standard respite service.

4.1.3.2 Measurement Difficulties

Differences between the findings of this study compared to other studies may reflect differences in the instruments used to measure parental stress. The measures used have varied among studies, with some using standardised measures and others not. Studies such as those by Joyce et al. (1983) and Marc & MacDonald (1988), which have reported improvements in parental stress, have not used standardised measures and may have found different results if standardised measures had been used. Although Singer et al. (1989) did not find improvements in parental stress in their control group using standardised measures, when asked their opinion of the usefulness of the service they received, the parents in this group reported finding the service beneficial. This highlights the differences which can occur as a result of different measurement techniques and further accentuates the need for standardised measures to be used in order that studies can be replicated.

4.1.3.3 Adequacy of Respite Services

Another possibility which was considered to explain the higher stress scores of those in the Respite group was that the amount of respite families were receiving at the time of the study was not sufficient to reduce their level of stress to a similar level to those who were not receiving respite.

If we consider the above argument that the stress in this group may have been initially higher, it seems even more important that the respite service the family are allocated is adequate to address their level of stress. The amount of daytime respite received by families averaged 4.29 hours per week with only around half of families receiving any overnight breaks. Of those receiving overnight breaks, the average nights per month

was 2.79. Studies which have examined the effects of respite on parental stress have often been reporting on the effects of intensive periods of respite. Botuck & Winsberg (1991) compared a 10 night respite break with 30 night hospital stays and Mullins et al. (2002) investigated the effect of a 3-7 day respite break. Only a few of the families in the current study received such an intensive or long term break and as such comparisons with previous studies may not be valid.

The level of care described as being received by families in the control group of the Singer et al. (1989) study was more comparable to the level of service the families in the current study received. Families in Singer et al.'s control group received up to 3 hours of in home respite per week during the period of the study and close examination of the control group data for this study reveals increases in depression post respite despite parents indicating both satisfaction with and perceived benefits of the basic respite package. The Intensive Support Group in this study which received stress management, parenting skills, support groups and additional community respite not only showed improvements in depression and anxiety post respite, but these gains were maintained at 1 year follow up. The families in the current study experienced a respite service more like Singer et al.'s control group, and so it may be that the increased stress scores of this group do in fact represent a real increase in score as opposed to a lack of detection of stress reduction due to a lack of longitudinal data. A possible explanation for this apparent increase in scores will now be discussed.

4.1.3.4 *Respite further highlights difficulties*

One possible explanation as to why parents who were receiving respite scored higher on measures of stress may be related to the fact that respite allows parents to

experience a few days without having to provide care for their child. During this time, families who have been under considerable stress may benefit from the break in caring but when those caring duties recommence they may have a better realisation of the degree to which their child impacts on their lives. The QRS-F measure used in this study focuses on various factors relating to the impact of the child on the family, (e.g. "Other members of the family have to do without things because of my child") and it may be that families are more aware of these impact issues following a period apart from their child. A period of respite care may also highlight issues about the child's future care which families had not previously considered and these would be picked up by the QRS-F by items relating to concerns about the child's future care.

4.1.3.5 *Effects of non child related stressors*

Another possible explanation for the apparently higher levels of parental stress in the Respite group, may be due to additional stressors, not relating to the child with a learning disability. If the families' main stressors were not related to the child with a learning disability, then respite alone would be unlikely to reduce stress. However, the results of this study do not appear to indicate that this is the case. The families in the Respite group were more likely to rate their child with a learning disability as their top stressor than families who were not receiving respite, and as such might be expected to experience improvements in their levels of stress due to respite.

4.1.3.6 *Summary*

Families in the current study who are receiving respite appear to be experiencing higher stress than those who are not. A number of reasons for this finding have been discussed including: initially higher levels of stress, measurement difficulties,

adequacy of service provision, respite further highlighting difficulties and the presence of non child related stressors. Methodological issues (which will be discussed later) do not allow these explanations to be fully investigated in the context of the current study, but the study by Singer et al. (1989) makes it clear that an increased number of respite hours, possibly in conjunction with additional parent training and support, are necessary for improvements in parental stress to be seen. In addition, non-child related stressors do not appear to be a likely reason for higher stress levels, since child stressors were rated more highly by parents.

4.1.4 Factors Associated with Requesting Respite

This study adds to the limited literature on the factors which differentiate those families who have requested respite from those who have not. As was discussed in the introduction, only one UK study (Chadwick et al., 2002) has set out to investigate directly the factors which differentiate these two groups of parents. Other studies (Grant & McGrath, 1990; Hoare et al., 1998) have also yielded information on these factors, although this was not one of the main aims of either of these studies. Other North American based studies have investigated these issues but, as previously discussed, the differences in resources when compared to the UK mean that these findings must be interpreted with caution.

Studying requests for respite is particularly important in the UK context, as a scarcity of respite resources mean that not all those who have *requested* respite will actually receive it. This in turn means that comparing those who *receive* respite with those who do not receive respite, without taking *requests* for respite into account, has the potential to lead to inaccurate comparisons. In North American studies such as those

by Marc and MacDonald (1988) and Factor, Perry, & Freeman (1990) all families had equal access to respite services, so the conclusions drawn about those receiving respite were the same as for those who had requested it. A similar conclusion could not be reached for families in the UK since there would be families in the No Respite group who had *requested* respite and therefore would have been included in the Respite group of both of the above North American studies.

The findings of the present study which relate to factors associated with requesting respite are discussed below. These will then be discussed together with the findings relating to respite group membership, and any differences highlighted. The terms Requested and Not Requested will be used in the discussion of these results to differentiate between the two groups.

4.1.4.1 Parental Stress and Requesting Respite

The present study found that parents who had requested respite were experiencing significantly higher levels of all aspects of stress when compared to those who had not requested respite. This finding was in keeping with those of Chadwick et al. (2002) and was again found in North American studies (Factor et al., 1990; Salisbury, 1990). Based on Quine & Pahl's (1991) suggestion that parental stress is experienced as a result of a perceived discrepancy between required and available resources, parents' requests for respite can be seen as an attempt to redress this imbalance.

When the results relating to stress and *requesting* respite are considered alongside the results relating to stress and *receiving* respite, an interesting, although perhaps not surprising, picture emerges. Those who have requested respite are more similar to

each other than they are to others in their particular respite group, (i.e. families who have *requested* respite, but who are not receiving any, are more similar to those who have requested respite and *are* receiving a service, than they are to families who have *never* requested any respite). Indeed, within each *requested* group, there were no significant differences in relation to respite group membership. In light of these findings, the results of the effects of respite on parental stress in this study and their interpretation in the light of previous research need to be reconsidered.

Consideration of the information relating to *requesting* respite results in the significant effect of respite on parental stress disappearing. The stress experienced by families within each requesting group does not differ significantly in terms of their respite status although there is a slight tendency for those *receiving* a service to score higher on the QRS-F. This difference is not significant and may be related to the allocation process which will be discussed in a later section.

An interesting point appears as a result of examining the Respite group in terms of requesting status. A small group of 5 families indicated that they were offered and accepted a respite service without having to first request one. Whilst the families in this group did not differ significantly in terms of their total QRS-F score on four of the five subscales, they did score significantly lower on the DEP5 subscale which is an indicator of depression. The other subscale and total scores were lower for those who had *not* requested respite but not significantly so. It might be that if families are allocated a service before requesting one that this prevents an increase in parental depression. If this is the case, there are huge implications in terms of the potential gains of respite. As discussed in the previous section, families who reach “breaking

point” may be too stressed to benefit from respite whereas it would appear that those who have *not* had to request respite are able to either gain or maintain lower levels of stress and in particular, depression.

The North American Studies (Factor et al., 1990; Marc & MacDonald, 1988) which considered differences between those who had requested respite and those who had not, were conducted under conditions whereby all participants had access to a respite service should they request one. This also means that the Requested and Not Requested groups in these studies are equivalent to Respite and No Respite groups. If this is the case in other North American studies, then the comparisons made between these and UK studies may not be valid since most UK studies will have, in their No Respite group, families who have *requested* respite and as such are more similar to those in the Respite group.

To summarise, in the current study, the effect of respite (i.e. the significant differences in stress between those who are receiving respite and those who are not) disappears when considered in relation to families’ requests for respite. However, the factors discussed in the previous section in relation to the effects of respite are still relevant and may explain, at least in part, why those who have requested and are receiving respite appear to be experiencing higher stress when compared to those who have requested, but are *not* receiving, respite.

4.1.4.2 Child Challenging Behaviour and Requesting Respite

Families in the current study who had requested respite were also found to have children with significantly higher levels of challenging behaviour. This finding is in

keeping with the UK studies by Chadwick et al. (2002) and Grant & McGrath (1990), with North American studies finding similar results (Marc & MacDonald, 1988). The higher numbers of children in the Requested group with challenging behaviour in the clinically significant range, (although not all differences were significant), is a further indication of the increased levels of behaviour problems in this group.

As mentioned earlier in this discussion, increased levels of child behaviour were found to be correlated with increased levels of parental stress in all parents in the current study. Parents coping with high levels of challenging behaviour on a daily basis seem more likely to feel the need for additional resources in order to cope with these behaviours and may have sought respite as one way of accessing additional resources.

4.1.4.3 Child Diagnosis and Requesting Respite

Another measure of the complexity of the children in the Requested group could be considered to be the number of additional diagnoses which children had in addition to their learning disability. Children in the Not Requested group all had either one or no additional diagnoses in addition to learning disability, whereas some children in the Requested group had more than one additional diagnosis. There were fewer children with Down's Syndrome in the Requested group although this difference was not significant. Stores et al. (1998) found that parents of children with Down's Syndrome experienced lower levels of stress than families of children with a learning disability but not Down's Syndrome, and this may explain why these families are more represented in the group who have not requested respite.

4.1.4.4 *Professional Support and Requesting Respite*

The number of professionals involved with the families who had requested respite was significantly higher than the number involved with those who had not requested respite. This finding is in keeping with one of the North American studies (Marc & MacDonald, 1988). One possible reason for this difference could be that the families of the children who have requested respite have more complex needs which necessitate the involvement of a greater number of professionals. Another possibility is that, in keeping with the notion of having sufficient resources to cope with the situation, these parents have sought out support in order to meet a perceived deficit in resources. The children in the Requested group do indeed have more challenging behaviour than those in the Not Requested group but the majority of professionals who parents listed as being involved with their child were not professionals who deal directly with challenging behaviour (e.g. speech and language therapist, occupational therapist, social worker). However, there was a greater tendency for children in the Requested group to have challenging behaviour which could be classed as clinically significant. By nature of having problems which can be classed as clinical, one would expect these families to have involvement from professionals who deal with challenging behaviour (e.g. clinical psychologists and child psychiatrist). This appeared to be the case with those in the Requested group being significantly more likely to have had clinical psychology input for their child at some point, either previously, or at the time of the study. While there was no significant difference in terms of the involvement of child psychiatry, there was a trend for those in the Requested group were more likely to have had involvement from a child psychiatrist.

Based on the higher levels of challenging behaviour and the presence of additional complicating diagnoses, it is reasonable to describe the children in the Requested group as having more complex needs which could explain the increased professional involvement in these families. Parents may indeed have sought help to redress an imbalance between required and available resources, and whilst it is not possible to say whether this imbalance is real or perceived, the children in the Requested group do appear to have additional, more complex needs to those in the Not Requested group.

4.1.4.5 *Family Size and Requesting Respite*

Findings from the literature have differed in the contribution of family size to requesting respite, with Chadwick et al. (2002) finding that smaller families requested more respite, and Marc & MacDonald (1988) finding that larger families were more likely to request respite. The present study found no significant differences in family size between those who had requested respite and those who had not. Both findings from the literature could be argued for in terms of resources, since smaller families could be said to have fewer “in house” resources, whereas large families have more family members available to assist with caring. Conversely parents in large families may find their resources stretched between more children, whereas those with small families might not experience this difficulty. Only three families in the current study had 3 or more children (Marc & MacDonald’s (1988) definition of a “large” family) so it is not really possible to draw conclusions based on family size from the current study.

4.1.4.6. Summary

Investigating differences between families who have *requested* respite and those who have not, yielded more useful information than the comparison between those who were and were not *receiving* respite. Due to the scarcity of respite resources in the UK any group of families who are not receiving respite is likely to include families who have requested respite but have yet to be allocated a service. Analysis found that those in each of the requesting groups had more in common with each other than with their respective respite group. It also highlighted which factors led to families requesting respite. The subgroup who were receiving respite without having requested it provide information that is of potential clinical and service relevance. These families appear to have been protected against depression by having respite provided before reaching the point where they felt the need to ask for it. It is not possible to firmly conclude this from the present study, but this finding will be discussed later in reference to directions for future research.

4.1.5 Factors Associated with the Allocation of Respite

Previous studies (Chadwick et al., 2002; McConkey et al., 2004; Treneman et al., 1997) have investigated factors which differentiate families who have been allocated respite from those who have requested a service but have not been allocated one. Not all of the factors identified in the previous research were within the scope of the current research but those which were will be discussed below, together with those factors from the current study which differentiated these two groups.

4.1.5.1 *Child Dependency and Respite Allocation*

Trenemam et al. (1997) found that children with high levels of dependency were more likely to receive respite than those who were less dependent. In the current study, no direct measure of child dependency was used but information from the Physical Incapacitation subscale of the QRS-F provides details of the child's need for assistance with a number of self care tasks (e.g. "My child can feed himself/herself" and "My child can walk without help"). It is the only subscale of this measure which does not include items related to parental perception or interpretation of some aspect of the child or family, so can reasonably be taken as factual information about the child's level of dependency. Whilst there was not a significant difference between those who had been allocated respite and those who had not on this subscale, there was a tendency for those who had been allocated respite to score higher on this subscale with the result approaching significance. This suggests that, as in Treneman et al. (1997) study, families are more likely to be allocated a service if their child is more physically dependent. More of the children who had been allocated respite had cerebral palsy, (a condition often associated with physical incapacity) when compared to those who had not been allocated a service. It was not possible to ascertain whether or not this difference was significant due to the limited numbers in each group but this might further indicate that children who are more physically dependent are more likely to be allocated respite.

These differences in allocation may reflect the fact that, as previous studies have suggested, respite services struggle to cope with children who have aggressive and challenging behaviour and children who are more physically dependent are perhaps less physically able to engage in these kinds of behaviour. It may also be that those

who are responsible for the provision and allocation of respite care (i.e. local authorities) believe that parents with physically dependent children are more in need of a break than those with behaviourally difficult children. Whilst level of dependency has been linked to parental stress (Beckman, 1983; Floyd & Gallagher, 1997; Sloper et al., 1991; Tomanik et al., 2004), an even greater body of literature points to the contribution of challenging behaviour. As such, it would seem that those considering the provision and allocation of services should place greater emphasis on the need of families whose children may have lower levels of dependency, but pose different challenges to their parents.

4.1.5.2 Age of child and Respite Allocation

Chadwick et al. (2002) found that children in their study who were allocated respite were more likely to be older than those who had not been allocated a service. Other studies have tended to suggest that older children are *less* likely to be allocated respite (Cutler, 1986; Intagliata, 1986; Orlik et al., 1991; Robinson, 1994; Stalker, 1988). In the present study, there was no significant difference between the mean ages of children who had been allocated respite when compared to those who had not. One possible reason between the Chadwick et al (2002) and the other studies mentioned above is that the differences in the ages of children in the Chadwick et al. (2002) study represent time spent waiting for a respite place to become available with children being older by the time they reached the top of a waiting list.

4.1.5.3 Professional Support and Respite Allocation

The only statistically significant finding of the present study in relation to respite allocation was the involvement of professionals with the child and their family.

Children who had been allocated a service had significantly more professionals involved in their child's care at the time of the study. One possible explanation for an increase in the number of professionals was discussed earlier and relates to the suggestion that children with more complex needs will have more professionals involved in their care. With this in mind, one could interpret the finding related to respite allocation as being related to the complexity of the needs of the child. Another possibility is that the professionals involved with the family are able to provide reports or information which supports the family's request for respite. Professionals involved with families are often called upon by the family to provide this sort of information or may feel, after assessing the family, that respite would be beneficial and so start the process of requesting respite.

4.1.5.4 *Child Challenging Behaviour and Respite Allocation*

As has been discussed previously, increased levels of challenging behaviour was one of the factors which led to families requesting respite. The present study investigated whether or not the child's level of challenging behaviour seemed to influence the allocation of respite. Whilst four of the five ABC-C subscale scores and the total ABC-C total were higher for those in the Allocated group, the differences were not statistically significant. One subscale, Inappropriate Speech, was higher for those in the Not Allocated group. A possible explanation for this subscale score being in the opposite direction to the others may relate to the level of disability of children in the Allocated group. The items included in this subscale refer to behaviours relating to spoken language such as talking loudly or repetitively. If the children in this group have a higher degree of physical dependency, as suggested above, then it may also be that these children have little or no spoken language, leading to a lower score on this

subscale. Children in this group may also have higher degrees of learning disability and as such lack spoken language. However, the level of learning disability was not measured in the present study so it is not possible to draw firm conclusions on this basis.

The numbers of children who met the criteria for clinical levels of challenging behaviour was higher in the Allocated group, although again the difference between the groups was not statistically significant. This, together with the above trend for those in the Allocated group to have higher ABC-C scores, seems to suggest a trend for those who have greater levels of challenging behaviour to be allocated respite, although due to the lack of statistically significant results it is once again not possible to draw firm conclusions.

4.1.5.5 *Parental Stress and Respite Allocation*

Since one of the main aims of respite care is to reduce the burden on carers and therefore presumably parental stress, the present study sought to investigate whether allocation of respite was influenced by parental stress. There are potential difficulties in the interpretation of these data. Since the present study was not longitudinal, comparisons of those receiving and not receiving respite cannot be separated from any effect on parental stress of the respite itself. This means that the differences captured in the questionnaires do not necessarily give the same information as might have been available to those allocating respite at the time when a respite was offered. The present study did not find any significant differences in parental stress between those who had been allocated respite and those who had not, although there was a trend for those who had been allocated respite to score higher. The reasons for this may be the

same as those discussed above in relation to the comparisons between the total Respite and No Respite groups. Ratings on a simple 5 point Likert scale revealed no differences between the groups in relation to either child related stress or overall stress.

As with child challenging behaviour, parental stress may be considered by those allocating respite, with resources being allocated to those who are more stressed. It is not possible to draw firm conclusions however due to the lack of pre-respite stress scores.

4.1.5.6 Summary

There are not enough significant results relating to the allocation of respite to allow any firm conclusions to be drawn. Despite this, there are some indicators as to the factors which are used in the allocation process. The data which were closest to statistical significance related to the degree of physical dependency of the child, with those who were more dependent being more likely to receive respite. Having an increased number of professionals involved in the child's care was significantly associated with the allocation of respite. However, it is not clear whether or not these professionals reflect the complexity of the child and that respite allocation was affected by this, or whether or not these professionals supported or initiated the parents' application for respite thus speeding up the allocation process.

4.1.6 Satisfaction with Respite and Parental Stress

As stated in the results section, it was not possible to compare parents who were satisfied with their respite with those who were not, due to no participants expressing

dissatisfaction with the quality of their respite provision. Given the scarcity of resources and the fact that McConkey et al. (2004) have suggested that families who are desperate for services will accept any service offered to them, it is perhaps surprising that none of the families in the study expressed dissatisfaction. There was however, a small group of parents who had been offered respite but declined it, as they felt the service offered was not appropriate. Previous studies (McConkey et al., 2004; Neufeld et al., 2001) have suggested that parents will accept inappropriate services, but this did not appear to be the case in the present study. Respite services appear to be being targeted appropriately in Lothian, and the majority of families are being offered services appropriate to the needs of themselves and their child.

An oversight of the present study, which will be discussed in a later section, was a failure to ask parents if they were satisfied with the quantity and type of respite they were receiving. The targeting of services may mean that some families, whilst receiving an appropriate type of respite, are not receiving a satisfactory amount of respite. For example, there may not be an appropriate overnight respite service to meet the needs of a particular child and so rather than offering an inappropriate overnight service the family are offered only a day service. They might be satisfied with the day service they receive, but not with the fact that they are not currently receiving any overnight breaks. This detail was not captured by the present study.

4.2 Section 2: Methodological Issues

The present study had a number of methodological strengths and weaknesses. These will be discussed in turn below.

4.2.1 Methodological Strengths

A strength of the present study was that all of the information captured was contained within four relatively brief questionnaires with very few open ended questions. Other studies have used more and longer questionnaires together with one or more interviews. For example, Hoare et al. (1998) required parents to complete five relatively long questionnaires and undergo an interview with a research assistant. Given that it was expected that many of the families in the current study would be experiencing high levels of stress and pressures on their time, the use of four relatively brief questionnaires may have resulted in a higher response rate than if more, and more complicated questionnaires were used.

The measures used were another strength of the present study. Many previous studies have used non standardised measures (Joyce et al., 1983; Marc & MacDonald, 1988) or have used measures which have not been specifically designed for children with learning disabilities or their parents. Examples of such questionnaires include The Parenting Stress Index (Abidin, 1995) or The Child Behaviour Checklist (Achenbach, 1991) Whilst these measures have been used in the study of this population they were not designed with them in mind, whereas the QRS-F and ABC-C were both designed specifically for a learning disabled population.

Another strength of the present study is that it adds to the information on parental stress, challenging behaviour and respite use in the UK. As there are considerable differences in how respite is funded and provided in the UK and North America, the literature from North America potentially has less validity when applied to a UK population. The study also adds to the very limited UK literature on factors

associated with requesting respite and provides some insight into the allocation of services. The study also adds to the very limited literature on requesting, allocating and using respite in the UK and in Scotland in particular.

The current study points clearly to a number of clinical implications, which will be discussed below. Given that health in Scotland is a devolved issue, it is very important that the information relating to clinical need is based on a Scottish population. This study provides information relating to possible clinical psychology resource issues in a Scottish (and specifically Lothian) population.

4.2.2 Methodological Difficulties

The present study had a number of weaknesses which may have affected the findings or which have limited the interpretation of these findings.

The current study was a postal study where participants indicated their willingness to take part by returning questionnaires which had been sent to them unsolicited. As mentioned previously, the return rate for postal questionnaires is typically low (Oppenheim, 1992) and as such a large number of questionnaires had to be sent out in order to ensure sufficient participants were recruited. This type of study can also result in the self selection of participants, although responses in the present study were relatively equally split between those who received respite and those who did not. Within these groups however, there may still have been a degree of selection taking place. None the less it is difficult to avoid self selection in a study of any design, as the process of recruitment and/or participation in a study of any sort requires a commitment from the participant which will inevitably lead to some choosing not to

take part. The only exception would be a study where data were already being collected for some other purpose for all subjects (e.g. census data) which would then allow researchers to draw from a less selected sample. Data of the sort required for this study was not available in this form as this sort of information (e.g. standardised stress scores) is not routinely collected for any other purpose.

A significant oversight of the present study was a failure to ask parents about their level of satisfaction with the amount of respite they received. In light of the scarcity of respite services in the UK, some families who are receiving respite may have felt that they would benefit from an increase in hours or nights. Very few of the UK studies have looked at this particular issue and collection of these data would have allowed for comparisons to be made between those who were satisfied with the amount of respite they were receiving and those who felt they needed more respite. This factor could have been considered separately from the other measures of satisfaction which were included in the present study and from which insufficient variation was found.

Studying changes in parental stress due to receiving respite was not an aim of the current study and as such it was not possible to draw firm conclusions about the effect of respite on parental stress due to a lack of baseline stress data for the studied population. Future studies collecting such baseline information might be able to draw conclusions about the effects of respite. Some or all families in the respite group may have experienced a reduction in stress since receiving respite, but this was not reflected in the data captured at one time point only. One possible way to address this in the context of a one time point study would have been to ask parents to rate how

much they felt their level of stress had decreased (if any) since receiving respite. This may not have been particularly useful however as previous studies (Singer et al., 1989) found that parents who indicated that they felt less stressed since receiving respite were not found to be less stressed when assessed using standardised measures. The only way to accurately assess this would be in a longitudinal study in which a standardised measure of stress was given to parents at the time they requested respite, when they first received respite and then at regular intervals after that. This was not within the scope or timescale of the present study and would require a co-operative approach with social workers and respite providers.

This study predominately used non parametric statistics for the analysis of data. The majority of the data in this study did not fulfil the criteria for the use of parametric statistics in that they were not normally distributed. In some cases it was possible to transform the data set to produce a distribution that did not differ significantly from normality and in these cases parametric tests were used. In other cases this was not possible and so a non-parametric test was chosen. Non parametric tests increase the likelihood of making a type II error when used with data which meet the requirements for parametric tests. However, if the requirements for parametric tests are not met (as in the present study) then non parametric tests are an appropriate choice (Clark-Carter, 2004). The number of participants required if a large effect size and Power of 0.8 were assumed was calculated on the basis of the parametric tests to be used, so it can reasonably be assumed that power will not be markedly reduced, if at all, when nonparametric tests based on ranks are used (Clark-Carter, 2004).

The current study also did not collect data relating to socio-economic status or indicators of poverty. Emerson (2003) found that families of children with learning disabilities were more likely to be living in poverty and found that socio-economic factors were associated with poor maternal mental health. Differences in stress found in families in the current study may in part be due to differences in socio-economic status. The most commonly used method of collecting such socio-economic data is by means of deprivation category scores which are associated with postcodes. Collecting postcodes may have compromised the anonymity of the current study and as such this data was not collected.

4.3 Section 3: Clinical Implications

Although the current study did not set out to specifically study a clinical population, it still has many implications for clinical practice. There were two main reasons for not directly studying a clinical population. Firstly, the child learning disability clinical population in Lothian is small. Calculations indicating the number of participants needed for the study (as detailed in Chapter 2) together with the expected low response rate from a postal study (Oppenheim, 1992) meant that using only a clinical population would have been likely to result in an insufficient number of participants being recruited. Secondly, a number of families who are receiving respite will not be known to clinical psychology services since their children are not considered to display sufficiently complex or challenging behaviours to necessarily warrant referral. Recruiting purely from a clinical population would have resulted in only a small proportion of those receiving respite being represented.

There are a number of clinical implications from the findings of the current study. Firstly, there are resource and service implications for the treatment of challenging behaviour given that the proportion of all children scoring above the clinical cut off for challenging behaviour in the current study, (24.66%), is relatively high compared to the small number of clinical psychologists currently working with children with learning disabilities. Secondly, given the link between challenging behaviour and parental stress found in previous studies and confirmed by the current study, the discrepancy between the number of clinical psychologists and the proportion of children with challenging behaviour also has implications for parental stress. Parents who are not able to receive professional help to manage their child's challenging behaviour are likely to perceive a shortfall between the services they require and those they are receiving and this, as hypothesised by Quine & Pahl, (1991), may lead to increased levels of parental stress. Finally, the current study has demonstrated that the demand for respite care exceeds the available resources and that those families receiving respite are experiencing higher levels of stress than those who are not. Not all families in the respite group were receiving input from a clinical psychologist or child psychiatrist and it is likely that they would benefit from support given their higher levels of stress.

In terms of how best to address these clinical implications, there are a number of possibilities. Existing clinical psychologists could increase the amount of consultation work they do with other professionals in order to allow these professionals to support parents. This would however, lead to a reduction in the amount of direct work they are able to do with families so may not actually result in dramatic increases in the number of families receiving support. Another alternative

would be to increase the number of clinical psychologists working within existing teams and departments so that more clinicians were available. There are obvious financial implications in doing this as the health service would bear the burden of financing these posts. The creation of new clinical psychology posts which allow more joint working with the voluntary sector and other agencies is another possibility. This would not only provide the opportunity for joint funding of these posts but would allow psychologists to work in new ways with parents and children that are perhaps not available to psychologists who are part of existing teams. This could include employing psychologists to work with respite providers in order to provide a more enhanced respite package such as that proposed by Singer et al. (1989) and found to be effective in producing long term reductions in parental stress.

The implications of the current study in relation to challenging behaviour, parental stress and respite will now be discussed in more detail, particularly in relation to population recruited for the current study.

4.3.1 Implications relating to challenging behaviour

Although the sample was not recruited from a clinical population, a reasonable proportion of all children on whom ABC-C questionnaires were completed (24.66%) had challenging behaviour which reached the level of clinical significance (Aman & Singh, 1994). This figure reached 36.36% for those in the Respite group. Whilst not all of the families in the study who had children whose challenging behaviour was classified as having reached a clinical level were necessarily known to the local child learning disability mental health service, 31.51% reported having seen a clinical psychologist and 20.55% a child psychiatrist. From these figures it can be seen that,

although not recruited directly from a clinical sample, some of the families in the present study represent a clinical population.

Regardless of whether or not children and families meet criteria for clinical significance, the link between parental stress and child challenging behaviour confirmed in this study has clear implication for the provision of clinical psychology services to families of children with learning disabilities. As suggested by Baker et al. (2003) the cycle set in motion by the link between child challenging behaviour and parental stress has the potential to lead to increases in both challenging behaviour and parental stress due to the cyclical interaction. Clinical psychologists are well placed with the skills to work with parents and children in addressing behavioural difficulties, but current resources are unlikely to be able to meet this need and referrals are often only made once problems reach unmanageable levels. The number of clinical psychologists working with children in Scotland is small; approximately 22% of all applied psychologists in Scotland (NHS Education for Scotland, 2005). Information is not available regarding the number of clinical psychologists working specifically with children with learning disabilities but the total number is likely to be even smaller. There is an argument for clinical psychologists to be involved in a consultative role with health visitors and other early years workers to try to deal with behavioural issues before they reach clinical levels and the cyclical interaction with parental stress begins.

4.3.2 Implications relating to parental stress

Although challenging behaviour has been identified as one of the main factors associated with parental stress, other factors including parental mental health have

also been implicated. Regardless of the root causes of stress, stress management techniques may be useful for parents of children with learning disabilities. These could be provided in conjunction with the interventions related to child challenging behaviour discussed above, but mainstream services also need to have an awareness of the specific factors associated with parental stress in parents of children with learning disabilities. Parents may present at primary care services, such as their GP, with symptoms of stress and professionals in these areas may need more training and information to enable them to best support parents. Research from the older adult literature suggests that treatment is often denied individuals if the treating professional feels that experiencing mental health problems is an inevitability based on their given situation and as such untreatable (Blanchard, 1992; Unutzer, 1999). Similarly, clinicians who view stress as an inevitable consequence of parenting a child with a learning disability, may deny parents access to treatments they would offer to patients with typically developing children. Clinical psychologists working with children with learning disabilities are potentially the best placed to provide training and raise awareness about stress in parents of children with learning disabilities but as mentioned above, clinical psychologists working in this area are relatively few and as such, the majority of their time may currently be spent on direct clinical work. By increasing the amount of consultation work they do and raising awareness amongst other professionals early intervention for parental stress may be possible. This in turn has the potential to reduce the strain on other services such as adult mental health services.

4.3.3 Implications relating to respite

The commissioning and allocation of respite care services are not roles for clinical psychologists but the profession has much to offer those who are responsible for the commissioning and allocation of services, particularly in relation to clinical psychology services for those using respite services. Since many of the children receiving respite will have challenging behaviour of some degree, there is a role for clinical psychologists in supporting both respite carers and parents in the management of this behaviour. An intensive care package as suggested by Singer et al. (1989) seems to be more effective in achieving long term reductions in parental stress, and the role for clinical psychologists in such a package is clear. The provision of stress management, coping skills and parenting skills to parents of children using respite services would be an innovative way of working with these parents. However, the problem of clinical psychology resources is again relevant, as current staffing levels would be unlikely to be able to accommodate the provision of this kind of service despite this being likely to reduce the impact of parental mental health problems and therefore decrease demands on other services.

The current study demonstrates clearly that the demand for respite outstrips current availability, and this information may be of use to those responsible for the provision of services. The differences between those who have requested respite and those who have not, demonstrate that parents who have *requested* respite are experiencing significantly more stress than those who have not and are therefore suitable candidates for respite services.

4.4 Section 4: Directions for future research

The findings of the present study and the limitations identified suggest several possibilities for future research.

As indicated above, the lack of baseline data makes it impossible to draw definitive conclusions of the effect of respite on stress from the current study. Future research which collected baseline stress data from participants prior to them commencing respite would allow the effects of respite on parental stress to be more clearly examined. This would potentially allow hypothesised explanations, such as an increase in stress due to the difficulties of the child being highlighted, to be explored further.

Seeking parents' views about their satisfaction with the *amount* of respite they receive would allow comparisons to be made between those who were satisfied with the amount of respite they received and those who were not. This would also provide information for those who provide respite services which might help them to plan future services. If it was found that satisfaction with the amount of respite impacted on parental stress then this would justify increased resources to provide parents with the amount of respite they feel they need.

The evaluation of a pilot enhanced respite service such as that outlined by Singer et al. (Singer et al., 1989) would allow the effectiveness of such a programme in a UK population to be assessed. Such a study would have to be controlled and participants carefully matched to ensure, as far as possible, that differences in parental stress could be attributed to the enhanced service. Information from a project such as this could

support the funding of additional staff in order to provide similar services more widely.

4.5 Section 5: Conclusion

This study set out to investigate the occurrence of challenging behaviour and parental stress in families of children with learning disabilities in Lothian and to examine their relationship to respite care. It was found that higher levels of parental stress and child challenging behaviour were both associated with families requesting respite but that the provision of respite was not associated with lower parental stress. Some possible explanations for the failure of the study to find respite effective in reducing parental stress were discussed and directions for future research suggested.

A significant correlation was found between parental stress and child challenging behaviour which is in keeping with a large body of previous research, (Floyd & Gallagher, 1997; R.P Hastings, 2003; Hodapp et al., 1997; Hodapp et al., 1998; Quine & Pahl, 1985, 1991; Ricci & Hodapp, 2003; Stores et al., 1998; Tomanik et al., 2004; von Gontard et al., 2002). This has implications for the provision of clinical psychology services to this population in order to prevent the cyclic interactions between parental stress and challenging behaviour (Baker et al., 2003) becoming detrimental to both parent and child.

The study highlighted the scarcity of respite resources by identifying a reasonable number of families who had requested respite but were not receiving a service. These families were very similar to those who *were* receiving a service in the level of stress experienced by parents, the level of challenging behaviour displayed by the child and

in a number of demographic factors. The similarities within the Requested group suggest that all of these families are in equal need of respite.

A number of clinical implications of the study were identified and their impact on the provision of clinical psychology services to children with learning disabilities and their families was discussed. The role of clinical psychologists in relation to consultation, training and joint working was also discussed and again resource implications were identified.

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(QRS-F)

APPENDIX 1

Approval letter from West Lothian Council



West Lothian

Education & Cultural Services

Lindsay House
South Bridge Street
Bathgate
West Lothian
EH48 1TS

Tel 01506 776000
Fax 01506 776378

8th February 2005

MBC/HD

Helen Downie
Trainee Clinical Psychologist
CFMHS
Learning Disability Team
3 Rillbank Terrace
Edinburgh

Dear Helen

Doctorate in Clinical Psychology: Thesis Research

Thank you for your letter of 18th January 2005, requesting the opportunity to include Pinewood School, Cedarbank School and Beattie School in your research. I read with interest your proposal and I am happy to agree to your request. You will of course require to negotiate with individual Head Teachers on the operational issues.

I wish you well with your research and would welcome the opportunity to read your final submission.

Please do not hesitate to contact me if I can be of further assistance.



APPENDIX 2

Approval letter from Midlothian Council

Psychological Services
Midlothian Council
Greenhall Centre
Gowkshill
Gorebridge
EH23 4PE

Education

Director
Donald S Mackay

Midlothian

26 January 2005

Helen Downie
Trainee Clinical Psychologist
Child and Family Mental Health Service
Learning Disability Team
3 Rillbank Terrace
Edinburgh



Dear Helen

Thank you for the copies of your research proposal and questionnaires. I am happy for you to proceed with the study and assume that the "score outs" on the ABC front page indicate it (the front page) will not be used to maintain anonymity.

I would also be interested in your results, as, like Sally, we would be interested to know whether there are options to reduce stress in parents regardless of respite.

Good Luck.

Regards

Alan Haughey
Principal Psychologist
alan.haughey@midlothian.gov.uk

Your Ref:
Our Ref: AH/jl

Tel 01875 825000
Fax 01875 823603
www.midlothian.gov.uk

APPENDIX 3

Approval letter from City of Edinburgh Council

◆ EDINBURGH ◆

THE CITY OF EDINBURGH COUNCIL

EDUCATION Quality Services

Ms Helen Downie
Trainee Clinical
Psychologist
NHS Lothian
Primary and Community
Division
CFMHS
Learning Disability Team
3 Rillbank Terrace
Edinburgh

Date 14 February 2005

Your ref

Our ref q/gm/lw

Direct Dial 0131 469 3121

Dear Ms Downie

Research Proposal

I am writing to confirm the permission given to you in principle in our recent telephone conversation, to approach parents of pupils at Pilrig Park and Prospect Bank schools.

The questionnaire you propose to send to parents has been seen by senior colleagues in the Department who have responsibilities in the area of special education, and they are happy with its content and with the wider research proposal.

As I explained when we spoke, however, our policy is to leave final discretion in relation to participation in research enquiries with the Head Teacher and staff of the school(s) concerned.

I would like to wish you success with the research, and with completion of your Doctorate. I would very much appreciate a copy of your thesis when this becomes available, as your work will be of considerable interest to the colleagues mentioned earlier (an unbound copy would be perfectly acceptable).

Yours sincerely,

Graham H Munn
Principal Officer (Administration and Support Services)

FIONA McLEOD
HEAD OF QUALITY SERVICES



APPENDIX 4

Approval letter from East Lothian Council



**East Lothian
Council**

**Mrs Lorna J MacLeod MBE MA
HEAD TEACHER**

Meadow Park
St Mary's Campus
Tynebank Road
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Helen Downie
Trainee Clinical Psychologist
CAMHS
Learning Disability & Autism Team
3 Rillbank Terrace
Edinburgh
0131 662 2202

21/1/05

Dear Helen

Thank you for your recent communication. We would be delighted to help you in any way with your research - it is an extremely worthwhile project.

I look forward to hearing from you in due course.

Yours sincerely

Lorna J MacLeod

APPENDIX 5

Parent Information Sheet

Parent Information Sheet

Research Project: Parental Stress and Respite

We are doing a study on the effects of respite on parental stress. You are being invited to take part in this research study because your child attends one of the special schools which has agreed to take part in our study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with friends, relatives or anyone else you feel would be helpful. You can contact us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Parents of children with a disability have been found to have high levels of stress. The amount of care the child needs and them having behavior and communication problems can lead to even higher levels of stress among carers. This stress is also associated with people requesting or using more respite services.

Studies have found that during respite, mothers felt better and were less depressed. Mothers receiving respite showed overall benefits when compared to those not receiving services. Respite care services have been found to be helpful in improving family relations, increasing social activities, and alleviating physical and emotional strains.

Reducing the level of carer stress and improving parental mental health by providing good quality respite seems likely to result in reducing the use of health care services (particularly mental health services) by both for children and parents.

We would like to investigate further the relationship between levels of parental stress and respite. We are also interested in the sorts of things that parents think are important in a good respite service, and whether parents who are satisfied with their respite care experience different levels of stress from those parents who are not satisfied with their respite. This research will be submitted as part of the academic requirement for a Doctorate in Clinical Psychology.

IMPORTANT INFORMATION

- This study is completely anonymous. It will not be possible for the researcher or anyone else to identify your family from the answers you give.
- Taking part in this study, or choosing not to, will not affect any respite you currently receive.
- Taking part in this study will not help you to get respite if you do not currently receive any.

What do I have to do to take part?

- All you have to do to take part is to complete the enclosed questionnaires.
- This should take no more than 1 hour in total. You do not have to complete all the questionnaires at the same time as long as you *return* them all at the same time, in the envelope provided.
- Most of the questionnaires require you to circle the answer that applies to you. There are no long answers to write.

There are 4 different questionnaires:

- 1) An Information Questionnaire about your family.
 - 2) A Respite Questionnaire about the respite you receive (if any) and the kind of respite you would ideally like.
 - 3) A Questionnaire about your child's behavior
 - 4) A Questionnaire about the stresses associated with caring for a child with special needs.
- Once you have completed the questionnaires simply put them all in the stamped addressed envelope to return them to the researcher by **15th APRIL 2005**.
 - You will not be contacted again by the researchers except for a thank you note that will be sent out to all parents at the participating schools.

Tips for filling in the questionnaires

- This study is totally anonymous so do not fill in any personal details like your name, your address or your child's date of birth even if there is a space on the form for this.
- Answer as honestly as possible. There is no need to feel embarrassed about your answers as no-one will be able to tell which questionnaires are yours.

What if I decide not to take part?

Taking part in the study is completely voluntary. If you decide you do not want to take part, do not fill in the questionnaires. You will receive a thank you note along with all the other parents at your child's school. Everyone will receive one of these notes as we will not be able to identify which families have decided not to take part.

What if I want more information?

If you are not sure about taking part or would like more information about the study you can contact the lead researcher, Helen Downie, or Dr Sally Cheseldine (Supervising Clinical Psychologist). If you decide to contact us you do not need to give your name, you can simply ask to speak to either of the people mentioned above about the study.

Many thanks for taking the time to read through this information.

Lead Researcher: Helen Downie,
Trainee Clinical Psychologist,
Learning Disability Team,
CFMHS
3 Rillbank Terrace,
Edinburgh.
Tel No. 0131 662 2202

APPENDIX 6

Information Questionnaire

Information Questionnaire

The following questions ask a few details about your child and family. None of the questions ask you to give information that would allow your child or family to be identified. The information will allow us to compare different types of families. This questionnaire should be completed by the person who spends most time caring for the child who brought home these questionnaires.

For the rest of this questionnaire, "your child" means only the child who brought home this pack of questionnaires.

Your child

The following 4 questions are only about your child.

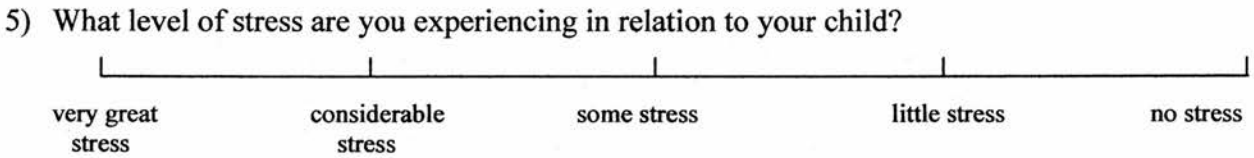
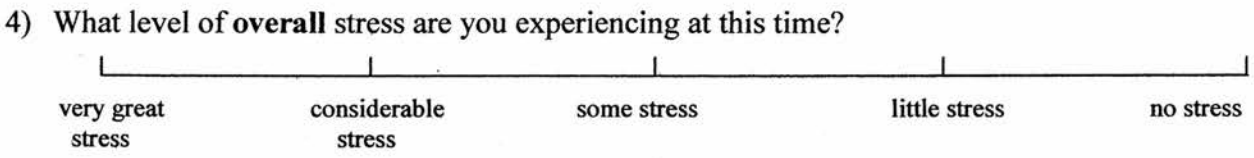
- 1) How old is your child?.....
- 2) Does your child have a diagnosis (apart from Learning Disability) which describes/explains their difficulties, (e.g. autism, downs syndrome, cerebral palsy etc)?
YES/NO (please delete as applicable)
If YES please give details.....
- 3) Do you consider your child's difficulties to be: (please tick one)
 Mainly physical
 Mainly behavioural
 Mainly communication
 An equal mix of 2 or more of the above. Please specify.....
- 4) Does your child have a sensory disability (e.g. sight or hearing)?
YES/NO (please delete as applicable)
If YES please give details.....

Your Family

- 1) How many adults live in your house? (including yourself)
 - 2) What is each adult's relationship to your child? (e.g. mum, gran, dad etc)
Adult 1
 - Adult 2
 - Adult 3
 - Adult 4
- 3) How many brothers and sisters does your child have?
Brothers
 - Sisters
- 4) How many of these brothers and sisters live in the same house as your child for most of the time?
Brothers
 - Sisters

About you

- 1) What is your relationship to your child?
- 2) Do you work outside the home? Full Time/Part Time/Not at all (please delete as appropriate)
- 3) Please list your top 3 stressors in your life at this time. These can be anything relating to work, home, finances, your children etc.
 - i)
 - ii)
 - iii)



Support Services

- 1) Please indicate whether your child/family currently have, or have every had, support from any of the following:

Community Learning Disability Nurse	Currently/Previously/Never (please circle)
Speech & Language Therapist at school	Currently/Previously/Never
Speech & Language Therapist at hospital/GP	Currently/Previously/Never
Occupational Therapist at school	Currently/Previously/Never
Occupational Therapist at hospital/GP	Currently/Previously/Never
Educational Psychologist (via school)	Currently/Previously/Never
Clinical Psychologist (via hospital/GP)	Currently/Previously/Never
Child Psychiatrist	Currently/Previously/Never
Social Worker	Currently/Previously/Never
Hospital Doctors (e.g. paediatrician)	Currently/Previously/Never
Other (please give details).....	

APPENDIX 7

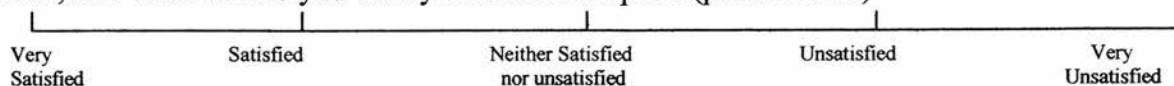
Respite Questionnaire

Respite Questionnaire

The questions below ask you about the respite you receive or would like to receive.

For the purpose of answering these questions, respite is: "Care/support provided by non-family members and not paid for by parents. Respite may be funded by Social Work or other organisations and the care/support provided can take many forms. Respite is care that takes places out with normal school hours and/or out with normal school term time.

- Please Circle
- 1) a) Have you ever been offered respite without asking for it? YES/NO
b) Have you asked for respite? YES/NO
c) If you have asked for respite was any offered to you? YES/NO
d) If you have been offered respite, did you accept what was offered? YES/NO
e) Are you currently receiving respite? YES/NO (If No go to Q9)
- 2) Which of the following kinds of respite do you currently receive? (Tick all that apply)
- A carer/carers providing care for your child in your own home during the day
 - A carer/carers providing care for your child in your own home overnight
 - A carer/carers taking your child on an outing
 - Your child going to spend time at a carer's home during the day
 - Your child staying overnight at a carer's home
 - Your child spending time at a respite centre during the day
 - Your child spending time at a respite centre overnight
 - Your child attending an after school club
 - Your child attending a playscheme during normal school holidays
 - Your child attending/staying at school at times when most schools are on holiday
 - Other. Please give details.....
- 3) How frequently do you receive respite?
- Daytime respite hours per day/week/fortnight/month
Overnight respite nights per week/fortnight/month
- 4) Is this respite:
- Provided directly by Social Work (e.g. Share the Care)
 - Paid for by social work but provided by another organisation (e.g. NCH, Autistic Society Vouchers)
 - Other Please give details
- 5) Who cares for your child when they have respite?
- Same 1:1 carer each time.
 - A small team of carers. They all know my child well
 - A number of different carers but my child has a key worker who knows him/her well.
 - A number of different carers. None of them know my child well.
- 6) Overall, how satisfied are you with your current respite? (please circle)



7) How satisfied are you with each of the following aspects of your current respite (please circle):

a) Knowledge & Skills of staff/carers

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
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b) Good communication between respite & home

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
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c) Physically fit carers/staff

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

d) Consistency of approaches/interventions/values between respite/home/school

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
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e) Transport to and from respite

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

f) Gender of carer

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

g) Communication methods used, (e.g. symbols, signing etc)

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

h) Safety of environment, (e.g. closeness to main roads, child proof doors etc)

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
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i) Ability to meet health/medical needs of child

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

j) Appropriate peer group for child

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

k) Suitable activities provided

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

l) Staffing ratio, (e.g. 1 to 1)

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
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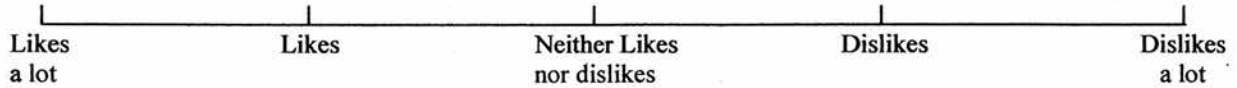
m) Same carer(s) each time

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

n) Location of respite, (e.g. family home/centre/carers home etc)

Very Satisfied	Satisfied	Neither Satisfied nor unsatisfied	Unsatisfied	Very Unsatisfied
----------------	-----------	-----------------------------------	-------------	------------------

8) How much do you think your child likes having respite? (please circle)



9) Please rank the following in order of which is most important to your family & your child when considering your "ideal" respite care, (1=most important, 14=least important).

- Knowledge & Skills of staff/carers
- Good communication between respite & home
- Physically fit carers/staff
- Consistency of approaches/interventions/values between respite/home/school
- Transport to and from respite
- Gender of carer
- Communication methods used, (e.g. symbols, signing etc)
- Safety of environment, (e.g. closeness to main roads, child proof doors etc)
- Ability to meet health/medical needs of child
- Appropriate peer group for child
- Suitable activities provided
- Staffing ratio, (e.g. 1 to 1)
- Same carer(s) each time
- Location of respite, (e.g. family home/centre/carers home etc)

10) If you have been offered respite but are not currently receiving any, please tick the box which best describes why this is. (Do not answer this question if you are currently receiving respite)

- I did not feel the respite offered was appropriate for my child/family (go to Q11)
- I do not feel that I need respite at this time
- I was receiving respite but this has been withdrawn
- I was receiving respite but felt I no longer needed it
- Other. Please give details

11) If you felt the respite was not appropriate for your child/family, please tick why this was the case, (tick as many boxes as appropriate)

- Knowledge & Skills of staff/carers
- Good communication between respite & home
- Physically able carers/staff
- Consistency of approaches/interventions/values between respite/home/school
- Transport to and from respite
- Gender of carer
- Communication methods used, (e.g. symbols, signing etc)
- Safety of environment, (e.g. closeness to main roads, child proof doors etc)
- Ability to meet health/medical needs of child
- Appropriate peer group for child
- Suitable activities provided
- Staffing ratio, (e.g. 1 to 1)
- Same carer(s) each time
- Location of respite, (e.g. family home/centre/carers home etc)

APPENDIX 8

The Aberrant Behaviour Checklist – Community

INSTRUCTIONS

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

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

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

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

- (a) Take relative *frequency* into account for each behavior specified. For example if the client averages more temper outbursts than most other clients you know or most others in his/her class, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.
- (b) If you have access to this information, consider the experiences of other care providers with this client. If the client has problems with others but not with you, try to take the whole picture into account.
- (c) Try to consider whether a given behavior interferes with his/her *development, functioning, or relationships*. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

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

1. Excessively active at home, school, work, or elsewhere	0	1	2	3
2. Injures self on purpose	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other children or adults (verbally or physically)	0	1	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3
<hr/>				
11. Stereotyped behavior; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behavior	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression; lacks emotional responsiveness	0	1	2	3

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

APPENDIX 9

The Questionnaire on Resources and Stress- Friedrich Short Form (QRS-F)

A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)



This questionnaire asks about your feelings about a child in your family. There are many blanks in the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide whether to circle True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please remember to answer all of the questions.

1. _____ doesn't communicate with others of his/her age group T F
2. Other family members do without things because of _____ T F
3. Our family agrees on important matters T F
4. I worry what will happen to _____ when I can no longer take care of him/her T F
5. Constant demands to care for _____ limit the growth and development of someone else in our family T F
6. _____ is limited in the kind of work he/she can do to make a living T F
7. I have accepted that _____ might have to live out his/her life in a special setting (e.g. institution or group home) T F
8. _____ can feed himself/herself T F
9. I have given up things I really wanted to care for _____ T F
10. _____ is able to fit into the family social group T F
11. Sometimes I avoid taking _____ out in public T F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress T F
13. It bothers me that _____ will always be this way T F
14. I feel tense whenever I take _____ out in public T F
15. I can go to visit friends whenever I want T F
16. Taking _____ on holiday spoils pleasure for the whole family T F
17. _____ knows his/her own address T F
18. The family does as many things together now as we ever did T F



19. _____ is aware of who he/she is T F
20. I get upset with the way my life is going T F
21. Sometimes I feel very embarrassed because of _____ T F
22. _____ doesn't do as much as he/she should be able to do. T F
23. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her T F
24. There are many places we can enjoy ourselves as a family when _____ comes along T F
25. _____ is over-protected T F
26. _____ is able to take part in games or sports T F
27. _____ has too much time on his/her hands T F
28. I am disappointed that _____ does not lead a normal life T F
29. Time drags for _____, especially free time T F
30. _____ can't pay attention for very long T F
31. It is easy for me to relax T F
32. I worry what will happen to _____ when he/she gets older T F
33. I get almost too tired to enjoy myself T F
34. One of the things I appreciate about _____ is his/her confidence T F
35. There is a lot of anger and resentment in our family T F
36. _____ is able to go to the bathroom alone T F
37. _____ can't remember what he/she says from one moment to the next T F
38. _____ can ride on a bus T F
39. It is easy to communicate with _____ T F
40. Constant demands to care for _____ limit my growth and development T F



- 41. _____ accepts himself/herself as a person T F
- 42. I feel sad when I think of _____ T F
- 43. I often worry what will happen to _____ when I can no longer take care of him/her T F
- 44. People can't understand what _____ tries to say T F
- 45. Caring for _____ puts a strain on me T F
- 46. Members of our family get to do the same kinds of things that other families do T F
- 47. _____ will always be a problem to us T F
- 48. _____ is able to express his/her feelings to others T F
- 49. _____ has to use a bedpan or a nappy T F
- 50. I rarely feel blue T F
- 51. I am worried much of the time T F
- 52. _____ can walk without help T F



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