AN INVESTIGATION INTO THE PARENTAL STRESS LEVELS OF FAMILIES WHO

HAVE CHILDREN WITH SEVERE DEVELOPMENTAL DISABLITIES USING

RESIDENTIAL SHORT BREAKS: A CONTRIBUTING FACTOR OF ITS STRESS

REDUCTION IMPACT.

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Abstract

This study represents a unique collaboration between the National Health Service and the London Borough of Sutton's social services. The focus and direction of this study was to examine and explore parental stress levels from a quantitative and qualitative perspective for those parents using residential respite care for their developmentally disabled child. The study sought to gain a better understanding of the influence that short breaks has on parents more specifically to gauge whether a reduction in parental stress is linked to the use of short breaks. Combinations of quantitative and qualitative techniques were used to provide a deeper and broader understanding of the research question. Semi-structured interviews were conducted by the researcher and information was analysed using interpretative phenomenological analysis (IPA). The Parenting Stress Index (short form questionnaire) provided psychometric estimates of parenting stress divided into subscales of parenting distress, parent child dysfunction, difficult child and total stress. Overall parents reported a significant reduction in parental stress when using residential short breaks which were validated by the psychometric measures. The limitations of the study are discussed and suggestions proposed for future research are highlighted.

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Preface

Caring for a child with developmental disabilities can be both fulfilling and complicated. Parenting a child with complex needs often places wide-ranging and unrelenting psychological pressure on families and carers. Research demonstrates that parents who have children with developmental disabilities generally experience higher parental stress levels compared to parents without children with disabilities (Baker, Blacher, Crnic & Edelbrock, 2002; Keller & Honig, 2004; Hastings & Johnson, 2001; Einfeld, 2002). Recent research provides much evidence to suggest that families with disabled children face additional and complex challenges in parenting (Spratt, Saylor & Macias, 2007). The nature of the stress parents experience has been shown to impact numerous aspects of family life such as daily living demands. High levels of emotional parental stress can often lead to anxiety and depression, financial problems and unfavourable social consequences such as social isolation (Pelchat & Lefebvre, 2004). Other negative effects include weariness, loss of freedom and marital conflicts. Existing studies reveal that families often feel plagued with feelings of negativity, denial, blame, remorse, helplessness and periods of disbelief. Lalvani (2008) found that parenting a child with developmental disabilities presents significant challenges to the family. Studies highlight the negative consequences when parenting a child with developmental disabilities (Walter & Russel, 2005) and it cannot be disputed that families and carers do experience a great deal of stress when caring for the needs of their child. Some families are able to cope, with varying degrees of success (Hendriks, DeMoor, Oud & Savelberg, 2000; Knapp, 2005; Smith, Oliver & Innocenti, 2001; Spratt et al., 2007).

According to the 2002 *Contact a Family Childcare Survey* 94% of families found that it was more difficult to locate appropriate support for their disabled child and 90% felt that there was not enough choice in childcare for disabled children. The Daycare Trust's *Everyone*

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Counts project (2004), involving focus groups and questionnaires with parents and childcare professionals, found that for 69% of parents of children with developmental disabilities found the process extremely difficult to manage. Research has therefore established that those parenting a child with disabilities often experience considerable stress. Much of the literature available examines the impact of psychological stress on families and carers. Although positive aspects associated with the caring role have been identified, such as self-fulfilment (Lane et al., 2000), there is a link between high levels of carer stress and parental ability to care for a child with developmental disabilities (Baker, Blacher, Crnic & Edelbrock, 2002; Johnston et al., 2003; Ong, Chandran & Peng, 1999; Raina et al., 2005).

The aim of Section B (research component) builds upon the existing research on short breaks and their overall impact on parental stress. Parenting a child with developmental disabilities requires unlimited involvement from families in relation to accepting responsibility and mastering new skills. The literature review illustrates the wide-ranging effects of caring for a child with developmental disabilities. Without a break from the caring role, parents are likely to become exhausted owing to the psychological demands of parenting. This thesis examines the experiences of parental stress from a quantitative and qualitative perspective. The study also examines and explores the research literature related to short breaks for children with developmental disabilities. Access to short breaks is known to have a beneficial impact on parents and carers. It is generally agreed that parental daily routines appear to be shaped and established directly around the needs of the developmentally disabled child (Davies et al., 2005; Swift et al., 1991; McConkey, 2008; Tomanik et al., 2004). Parents whose children are receiving regular short breaks generally display a much improved ability to cope. Mencap's up-to-date review on short breaks, *Breaking Point* (2003), and *Breaking Point: Still Need a Break* (2006) outline several poignant advantages of this service. Wilkie and Barr (2008) found that most families using short breaks have more

time for other day-to-day activities as well as experience improved energy levels. Previous investigations have suggested that short breaks may act as a means to help decrease stress and increase coping ability when parenting a child with developmental disabilities. For example, Laverty and Reet (2001) document such parent's views of short breaks as allowing therapeutic opportunities, quality time and independence for the child and the family. Parents believe that family members feel supported as a result of using short break services. Various aspects around short breaks include making sure the child is engaged in therapeutic activities in conjunction with the promotion and enhancement of teaching independent daily living skills. These skills are seen as crucial to helping the child develop as well as promoting their child's ability to make new friends and the encouragement in engage in the active participation of typical childhood activities. The reviewed literature clearly illustrates the wide-ranging effects that caring for a child with developmental disabilities can have on the whole family unit. Without a break from the caring role most parents are likely to suffer from exhaustion or even illness, due to the constant physical, psychological and social demands of caring. Moreover, it has been recognised that the availability of short-break services can vary significantly and be dependent on social agencies. The benefits of short-break care to families should not be underestimated (Catherall & Iphofen, 2006). Mencap (2006) contends that families should be allowed frequent breaks, bearing in mind that these breaks are beneficial for parents and the young person with a disability. The suitability of the proposed design for the present study is also supported by reference to the techniques employed in past studies and their demonstrable effectiveness in producing validated results. This research design followed a pragmatic approach, integrating multiple methods, diverse world views and unique assumptions, all of which were gathered for analysis. Upon examining the methodologies a combination of a quantitative and a qualitative approach was used in an attempt to provide a deeper and broader understanding of the research question. The study

sought to gain a better understanding of the effect that short breaks have on parents more specifically to gauge whether a reduction in stress is linked to the use of residential short breaks. Analysis of the content was explored to discover the nature and implications of participant's experiences.

Section C (professional practice component) is an example of direct clinical work in a Child and Adolescent Mental Health Services (CAMHS) team with a child presenting with severe learning disabilities. This case highlights the implementation of functional analysis together with a behavioural support plan. Section C also highlights the strengths of this clinical intervention. The final component of this thesis, Section D, comprises a critical review of the literature when conducting functional analysis and the need to include the client. Although the three components of this thesis are separate, they are connected in that they reflect some of the current practical interventions used within the NHS in day to day clinical practice with children who have severe developmental disabilities.

References

Baker *B. L.,* Blacher J., Crnic K. A. & Edelbrook *C. (2002). Behaviour problems and parenting stress in families of three year old children with and without developmental delays.* American Journal of Mental Retardation *107,* 400-444.

Catherall, C. & Iphofen, R. (2006). Living with a Disability*, Learning Disability Practice, 9*, 5, 10-30.

Davies, B., Collins, J. B., Steele, R., Cook, K., Brenner, A. & Smith, S. (2005). Children's perspectives of a paediatric hospice program. Journal of Palliative Care, 21, 250-259.

Enfield, S. L., & Tonge, J. (2002). Manual for the Development Behaviour Checklist: Primary Carer Version (DBC-P) and teacher version (DBC-T) 2nd edition Melbourne: Monash University Centre for the Developmental Psychiatry and Psychology.

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young children with autism. Journal *of Autism and Developmental Disorders, 31*, 300-335.

Hearne, M., & Dunne, J. (1992). *Home Sharing: An Evaluation of Family based Respite Care.* Jay Lee Printers, Galaway.

Hendriks, A. H. C, DeMoor, J. M. H., Oud, J. H. L., & Savelberg, M. H. W. (2000). Perceived changes in well-being of parents with a child in a therapeutic toddler class. *Research in Developmental Disabilities, 21*, 400-450.

Hoare, P., Harris, M., Jackson, P., & Kerely, S. (1998). A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research, 42*, 200-224.

Johnston, C., Hessel, D., Blasey, C., Eliez, S., Erba, H., Dyer-Friedman, J., et al. (2003). Factors associated with parenting stress in mothers of children with fragile X syndrome.

Keller, D., & Honig, A. (2004). Maternal and paternal stress in families with school aged children with disabilities. *American Journal of Orthopsychiatry*, *74*, 3, 330-340.

Knap, J. (2005). Raising a child with autism: The impact on the quality of marital relationships. Dissertation Abstracts International. *The Sciences and Engineering, 65*, 1.

Lane, P., McKenna H. P., Ryan A., & Fleming, P. (2000). *Listening to the Voice of Carers: An Exploration of the Health and Social Care Needs of Informed Carers of Older People.* South Eastern Health Board, Kilkenny.

Lalvani, P. (2008). Mothers of children with Down Syndrome: Constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities, 46,* 430-440.

Laverty, H., Reet, M. (2001). Planning care for children in respite settings. Kingsley, London.

McConkey, R. (2008). Developing services for children and young people with complex physical healthcare needs: Proposals for the development of short breaks provision. Report for the Department of Health, Social Services and Public Safety. Institute of Nursing, University of Ulster, Ulster.

Mencap, (2003). Breaking point: Report on caring without a Break for Children and Adults with Severe and Profound Learning Disability. London: Mencap.

Mencap, (2006). Breaking point: Families Still Need a Break. Report on the Continuing Problem of Caring without a Break for Children and Adults with Severe and Profound Learning Disability. London: Mencap.

Ong, L., Chandran, V., & Peng, R. (1999). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from and evaluation. *Journal of Advanced Nursing, 34*, 603-608.

Pelchat, D., & Lefebvre, H. (2004). A Holistic intervention programme for families with a child with a disability. *Journal of Advanced Nursing, 48,* 120- 129.

Raina, PP., O' Donnel, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russel, D., et al. (2005). The health and well being of caregivers of children with cerebral palsy. *Paediatrics, 115*, 600-610.

Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry, 71*, 200- 240.

Spratt, E., Saylor, C, & Macias, M. (2007). Assessing parenting stress in multiple samples of children with special needs. *Families, Systems, & Health, 25,* 400-420.

Swift, P., Grant, G., & McGrath, M. (1991). Parent's views of different respite care services. Mental Handicap Research, 7, 90-117.

Treneman, M., Corkery, A., Dowdney, L., & Hammond, J. (1997). Respite care needs – met and unmet: assessment of needs for children with disability. *Developmental Medicine and Child Neurology, 39,* 550 - 554.

Tomanik, J. Y., Washington, O.G.M. & Hawkins, J. (2004). The relationship between behaviour exhibited by children with autism and maternal stress. Journal of Intellectual Developmental Disability, 29, 10-20.

Wilkie, B., & Barr, O. (2008). The experiences of Parents of Children with and Intellectual Disability Who Use Respite Care Services, *Learning Disability Practice, 11*, 4, 29- 32.

Chapter 1: Introduction

1.1 Overview

Over the last two decades the UK government policy towards children with developmental disabilities has shifted away from institutionalisation to care in the community. The main factor in this move has been the adoption of the philosophy of normalisation. Wolf Wolfensburger presented the principles of normalisation, underpinned by a set of beliefs that abandon the stereotypes and ideologies of difference and replace them with the rule of inclusion. In this context, inclusion refers primarily to all people being valued, accepted and respected regardless of their ethnic and cultural backgrounds, socio-economic status, abilities, gender, age, beliefs and behaviours. Ainscow (2005) expands significantly on the term "inclusion", describing it as a basic human right and social justice principle that embodies values such as equity and fairness in society. The implementation of normalisation was the rallying plea on behalf of those with disabilities and was the force behind the breakdown and execution of the deinstitutionalisation process. The need for support towards parents of children with developmental disabilities is recognised by the Department for Education and Skills (DFES) (2004) in *Every Child Matters: Change for Children* and by the Department of Health (2004) in the *National Service Framework.*

It is well-documented that parents of children with developmental disabilities often experience chronic psychological stress. The literature is consistent in reporting the occurrence of high stress levels in families (Hendriks, DeMoor, Oud & Savelberg, 2000; Knapp, 2005; Smith, Oliver & Innocenti, 2001; Spratt et al., 2007). A vast amount of research has explored the psychological stress linked to parenting a child with disabilities and the effects this stress has on overall well-being (Baker, Blacher, Crnic & Edelbrock, 2002; Johnston et al., 2003; Ong, Chandran & Peng, 1999; Raina et al., 2005). Frude (1992) found

that such parents are often plagued with feelings of pessimism, helplessness and inadequacy, whereas other parents experience periods of disbelief and self-blame. Although parents of children with disabilities do experience stress, they also receive joys and gain strength and skills in the care-giving environment (Taanila et al., 1999). Very few studies have investigated the characteristics of successful parents; however, it is beyond this scope of this study to explore this aspect. The recognition of child behaviour characteristics and how this recognition impacts on parental stress has been highlighted in recent literature (Blacher & McIntyre, 2006; Chan & Sigafoos, 2000; Dunn, Burbine, Bowers & Blacher, 2005; Osborne, McHugh, Saunders & Reed, 2008). As a result of this identification of the stresses incurred in caring for a child with developmental disabilities, various support systems have been put in place. One way of helping families with a disabled child is to provide short breaks. These have several useful functions, such as offering the child additional experiences outside the family home and providing respite for parents. The term "short breaks" has a number of specialised definitions and is generally described as an intervention specifically designed to provide families with a break from the caring role. Hirst (2004) found that caring for a person with disabilities can significantly impact the carer's physical and psychological health. Mencap (2006) acknowledge the importance of the carer's entitlement to frequent, high-quality breaks, which should be enjoyable for both the parent and the child who has a developmental disability. Wilkie and Barr (2008) conducted a small-scale qualitative study on parental experiences of short breaks. This revealed positive outcomes in that most parents reported renewed energy levels, reduced stress and more time available for other activities. Parents also noted negative outcomes such as feelings of guilt and embarrassment at allowing their child to attend short breaks, largely owing to the perceived quality of services available in the local community.

Disabled children wish to lead ordinary lives and as such do not always want breaks without their families. Parents with disabled children seek practical, flexible help and a break from the physical and emotional demands of caring for their child. Parents often wish that their relationship with their disabled child could be more ordinary, that is, not always having to perform caring or nursing roles. Bringing a child with developmental disabilities into the world can have life-changing implications for both child and family. Such parents provide intense and challenging care in the home, and unlike healthcare professionals who provide care in institutions, many families do not receive breaks from care giving. These parents may therefore experience health and social consequences directly related to care giving. Demands faced by families often include exceptional daily care-giving activities, concerns about the child's future, rising financial costs and often lifelong associations with health and social service agencies (Hastings & Johnson, 2001; Einfeld, 2002).

1.1.2 Chapter presentation

This first chapter introduces the topic of parental stress and developmental disability. The chapter reviewed prior research into the impact of parental stress and its impact on the family system. In chapter two the scope of the study and background to the development of respite care is introduced, together with preliminary hypotheses. It also details factors that contribute to parental stress, theoretical viewpoints as well as contextual and environmental factors in overall parental stress levels. Chapter three expands on the preliminary review, taking into account a broader selection of studies into the effectiveness of short breaks as a means to reduce parental stress. The impact on the whole family of having a child with a developmental disability is considered, including family resources, parent functioning and sibling relationships. Chapter four provides a foundation for assessing stress levels by presenting several methodological issues in relation to current research. The chapter presents

the detailed aims and hypotheses of the present study. This aims to improve the definition of the variables in the level of benefit, principally in terms of stress that respite care services bring to parents who have children with developmental disabilities. The aim of the study was to explore any changes to stress levels before and after use of short breaks. The psychological experiences that parents face on a day to day basis is highlighted as well as the demands of caring for a child with a developmental disability. Chapter five presents the descriptive data relating to parents responses on the PSI. The results of analysis of the PSI are described and compared. Finally, chapter six discusses the results in relation to previous research, the implications of these findings, the limitations of the current study and suggestions for future research.

1.2 Stress Intervention Programmes

Research has examined the link between parenting a child with special needs and parental stress, psychological resources and coping strategies. Healthcare professionals supporting families of children with disabilities acknowledge the importance of ameliorating overall parental stress (Baker, Blacher, Crnic & Edelbrook, 2002, Crnic & Low, 2002; Deater-Deckard, 2005; Tomanik, Washington & Hawkins, 2004; Spratt & Macias, 2007). Rossiter and Sharpe (2001) found that this support has various implications, including the psychological well-being of parents. In some cases where there is no support children within the family may also be at risk of developing psychological problems. Generally, parents with high stress levels tend to engage in parental behaviour that impacts child outcomes. Little research in the developmental-disabilities literature specifically explores the possibility of a direct link between parental stress and resultant parental behaviour. Interventions that have successfully improved parental skills and reduced challenging behaviours of children with developmental disabilities appear to benefit overall parental well-being. Predictors of stress in

parents seem to be inextricably linked to child characteristics. Outcome studies provide evidence of a firm link between the severity and complexity of behaviour in children with developmental disabilities, parental stress and psychiatric problems such as clinical depression (Baker, Blacher, Crnic & Edelbrook, 2002; Stores, Fellows & Buckley, 1998). Psychological interventions that improve parental skills and reduce behavioural problems in children appear to enhance overall parental well-being. Feldman and Werner (2002) found that parents in receipt of behavioural training skills report an increase in self-efficacy in managing complex and challenging behaviour.

Parent-managed support groups are another way of offering effective interventions for families within the local community. Parental support groups are considered extremely valuable as they can often provide guidance to families in managing day-to-day events as well as offer advice on complex difficulties experienced at home. Although parental support groups are a rich source of support for families, some may require more focused intervention delivered by healthcare professionals. Barlow et al. (2002), in a meta-analysis of parenting programmes, found significant reductions in maternal stress after the completion of group work. However, it is difficult to draw conclusions, as published research on group interventions for parents of children with developmental disabilities is limited and more often than not contains multiple components. Implementing any form of structured or unstructured intervention seems to have a positive impact on parental well-being. Parents in similar circumstances can be effective in helping other parents and may provide an extended social support system. A number of other research questions need to be explored in order to determine the most efficacious psychological interventions for parents under stress as a result of parenting a child with developmental disabilities. Short-break services have been identified in the literature as a key support for families (Tarleton & Macaulay, 2003). Although there is a paucity of research on the impact of short breaks on children with developmental

disabilities, studies have identified the positive effects upon parents. Chan and Sigafoos (2000, 2001) for example found that short breaks can prevent family breakdown.

1.3 Short Breaks

Short breaks are generally defined as the shared care of a person with learning difficulties either at home or in a residential setting with the goal of giving the family a break from day-to-day care-giving. Judd (1994, p. 218) defines short breaks as "complementary, flexible care in the home or home from home setting with appropriate medical and nursing support, offering parents or carers an interval of relief". Short breaks are intended to have positive effect for both children and carers and are designed to support children to families. Prewett (1999) defined various types of short breaks such as sitting services, befriending services, youth clubs, play schemes, overnight stays and the use of sessional outreach workers. Residential short breaks provide young people and their families with an opportunity to spend time away from parents or carers. This break can be invaluable for parents to gain much needed rest or in being able to spend time with their other children. Residential short breaks involve overnight stays. Provision of short breaks is based on assessment of need addressing personal and social needs. Residential short breaks are usually an integrated package of support which is reviewed on a regular basis (McConkey 2000). Correlation studies suggest that appropriate support from services such as short breaks is likely to decrease parental stress and can be useful to families with children who have developmental disabilities (Sloper & Turner, 1992). Changes in patterns of need in community provision mean that a significant number of families care for a child with developmental disabilities at home. This can place unrelenting and often overwhelming financial, emotional and social pressures on the family (Briggs-Gowan, Carter, Skuban & Horwitz 2001; Innocenti, Huh & Boyce, 2002; Orr et al., 2003; Roach, Orsmond & Barratt, 2009). As a result, families often require services to

support both their child's and their own needs. Short-break provision is a service that allows therapeutic opportunities, quality time, independence and a break from the stressors and strains of parenting a child with developmental disabilities. In Laverty and Reets's (2001) view, short breaks offer quality time and provide all family members with the opportunity to live their own life. Laverty and Reets suggest that short breaks also aid in the enhancement of family empowerment and balance.

Geall and Host (1991) found that the overall experience of short breaks is generally a positive experience for both child and parent. Similarly, according to Gerrard (1990), while in the past short-break provision was recognised as beneficial only to the parents, it has now been acknowledged as a positive experience for the child. Halpern (1985) argues that the benefit of short breaks extends well beyond their period of use and that the overall experience for both child and parent is mutually reinforcing. Traditionally, services providing short breaks have focused on residential care solely for the disabled child. Developmental disability services have pinned their hopes on reducing parental stress levels through the use of short breaks. New types of short breaks are being developed that are more flexible and offer different types of support. There are many reasons for developing new ways of working in relation to short breaks, including parental expectations, which have changed dramatically over the years. Parents want services to offer more rewarding experiences that will contribute to their child's overall development.

1.4 Summary

Short breaks are a highly valued service by parents of children with disabilities and are recognised as alleviating stress and helping families to cope (Baker, Blacher, Crnic & Edelbrock, 2002; Keller & Honig, 2004; Hastings & Johnson, 2001; Einfeld, 2002). This section highlights and reviews a number of issues for discussion and further exploration

around families using short breaks. Research in the areas related to short breaks suggest that most children enjoy them; however, this should be interpreted with caution. The majority of children accessing short breaks have complex healthcare needs as well as challenging and multifaceted behaviours. Data collection for most outcome studies has been collected from parents or healthcare professionals, who may have differing perceptions of need. Other shortcomings include restrictions on the types of short breaks being offered, and the samples of participating families are not necessarily representative of all service users. Furthermore, there has been a reliance on self-completion questionnaires by families and limited research in terms of how the child feels about using short breaks.

1.5 Parental Stress and Short Breaks

The majority of the studies reviewed were chosen as they address questions closely aligned with respite care and their families. Two meta-analyses have been included to deepen the understanding and perspectives of families parenting children with developmental disabilities. Bigras et al. (1996) focused on the Parenting Stress Index (PSI) to establish the validity of the scale and its link to sources of potential stress. The main body of their work consisted of administering the PSI (short form) in conjunction with other well-validated instruments. The Beck Depression Inventory, the Child Behaviour Checklist and the Parent–Child Attachment Q-sort were predicted to be more linked to the child scale of the PSI. The study revealed that higher stress levels correlated with increasing levels of social isolation, clinical depression, increased negative attitudes in children and more controlling parenting styles. These findings are important in light of the current investigation as it demonstrates the discriminant as well as convergent validity of the PSI. Their study also highlights the potential predictive qualities of the PSI as valuable indicators of parental stress levels. Mullins et al. (2002) investigated the impact on parental stress levels of a three-to-seven-day

respite care admission versus a thirty-day inpatient treatment admission. Mullins et al. (2002) understand respite as time-limited care provided to a person with developmental disabilities, with the purpose of offering relief to their caregiver. They administered PSI at the start of care, towards the end of care and during a six-month follow-up discharge. Interestingly, it was found that psychological distress reduced significantly at the time of discharge for both groups. This improvement in distress continued until the six-month follow-up. Levels of parental stress increased to pre-admission levels at the start of the follow-up procedure.

Stalker and Robinson (1994) examined the differences in respite care and found that 22% of recipients reported reduced stress levels. Their study has influenced the particular design of the present study, as it demonstrates the value of assessing the long-term impact of respite care. Knight et al. (1993) carried out a meta-analysis of randomised controlled trials, revealing a moderate benefit when using respite care. In Ashworth and Baker's (2000) study involving interviews with 23 caregivers in the London Borough of Lambeth, interviews were analysed using grounded theory. In their research, carers acknowledged problems with respite care and reported that the benefits far outweigh the problems identified. Chan and Sigafoos (2001) reviewed the literature on respite care and its impact on stress levels on parenting a child with a developmental disability, identifying significant limitations. The authors note that the provision of respite care services is primarily seen as a strategy to reduce stress among parents, with the aim of improving overall family functioning. In a separate study, Chan and Sigafoos (2000) focused on respite care services and made several distinct points in response to critics of service provision. The main criticism was the overly broad definition of the patient group, as the authors found that most studies included a wide range of diagnoses. The other was that the benefits of respite care were often not measured in a standardised way, making comparison to other studies difficult. Interpretative Phenomenological Analysis (IPA) was used to assess the psychological processes experienced by two Irish mothers whose

children were recipients of respite care. This study revealed interesting findings in relation to the mothers' experiences, primarily related to feelings of guilt, which were expressed in a written reflection on the use of respite care services. In this study mothers reported increased guilt in relation to needing a break from the challenging demands of caring for their disabled child. Mothers also recorded higher levels of parental stress often amplified by the constant challenge of managing the child's disability and problematical behaviour. Seeking respite did induce a sense of guilt for mothers in this study. Other areas highlighted in this study were the understandable desire to obtain a break from constant, demanding and caring responsibilities, the innate desire to be close to their child and the difficulty in admitting to a need to use respite care services in order to cope. Degrees of variance may differ from culture to culture in overall responses to receiving such services. Some cultures hold traditional opinions on parenting and may not take a progressive view on the involvement of outside agencies as a support mechanism (Hartley & Wells, 2003). The conclusions of the Bigras et al. (1996) study are supportive, indicating that the PSI can be relied upon and is valuable in highlighting areas of particular difficulty so that these can be avoided. The published studies provide examples of confounding factors and a quantitative interpretation of the PSI that brings broader insights into the present study.

1.6 Parental Stress and Parent–Child Interaction

Parents of children with developmental disabilities experience higher parental stress levels compared to those without such children (Baker, Blacher, Crnic & Edelbrock, 2002; Keller & Honig, 2004; Hastings & Johnson, 2001; Einfeld, 2002). The severity of the disability has been shown to affect the level of parental stress (Keller & Honig, 2004). Parenting a child with severe developmental disabilities is generally viewed as placing the parents at greater risk for debilitating levels of stress, compared to those with general disabilities. Stress

reaction by mothers is part of a complex set of responses with many dimensions (Orsmond, 2005). Their responses to stress have been found to be linked to the child's characteristics, including stress generated by the child's inability to adapt to new situations, problems with mood and emotional stability as well as overall difficulties presented by daily challenges in meeting the child's needs. Beyond these child-related dimensions, stress is represented by its more general effects on parental well-being. Other forms of stress can manifest in relation to increases in depressive symptoms, restricted roles, health factors, ability to bond with the child and a sense of competence with respect to perceived ability to parent a child with a disability.

In addition to experiencing higher overall levels of child-related stress, a larger proportion of mothers of children with developmental disabilities face significant emotional difficulties (Baker, Blacher, Crnic & Edelbrock, 2002). Child-related stress increases during early childhood, and by middle childhood a substantial proportion of mothers report significant stressful reactions (Orr, Cameron, Dobson & Day, 2003; Hauser-Cram, Warfield, Shonkoff & Krauss, 2001). The psychological state of mothers and primary caregivers is a significant consideration for the early development of children with developmental disabilities and impacts the interaction with children. Over the past several years considerable research has examined how stress-related symptoms directly affect how parents care for their disabled children (Briggs-Gowan, Carter, Skuban & Horwitz 2001; Innocenti, Huh & Boyce, 2002; Orr et al., 2003; Roach, Orsmond & Barratt, 2009). The children's characteristics are also factors to consider, with consistent associations and links between higher levels of the various dimensions of parental stress (Floyd & Gallagher, 2007; Baker, McIntyre & Blacher, 2003). Social support provision for parents has been shown to be reliably and strongly related to parental stress and plays an essential role in family adaption and personal well-being (Dunst, Trivette & Bowers, 2006). Well-developed social networks provide informal support for

parents to cope more effectively with parenting their disabled child (Cochran & Brassard, 2009). Studies of parents of children with developmental disabilities have documented the existence of a concurrent association between social support and parental stress during both early childhood and school age (Beckman, 2001; Krauss 2003; Duis & Summers, 2007; Shin, Nhan, Crittenden, Flory & Ladinsky, 2006).

1.7 Definition

Although the numbers of children with developmental disabilities and complex needs and those diagnosed with autistic spectrum disorders are increasing, some statistics do not reflect this. The definition of disability is also changing to become wider and more inclusive; some services, however, are still working with older definitions. The International Classification of Functioning, Disability and Health (ICF), compiled by the World Health Organization (WHO), is the most frequently used framework for defining disability (WHO, 2001). The ICF describes disability as a multidimensional concept understood in the context of either a health condition or clinical diagnosis. This conceptual framework incorporates bodily functions such as the extent of physical impairment, activities such as the degree of activity limitations and environmental factors such as family issues and societal attitudes. York and Bricknell (2004) categorise disability based on activity limitations and participation restrictions shared by those with differing health conditions. These groupings are often used in disability literature that includes broader categories of intellectual, developmental and physical disability. International differences in the use of specific terms can significantly impact the validity and consistency of research findings. In the USA for example, developmental disabilities is a general concept alluding to severe or chronic disability that results in activity limitations linked to mental or physical impairment. Stoneman (2007) found that the term "learning disability" is used to describe anyone with below average intelligence in the UK,

which has different implications in the USA. Schalock et al. (2007) suggest that "mental retardation" be replaced with the term "intellectual disability". Several poignant difficulties have emerged when comparing the results of studies. However, broader definitions have now been included and conclusions can be drawn from factors that contribute to the outcomes of parents of children with disabilities.

1.8 Medical Support

Some 60% of parents spend more than 10 hours a day on basic physical care of children with developmental disabilities, and around one third of parents are providing 24-hour care. Several areas of parental functioning can be impacted, such as work opportunities and overall psychological well-being (Catherall & Iphofen, 2006). Such children and their families often rely on effective provision of equipment as part of their care. This could be specialist chairs, sleep systems, standing frames, suction machines and hoists. In 2007, it was estimated that 150,000 children with developmental disabilities nationally required equipment when in fact only 25% received a sufficient service (*Disabled Children's Strategy*, 2009–2012). Furthermore, transitions at all stages of the child's life can be extremely difficult, and without appropriate support and planning, parents tend to describe it as a time of considerable stress.

1.9 Parental Impact and Daily Hassles

Parenting children with developmental disabilities can be exhausting and distressing. Studies have shown that parents caring for children with disabilities experience considerable stress, which can influence the children's problem behaviours. There is increasing awareness in society of the needs of a particular group of families whose children have complex developmental disabilities. In the majority of cases, parents are the main carers, and this role often impacts their physical and psychological health (Hall, 1996; Hirst, 2004; Kirk & Glendinning, 1998; Mitchell & Sloper, 2001; Olsen et al., 2001; Robinson et al., 2001;

Cowen & Reed 2002; Watson et al., 2002). Looking after a child with developmental disabilities is a fulltime job, placing great strain on the family system. Parents often report physical and emotional stress, often leading to exhaustion (Llewellyn et al., 1999; Ong et al., 2007). Some families have felt imprisoned in their own homes, as their children often require specialised care (Brinchmann, 1999; Yantzi, Rosendberg & NcKeever, 2007). The entire family, including siblings and grandparents, often provide a network of additional support and suffer some of the stress associated with caring for these children (Dobson, Middleton & Beardsworth, 2001). Most parents and carers need a break and time for themselves away from the responsibilities of caring for their children. Some parents may feel uncertain about the future, and hopes and expectations for their child may be shattered. When a child is born with a developmental disability, the psychological stress and strain surrounding the new baby is intensified. Additional hospital appointments and care tasks can place considerable pressure on the overall well-being of family functioning. Parents may experience increased levels of fear for their children, worrying that their care-giving role may extend indefinitely into the future as well as whether they will be able to manage the demands placed on them. The continual stress of day-to-day care for a child with developmental disabilities and negotiating service providers can be confusing and exhausting. Parents may suffer higher levels of tension as they attempt to manage with the added complications associated with their child's disabilities. Family stress levels are amplified by the constant challenge of managing the child's disability and problematical behaviour. Gavidia and Payne (2002) found that mothers in particular may feel higher levels of stress than fathers because of the demands associated with daily care. Their research established that mothers were more prone to depression and would question their own competency. Floyd and Gallagher (2007) found that single mothers experience higher levels of child-related stress, partly as a consequence of having limited support.

Deater-Deckard (2004, p. 7) defines parental stress as "a set of processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood". One of the most recent developments in the conceptualisation and measurement of parental stress is the daily-hassles approach. Crnic and Greenberg (1990) formulated their model based on parenting daily hassles in which stress is understood within a minor-event perspective that incorporates day-to-day frustrations accompanying childrearing. Parenting daily hassles are defined as persistently occurring, repetitive, bothering unavoidable tasks that are involved in a parental context. The cumulative impact of these daily hassles may significantly impact both child and parent. Parenting daily hassles are not isolated events; rather they accumulate, leading to parental stress. According to Crnic and Acevedo (1995), daily hassles are not confined to any specific population group, as it is assumed that they are shared by all families regardless of demographic status. Repetitive disability-related parental tasks and delayed child development often place parents at risk for stress resulting from daily hassles. There is evidence that parenting daily hassles are linked to aspects of child and parent well-being. Research comparing daily hassles and life stress confirms the notion that daily parental experiences of minor hassles significantly impacts children's development as well as parental stress levels (Crnic & Greenberg, 1990).

1.9.1 Focus of study

The present study focuses directly on parental stress levels and attempts to measure any changes before and after the use of residential short-break services. The research aims to improve the definition of variables that impact on the level of benefit in terms of stress reduction that short-break care services potentially bring to parents of children with developmental disabilities. The study acknowledges that individual differences can influence the relationship between parenting variables for families with children who have

developmental disabilities. Literature on the relationships between variables and demographics is an important focus; however, a formal hypothesis related to the relationship between demographic variables was not proposed in this study. The following research questions are used to guide this study:

1. Is there a reduction in parental stress following the use of short breaks as measured by the PSI (short form)?
2. Are there differences in the subscale scores pre and post short breaks, namely Difficult Child (DC), Parental Distress (PD) and Parent–Child Dysfunctional Interaction (P-CDI)?
3. What are the common themes in parents' subjective experiences of using short breaks?

1.9.2 The purpose of the study

The purpose of the present study is to inform and deepen our understanding of the stress levels of parents who have children with developmental disabilities using residential short-break services. The study seeks to gain a better understanding of the influence that residential short breaks have on parents, more specifically to gauge whether a reduction in stress is linked to their use. The study attempts to inform therapeutic practice and highlight the common themes for parents taking up short breaks and to investigate the degree of reduction, if any, on domains of stress such as defensive responding, PD, P-CDI and DC. The study provides an overview of existing literature on the impact that short breaks have on parental stress levels and other indicators of psychological dysfunction. The research is designed to contribute to the existing body of literature in several ways. The study addresses methodological problems as well as highlighting closely aligned questions regarding respite care and families affected by developmental disabilities. The study also highlights strategies

that boost the probability that parents benefit from using short breaks. Any gains in knowledge should suggest where improvements may be made in residential short break services and possibly in data-gathering techniques with families who parent a child with developmental disabilities. Improvements in our understanding of parental stress levels may have implications for better well-being, quality of life, functionality and interpersonal relationships. The main objective of this investigation is to assess responses to the PSI and determine any reduction in stress before and after use of residential respite care. There is considerable speculation over the actual effectiveness of respite care services in reducing stress among caregivers, and it is therefore imperative that social care providers improve their understanding of what drives achievements and breakdowns in social service development. It is hoped that, should stress reduction levels be found, relevant psychological strategies are developed to enhance the benefits of using residential short break services. These strategies could be set out in a leaflet for parents that may be helpful for those considering using short breaks for the first time.

1.9.3 Summary

Healthcare professionals need to understand the extent to which families' emotions are affected when parenting a child with developmental disabilities. The stress and coping difficulties associated with having such a child has been studied from several positions. A vast amount of research focuses on the negative aspects of parenting a child with disabilities. Some of these include effects on family social cohesion, impacts on self-esteem within the family and burdens on the parent's emotional resources in terms of stress. In light of this and other variables, some families reconsider their working lives in order to adapt to the on-going needs of their child. Parents can feel socially isolated; participation in social events is difficult as it involves the management of wheelchairs, medical supplies, special diets and

challenging and complex behaviours (Strohm, 2002). If healthcare professionals can make

parents more aware of the short breaks that are available to them early in diagnosis, this may

help alleviate stress. Short breaks have been developed in response to the ever-increasing

stress that families face on a day-to-day basis. Residential short breaks provide temporary

childcare support to families. Respite care is generally thought to be a critical component of

formal social support interventions deemed necessary to promote positive family functioning,

and short breaks commonly involve the temporary care of a child with disabilities for the

purpose of providing relief to the family.

Chapter 2: Parental Stress

2.1 Introduction

This chapter presents an overview of existing literature as well as a discussion on the psychological impact in terms of parental stress when caring for a child with developmental disabilities. This overview highlights some of the complexities in current research available on parenting stress and child outcomes. Previous research is examined including diversity in research designs; analysis and contributions to the existing body of literature used in this study. Cross-sectional and longitudinal studies are represented with results that offer validated confirmation in the area of stability and the prediction of parental stress levels. As previously mentioned the recognition of past research in parenting stress comprises of different aspects of parental stress such as major life events and parenting daily hassles each of which will be described in detail. The chapter also explores studies that have evaluated stress levels of families who have children with developmental disabilities. Parental stress is a complex problem resulting in a variety of negative outcomes for children. There appears to be a significant link between parental stress and child behaviour.

Stress has been conceptualised on various levels such as generalised stress; satisfaction with the marital relationship; conflicts and financial aspects of family functioning. Parents of children with developmental disabilities generally experience a higher level of parenting stress that can ultimately compromise their capability to parent effectively (Baker, Blacher, Crnic & Edelbrock, 2002; Johnston et al., 2003; Ong, Chandran & Peng, 1999; Raina et al., 2005). Parents continue to be an important influence on the development of their child. Higher levels of parental stress can be linked to negative parenting, which has a direct impact on child development and health (Crnic & Low, 2002). According to Critchley and Sanson (2006) parents who have higher levels of stress have been found to use less positive

discipline strategies in favour of authoritarian discipline practices. Parental stress and beliefs about parenting have been identified as important individual factors related to parenting practices.

The model for this research draws upon Abidin's (1995) parenting stress index. The framework in this thesis incorporates multiple variant determinants of parenting stress divided into the following domains. The first domain includes individual characteristics of the child, such as age, social skills, education, primary diagnosis, length of diagnosis, past use of short breaks, first time users of short breaks and child problem behaviours. The second domain assesses the parental characteristics, such as gender, health, age of parent, number of children living at home, years of diagnoses and marital status. The third domain focuses primarily on contextual factors such as social supports and networks available to the family. The current study seeks to determine the correlates of parental stress and how parental stress varies across parent, child and contextual domains. The study aims to test the hypothesis: that there is a reduction in parental stress levels after using residential short break services.

The vast amount of research on parenting stress levels is evidence that researchers seek to understand the relationship between this construct and other complex family variables (Ainge, 1995; Barnett & Boyce, 1995; Wikler, Hanusa & Stoycheff, 1986). When a child with disabilities is born, patterns of familial functioning may need to change. Family routines are altered, family roles examined, new coping mechanisms emerge and new expectations developed. These changes can add to family stress and have a significant influence on family well being. Stress can be influenced by how the individual perceives the demands of society and their perceived ability to cope with these demands.

Parental stress may be a reaction to challenges such as fear, anxiety or conflict, which can manifest on a physical as well as psychological level. Physical stress can cause changes to

cortisol levels, temperature and other bodily functions (Janssen, Schuengel & Stolk, 2002). Research conceptualizes parenting stress as the parental perceptions of a lack of financial resources, difficulties in emotional and physical resources in order to successfully manage significant life events (Baker, Blacher, Crnic & Edelbrook, 2002, Crnic & Low, 2002; Deater-Deckard, 2005; Tomanik, Washington & Hawkins, 2004; Spratt & Macias, 2007). It is not inconceivable that the amount of stress some parents experience from caring for a disabled child could be disruptive to family functioning leading to family breakdown.

Despite a correlation between stress and significant life events, researchers now argue that there may be other areas that contribute to overall parenting stress levels. Repetitive parenting duties and cumulative minor daily parenting stressors can lead to perceptions of inadequacy or resources and difficulties in coping (Crnic & Acevedo, 1995). A parent who is experiencing chronic stress generally struggles to respond in an appropriate way to their child's ever increasing developmental needs. Relationships are impacted significantly from chronic stress resulting in challenging and hostile outcomes (Crnic & Low, 2002). Chronically stressed parents have far less sensitivity when responding to their child's general day to day needs resulting in a difficult parent-child relationship. Stress impacts both parent and child in negative ways (Chan & Sigafoos, 2000; Robinson, Jackson & Townsley, 2001; McConkey & Adams, 2000; Grant & Whittell, 2000).

Mental health professionals working directly with families distinguish the significance of reducing parental stress, the psychological well being of the parents, including the well being of siblings who may be at risk (Rossiter & Sharpe, 2001). Professionals are acutely aware that parenting a child with special needs can be more stressful than parenting children without such difficulties. There are common stressors associated with parenting children with developmental disabilities. Some parental stress can be linked more specifically to the degree and type of disability. There is widespread recognition that families demonstrate remarkable

resilience in parenting children with complex developmental disabilities, however this can still compound the problems and add significant psychological and physical stress for the family (Eisenhower, Baker, & Blacher, 2005; Hastings & Brown, 2002; Hastings & Johnson, 2001). Research has suggested that specific behavioural characteristics associated with the developmental disability are important correlates of parental stress (Limperopoulos & Shevell, 2006). Studies support the idea that the child's behavioural problems can be the central focus of added stress for parents looking after a child with special needs (Baker, Blacher, Crnic, & Edelbrock, 2002; Johnston, Hesssl, Blasey, Eliez, Erba & Dyer-Friedman, 2003; Ong, Chandran & Boo, 2001; Raina, O' Donnel, Rosenbaum, Brehaut, Walter & Russel, 2005). Several studies reveal that problematic behaviour in children with developmental disabilities could be a valid predictor of parental distress (Hendriks, DeMoor, Oud & Savelberg, 2000; Knapp, 2005; Smith, Oliver & Innocenti, 2001; Spratt et al., 2007).

There is a well-documented association between high levels of parent stress when looking after a child with developmental disabilities (Gavidia-Payne & Hudson, 2002). Parenting children with special needs can be much more stressful than parenting children without special needs. There appears to be common stressors associated with parenting most children with developmental disabilities. However some stressors may be particularly unique and in some cases linked directly to the actual diagnosis and or resultant disability. Research has clearly demonstrated that families with children who have developmental disabilities more often than not experience higher levels of personal distress and psychological discomfort related to raising their child (Seltzer et al., 2001; Risdall & Singer, 2004; Glidden & Jobe, 2006). Health care professionals acknowledge the resilience of parents, and the complex and enduring challenges associated with the child's condition, that can increase psychological stress for the family, including the extended family network.

Research has focused on understanding this variability as well as isolating factors that may predict or enhance parental stress levels. Singer (2006) compared studies of parents with and without children with a developmental disability and reported differences in psychological distress in several studies of mothers conducted over a span of 25 years. More or less 30 percent of the mothers of children with developmental disabilities in his cohort had significantly higher levels of depressive related symptoms. Direct observation research which compared mothers with and without high levels of depressive symptoms revealed interesting results (Downey & Coyne, 1990). The study showed that mothers with high levels of depressive symptoms interacted far less with their children with disabilities, much less able to respond to their child's needs, suffered increased irritability, presented with negative affect and were much more likely to respond by using volatile means to discipline their child as compared with mothers without prominent depressive symptoms (Downey and Coyne, 1990). Research suggests that depressive symptoms in mothers are linked to problematic behaviour in children with developmental disabilities (Hastings, Daley & Burns, 2006; Lecavalier, Leone & Wiltz, 2006).

The severity of a child's disability is often associated with the level of parental stress and it appears that child behavioural characteristics seem to add significantly to parental stress levels. When children act out moderately difficult behaviour parents generally reported a higher quality of life and overall wellbeing as compared to those whose children engaged in complex and challenging behaviour (Dunst, Trivette, Hamby & Pollock, 1990). Behavioural problems can often be attributed to increased stress levels for parents with a child who has developmental disabilities (Johnston et al., 2003; Raina et al., 2005). In a study with children with intellectual disabilities, the parental stress levels correlated with negative child behaviour difficulties, general self esteem levels of parents as well as overall parenting satisfaction (Hassal, Rose & McDonald, 2005). Extensive research has already been done in

the area of child problematic behaviour. Studies have confirmed problematic behaviour to be a dominant predictor of parental distress. Bailey et al. (2007) reported significant correlations of depressive symptoms, in parents as well as associated behavioural problems in their children.

Families caring for children with developmental disabilities have been found to experience a number of additional stressors. Complex behavioural problems, in the presence of multiple conditions contribute to the stress experienced by families (Baker et al., 2003; Feldman 2002). In addition, a child with complex developmental disabilities often results in long term dependence, requiring complex parenting skills. As a result the general stress experienced by parents is considerable which can have a direct impact on family functioning. Parenting a child with developmental disabilities can be challenging and general stress levels are significantly higher than parents who do not have a disabled child (Baker et al., 2002, 2003; Tomanik et al., 2004; Spratt et al., 2007). Parenting a child with developmental disabilities often requires constant and consistent supervision especially if the child has additional emotional, behavioural and communication problems (Beck et al., 2004).

The care of a child with learning disability can also involve lifting, feeding, toileting, bathing and dressing. This intense support brings with it personal costs which include feelings of being isolated from others as well as reduced social contact with friends in the community (Lane et al., 2000). Longitudinal research by Glidden and Jobe (2006) with biological parents of children with Down's syndrome demonstrated significantly higher levels of depressive symptoms when compared to adoptive parents, following the first five years of life. Depressive symptoms have been associated with challenging behaviour in children with developmental disabilities (Hastings et al., 2006; Lecavalier et al., 2006).

The demands associated with raising a child with developmental disabilities are significantly high. Stress experienced by parents may impact their ability to parent their child with developmental disabilities. Multiple factors are involved in assessing stress levels in parents, in some cases it was found that mothers experienced much higher stress associated with their child's self sufficiency abilities, complex and challenging behavioural issues in comparison to fathers (Moes, Koegel, Schreibman & Loos, 1992). Maternal stress levels have been directly correlated to the level of social skills in children with developmental disabilities (Baker-Ericzen et al., 2005). Knussen and Sloper (1992) found similar results in their work, concluding that mothers of children with disabilities experienced higher stress levels as a result of complex behaviour, total dependence of care, child's own anxiety levels and limited communication skills. Mothers of children with disabilities often experience feelings of exhaustion, emotional instability and stress. Fathers on the other hand appeared to be more effected by the family's financial position, communication skills of the child as well as overall physical development. Stress experienced by parents could influence their ability to look after a child with developmental disabilities. Positive adaption to a child with disabilities depends on how parents cope with stress (Baker, Blacher, Crnic & Edelbrook, 2002, Crnic & Low, 2002; Deater-Deckard, 2005; Tomanik, Washington & Hawkins, 2004; Spratt & Macias, 2007).

Parental stress is often viewed as a major issue for families with children with disabilities. In the past decades a significant amount of research has repeatedly highlighted that parents with children who have developmental disabilities show a wide variability in adaption to family life (Singer, 2006). Several authors are of the view that there are negative impacts on parents, which include physical and mental health problems (Witt, Riley & Coiro, 2003). Meta – analyses and longitudinal studies differ in their findings, and it was found that these negative impacts were not as severe as originally suggested (Seltzer et al., 2001; Risdall &

Singer, 2004; Glidden & Jobe, 2006). Singer (2006) and their meta-analysis of 19 comparative studies gathered information on depressive symptoms in mothers of both children with and without developmental disabilities found that well over half of the mothers of children with disabilities did not have prominent symptoms. Despite these findings, it seems clear that caregivers having children with developmental disabilities report greater parenting stress than the general population (Baker et al., 2003; Feldman, 2002). Research has focused on the caregivers specific depressive symptoms as indicators of stress (Seltzer et al., 2001; Risdall & Singer 2004; Glidden & Jobe, 2006). Parents of children with disabilities do demonstrate some of the same patterns of stress seen in families with typically developing children. Stress is often cited as one of the main problems when looking after a child with developmental disabilities (Bristol, 1987; Johnston et al., 2003).

Studies confirm that parents of children with developmental disabilities demonstrated increased parental stress in comparison to parents who do not have a disabled child (Emerson, 2003). Stress levels also appeared to be unremitting and persistent over extensive periods of time (Glidden & Schoolcraft, 2003). Parental stress has been understood on several levels, identified as interpersonal isolation, clinical depression and the breakdown in the ability to manage conflicts. Significant increases in parental stress levels have been correlated with child characteristics such as increased moodiness, chronic irritability and demanding behaviours (Johnston et al., 2003). Parenting provides the structure for children to grow and develop. At one time or another, most parents experience varying degrees of stress as they attempt to meet the challenges of caring for their child. Parenting children with emotional and behavioural difficulties is often exhausting and distressing (Morgan, Robinson & Aldridge, 2002). As previously discussed parenting stress can often exacerbate problematic behaviours in children. Research has suggested an association between parenting stress and problematic behaviour patterns in childhood (Crnic & Low, 2002; Deater-Deckard, 2005). Parenting that

is effective in the promotion of healthy child development is characterized by a combination of authoritative parenting styles that combines with warmth and nurturing and moderate amounts of control (Carr, 2006). The duty of parenting a child with developmental disabilities is a highly complex one, often demanding, with limited personal and physical resources available (Abidin, 1990).

The level of parenting stress experienced varies in relation to the frequency and intensity of stressors as well as the personal coping resources. Most parents regardless of their children's individual characteristics, culture or economic status experience various levels of stress (Deater-Deckard, 2004). The variables that contribute to stress vary from parent to parent. Research has focused on identifying ways to define parental stress, develop tools to measure stress and build up a knowledge base of models that explain the complex factors involved in parenting stress. According to Deater-Deckard (2004) stress can be understood in terms of a set of processes that lead to aversive psychological reactions, directly related to the demands of parenthood. These reactions are experienced as negative feelings and beliefs directed primarily towards the self and child, which are linked inextricably to the parental role. This definition moves towards an understanding that parenting stress involves negative perceptions about one's own ability to function as a competent parent as well as unhelpful feelings towards their child. Parenting a child brings with it a collection of demands which could include providing the basic necessities of life such as food, clothing, protection and shelter. Other demands on the parents are being able to provide emotional support and affection (Deater-Deckard, 2004). Factors such as housing, financial income and availability of social support networks play a significant role in parental stress levels. Interpersonal relationships in social networks can also be impacted due to the demands placed on parents often leading to physical and psychological isolation. Furthermore the complexity of daily

life, restricted choices as well as living in unpredictable times can all contribute to parental stress levels.

2.2 Individual Factors that Contribute to Parental Stress

According to Carr (2006) parents growing up in unstable environments or within disorganised and abusive families are more likely to encounter major difficulties in their adjustment to parenting. Parents receive little preparation beyond the experience of being parented themselves. In most cases parent's psychological well being determines the quality of care provided to infant distress, abusive behaviour and insecure child care-giver attachments. Unresolved attachment difficulties may contribute to parenting in several ways, such as an impaired capacity to parent and interpret accurately and respond in a sensitive way and appropriate manner to their child's mental states. Carr (2006) contends that parental psychopathology undermines the capacity of parents to provide a safe environment having on-going effects on the child's psychological and social development.

2.3 Family Cohesion

Family functioning can be adversely affected by stress, stemming from a variety of sources. Family cohesion is important to understand in relation to raising a child with developmental disabilities. Family cohesion is an important part of family functioning and in order to understand this complex process it will be helpful provide a broad and inclusive definition. Olson (2000) defines the concept of cohesion as a form of togetherness which includes emotional bonding that takes place within families. Olson (2000) formulates family cohesion as "the emotional bonding that family members have towards one another" (p.145). Family cohesion explores the amounts of independence and connectedness of each family member. The definition explores family cohesion on several levels which can be measured by assessing boundaries, conditions, space, decision making skills and general interests within

the family system. The definition also identifies cohesion, flexibility and communication as three central components of marital and family functioning (Olson, 2000). The model rates family cohesion on a scale ranging from disengaged, separated, connected and enmeshed. The more extreme levels are disengaged and enmeshed. According to Olson (2000) families that have moderate levels of cohesion will tend to function positively. Members in a disengaged family tend to value their own independent interests over and above others, consequently finding it difficult to support each other. Enmeshed families are characterized by entangled relationships within the family, with few relationships outside family. The model views separated and connected relationships as more balanced family types. The connected relationship is characterized by emotional bonding within the family and valued time spent together more than time spent alone. Family members in a separated relationship generally spend time apart but are able to offer support and decisions in a competent way.

Family cohesion has also been known to be an important source to cope with the demands of stress. Olson (2000) contends that families who fall within the connected or separated category tend to react to changes within the family in a much more constructive and positive way. From a broader perspective it appears that families that fall within the balanced range (connected and separated) are more likely to deal with stress successfully. Family cohesion has been cited as a helpful family resource. From this perspective higher levels of family cohesion could contribute to families becoming enmeshed which could ultimately be disadvantageous to family wellbeing. Conversely families with lower levels of family cohesion can result in detachment. According to this model of family functioning families that achieve balanced cohesion usually seem to be most able to manage and cope with stress.

Research suggests that parenting a child with developmental disabilities can impede with the process of maintaining cohesive relationships. Bristol et al. (1988) in a study that explored adaption and spousal support assessed fifty six two parent families. Thirty one

families had boys with a diagnosis of autism and severe communicational impairments. Twenty five families had boys with no developmental disabilities. This study revealed interesting results, where fathers of sons with developmental disabilities reported to be at a greater danger of experiencing marital problems, as compared to those fathers of sons without a disability. This study revealed that those parents of boys with disabilities reported experiencing more problems within the family system than did parents of boys with no disabilities. In both groups mothers reported receiving less emotional support from their spouses in comparison to fathers reporting receiving support from their wives. All these factors could contribute to the family feeling less cohesive and less able to respond positively to the stressors within the family. Research that examined the cohesion levels of families raising a child with developmental disabilities yielded interesting results. Nelson et al. (1992) used the family environment scale (FES) to collect data from ten families who had a child with a developmental disability. The study revealed that families perceived their cohesion levels to be within the normal range. Most of the families in this study concluded that raising a child with developmental disabilities bought them together, therefore enhancing cohesion. Families that are cohesive tend to report reduced levels of parental stress. Families parenting children with disabilities tend to perceive their personal situation as cohesive, flexible and together.

2.3.1 Cohesion summary

In summary family cohesion is described as emotional togetherness or separateness of members of the family (Olson, 2000). Olson (2000) suggests that cohesion can be measured by assessing the emotional boundaries, coalitions, space, decision making and interests within the family system. Each family needs to negotiate the balance between separateness and togetherness. Families functioning in the separated to connected range are able to balance family togetherness with their own independence. Families that function on the enmeshed

level have extreme amounts of emotional closeness and limited privacy or independence from the family system. In contrast those families in the disengaged ranged experience limited emotional closeness and increased independence. McCubbin et al. (1995) define cohesion as an essential component within the family that enhances resiliency of families; parenting a child with developmental disabilities may enhance levels of family cohesiveness and togetherness. Family adaption to the stressors of caring for a disabled child has been linked to cohesiveness and positive interpersonal relationships (Mahoney, O'Sullivan, & Robinson, 1992).

2.4 Factors Related to Using Short Breaks

The severity of a child's disability is often associated with the level of parental stress; child behavioural characteristics seem to contribute more substantially to overall stress levels. Child related parenting stress is complex and includes a variety of factors such as: the child's level of disability, initial diagnosis, identities, roles and access to relevant services. The child's individual characteristics can significantly increase parental stress (Cole, 1986; Kobe, Rojahn, & Schroeder, 1991). Initial diagnosis can have a considerable impact on parental stress levels. Martin and Colbert (1997) found that families often react with denial, shock and disbelief at discovering their child has been diagnosed with a developmental disability. Families react to the news in various ways, which can follow a pattern of loss. Wikler (1981) found that this painful process can be associated with anger, depression, grief, resentment and sadness. Incongruities between child achievement, parental expectations and lapses in developmental milestones more often than not bring renewed feelings of bereavement and loss throughout life. Following these reactions parents mourn for their child. Acceptance of the disability faced by their child becomes easier over time, the surfacing of new challenges, incongruities between child achievement and parental expectations such as

unmet developmental milestones can bring renewed feelings of grief throughout the life cycle.

Levels of disability have been globally defined as mild, moderate and severe. Bromley and Blacher (1989) found that the severity of the child's disability is positively correlated with negative parental perceptions, family deterioration and pessimistic parental attitudes. Children with severe and profound developmental disabilities also have complex health care needs, which place more demands on the family. The more serious the impairment the more intensely stressors are experienced by the family. Considerable evidence suggests that families who have children with severe developmental disabilities are more likely to use short break services (Treneman et al., 1997; Hoare et al., 1998). The more severe the developmental disabilities seem to be positively correlated with the family making use of short break services. Factor et al. (1990) suggested a link between parental stress levels and the severity of diagnosis which in turn leads to an increase in using short break services. Research suggests that the severity of a child's disability is positively correlated to time demands, parental attitudes, negative parental perceptions and family breakdown (Blacher & Baker, 1994; Martin & Colbert, 1997). Children with severe and profound developmental disabilities are more likely to require special care largely due to their associated impairments. In light of these findings it appears that parent stress increases in relation to levels of disability. The more serious the disability appears to be correlated with increased parental stress and the need for special care and service provision.

Availability and access to services can be a salient source of stress for families. Securing appropriate services can prove to be a stressful responsibility for families. Karp and Bradley (1991) note that securing appropriate services can be a stressful, confusing and often a frustrating process for families. Martin and Colbert (1997) found that parents have additional stressors, having key responsibilities for enhancing their child's development that often

require special training. They found that parents are regularly encouraged to become actively involved with education and to actively contribute to their child's individual education plans. Families can often become disillusioned when their disabled child struggles to meet academic expectations as well as not being able to meet their individual education plans. Acquiring services can be confusing and families often have to deal with waiting lists and conflicting professional recommendations. Martin and Colbert (1997) noted that even after appropriate service provisions have been made, families and children have to deal with high staff turnover rates and ever changing transitions that require complicated decisions. Level of family support systems plays a significant role in mitigating the effects of parental stress. Salisbury (1990) found that social support systems such as the extended family, co-workers and friends contribute to helping the family in caring for their disabled child. Short breaks can be viewed within a context of a social support system for the family. Salisbury (1990) found that children that require more complex levels of personal care are more likely to use short break services. In conjunction with family support systems families often have to deal with the process of obtaining the necessary services for their child. Securing appropriate services can prove to be an additional stressful responsibility.

Salisbury (1990) also found a positive correlation between mother's level of stress and their child's level of functioning and behaviour. Severe, challenging and complex behaviour has been linked to increased use of short breaks (Duff, 1992). MacDonald and Gallery (2004) confirmed this finding and reported that children using short break services usually presented with more complex behaviours. The presence of challenging and complex problematic behaviours has been associated with increased use of short breaks (Duff, 1992; Jawed et al., 1992). Challenging behaviours such as biting, hitting, running away, self-stimulation, poking eyes, head banging and picking nails off can be a major source of stress and a powerful predictor of using outside services (Cole, 1986; Kobe et al., 1991). Complex, enduring and

dangerous behaviours all add to the overall stress experienced by parents. These behaviours often require twenty four hour supervision to guarantee the safety of the child and other family members. There is overwhelming evidence that age and physical size of the child plays a significant role in overall parental stress levels.

2.4.1 Summary

Several factors appear to influence the use of short breaks among families with children with developmental disabilities. Some of these factors are related to child characteristics and others to family characteristics. Individual characteristics include initial diagnosis, severity and level of diagnosis, level of care and behavioural / communication difficulties, age and size. Family characteristics include level of support within the family system. The extent to which parents of children with developmental disabilities experience stress, tends to depend on the level of their child's disability.

2.5 Theoretical Viewpoint of Parental Stress

Parental stress is influenced by a host of complex variables that over time have contributed to the perception of stress. The emergences of several poignant theories have developed overtime in an attempt to describe some of the underlying causes of parental stress (Crnic & Low, 2002). Every day parenting involves the resolution of everyday tasks. The daily hassles theory of parenting stress, reviews the day to day stress of being a parent and its overall impact on psychological functioning. Crnic and Greenberg (1990) created the Parenting Daily Hassles measures, based on a model of parenting where parenting stress is conceptualised within a daily event perspective that focuses on day to day frustrations that accompany parenting. According to this model a single event may not always be deemed a hassle; however the cumulative impact of these events may adversely impact child and

parental adjustment. Consequently this viewpoint focuses primarily on minor stressful events that can accumulate over longer periods of time (Crnic & Low, 2002; Deater-Deckard, 2004).

Stressful events within this theoretical framework include dealing with a child's problematic behaviour or trying to balance conflicting work and family demands. Parenting daily hassles are defined as consistently occurring, repetitive, bothersome but unavoidable day to day tasks (Crnic & Acevedo, 1995). The daily hassles model not only considers the daily hassles arising out of challenging child behaviours but also the stressors associated with everyday parenting tasks. Day to day hassles at home is common, including managing difficult and complex child behaviour as well as child rearing activities. Overall parenting daily hassles are repetitive and described as continually growing with the ever increasing needs of looking after a developmentally disabled child. Daily hassles are not confined to a particular group of families and all families experience this phenomenon despite structural or demographic differences. Consequential stress from daily parenting hassles may be an important form of parental stress.

General responsibilities at home as well as the hassles of parenting a child with developmental disabilities may consistently place added stress on families. The daily hassles theory of parenting stress helps to explain how everyday life events within the context of family can contribute to the mounting impact of stress. Parenting often requires having to constantly clean up at home. Parent can often be isolated from other adults, managing schedules of activities and being involved in day to day tasks, all of which can lead to parental frustration and confusion which in turn can lead to additional stress. Some parents experience chronic and acute stress, which leads to decreased satisfaction with the parenting role. Research indicates that complex, frequent daily hassles correlated negatively with parenting efficacy and overall satisfaction (Crnic & Acevedo, 1995; Singer & Farkas, 1989). Research suggests that parenting daily hassles is positively related to problematic childhood

development. A revealing study by Crnic and Greenberg (1990) assessed 74 mothers of five year old children, where a positive correlation was found between parenting daily hassles and child behaviour problems and lowered levels of social competence for children.   Subsequent research using the parenting daily hassles measurement scales has confirmed its validity as a meaningful stress context for the assessment of parental stress and child development (Belsky, 2006; Crnic, Gaze, & Hoffman, 2005; Phelps, Belsky & Crnic, 1998). The parenting daily hassles paradigm has been used in several poignant studies to highlight the impact parental stress has on the overall development of children.

2.6 Social Cognitive Theory

At the centre of social cognitive theory is the notion of Bandura's (1986) contribution, which contends that people are not motivated by inner forces alone nor are they controlled by external stimuli. Bandura (1986) defined self-efficacy as an individual's beliefs in their ability to succeed in specific situations. The concept of self-efficacy lies at the centre of social cognitive theory, as it highlights the role of observational learning and social experience in the overall development of personality. Self-efficacy theory is testable and rich in heuristic value. One of the striking themes in this theory is that an individual's actions and reactions in most social situations are heavily influenced by the actions that individual has observed in others. According to Bandura's theory, those with higher levels of self-efficacy are those that sincerely believe they can carry out a task in a competent way, are generally more likely to view difficult tasks as a goal to be mastered as opposed to avoiding the task.

Bandura's (1993) social cognitive theory postulates that perceived self-efficacy impacts individuals in most areas of everyday life. Beliefs about one's competence to perform a task in a positive way can impact enthusiasm, interest and overall achievement. Bandura defines self-efficacy as "judgements of how well one can execute courses of action required to deal

with prospective situations" (Bandura, 1982, p. 122). According to this theory the higher perceived efficacy and the higher the goal aspirations people take on have a direct bearing on commitment to achieving those goals. Human behaviour according to this theory is explained in terms of a triadic reciprocal deterministic approach. This approach can be viewed as an interaction of behaviour, cognitions and environmental events that work as determinants of each other. The person can thus be understood and defined from this triadic perspective. The term reciprocal refers to the mutual action whilst determinism signifies the production of effects. There is a host of interacting influences within this triad and different conditions produce different effects. Generally, most people possess self-directive capabilities they are able to control over their thoughts, feelings, behaviour and actions. Self-regulation forms an integral component of social cognitive theory.

According to this theory, people generate guides for their own behaviour providing self-motivators and have the capacity to respond to their behaviours in a self evaluative manner. Albert Bandura (1977; 1982; 1986; Adams & Beyer, 1977; Bandura & Schunk, 1981) galvanised the construct self-efficacy to account for psychological change. Self-efficacy can be conceptualised as one's expectations that we can perform competently in a variety of situations that are potentially challenging, requiring effort and perseverance. Self-efficacy expectancies are convictions related to our ability to perform behaviours that will bring desired results. People who regard themselves as very self efficacious will normally act, feel and think differently from those that recognise themselves as inefficacious. According to Bandura (1986) self- reflection is a central component of social cognitive theory. The process of self-reflection helps people make sense of their unique experiences, which in turn encourages the process of cognitive exploration. Self-evaluation is a process where the individual explores their self-belief and alters cognitions and behaviours accordingly. Of all the thoughts that affect human functioning and standing at the very core of social cognitive

theory, are self-efficacy beliefs. "Peoples judgements of their capabilities to organize and execute courses of action required to attain designated types of performances" (Bandura, 1986, p. 391).

Bandura's (1977; 1986a; 1986b) self-efficacy theory examines the process of developing efficacy beliefs, how they are maintained and connected to social support. Self-efficacy theory asserts that efficacy is linked to role satisfaction, however empirical results suggest that efficacy and parental satisfaction are linked yet conceptually different (Bandura, 1977). Self-efficacy theory includes four major bases of self-efficacy beliefs through which self-efficacy is developed. These include vicarious learning, verbal persuasion, physiological state and overall performance attainment. Vicarious learning is a route to self-efficacy that originates from observing others acting in a particular domain whether positive or negative. Social settings provide the opportunity for modelling as well as verbal persuasion.

There has been an increased appreciation of cognitive factors associated with parenting and self-efficacy has been found to be an influential predictor (Coleman & Karraker, 1997). McGrath (2006) found that families who have children with autism report significantly higher number of stressors when compared to those with other disabilities. Fleischmann (2005) also found that the child's psychological state has a direct influence on higher stress levels of parents. Higher self-efficacy levels could be an area of particular vulnerability when parenting a child with developmental disabilities. Challenging behaviours and complex behaviours that are associated with parenting a child with developmental disabilities often leave parents feeling perplexed and exhausted. Generally most parents do not have a frame of reference for ideal parenting however parents whom are able to observe successful parenting tasks often feel more knowledgeable and efficacious regards their own abilities and skills.

Parenting a child with developmental disabilities more often than not leaves a parent feeling unsure and unsure around their abilities to parent successfully. Social situations provide parents with opportunities to be verbally encouraged and supported about their own abilities to parent. Therefore it is likely that parents increased perceptions of efficacy can be linked to socially supportive interactions with other parents. Self-efficacy theory states that the performance attainment of an individual is related to actual perceptions of efficacy (Bandura, 1986a). According to Bandura's theory the inability to reflect on past successes is related to poor perceptions of efficacy (Bandura, 1986a). Parental self- efficacy is subjectively determined by parents. Therefore a parent's ability to complete a parenting task is directly related to perceptions of parental efficacy.

Parenting a child with developmental disabilities can lead to parents feeling unsuccessful at adequately completing parental tasks (Baker et al., 2003; Feldman 2002). The combination of daily hassles and the impact perceptions of efficacy can have on parenting a developmentally disabled child is crucial in understanding the associated risks for negative interactions with their children. Hastings and Brown (2002) investigated the relationship between child behaviour problems, parental anxiety, depression and efficacy, which included a sample of 26 mothers and 20 fathers of children with developmental disabilities. The study revealed that the lower efficacy a mother experienced in her parenting correlated with an increase in overall psychological problems including stress and anxiety. Social support has been identified as decreasing negative mood with its positively associated link with self-efficacy (Cnric & Booth, 1991; Cnric & Greenberg, 1990; Muslow et al., 2002). Belchic (1995) studied the relationship between stress, social support and overall parenting abilities. This study involved children with various levels of developmental disabilities, including autism and Down's syndrome. Interestingly one of the outcomes of this study was that social

supports for parents should be encouraged to help improve the relationship between parental stress levels and negative parental wellbeing.

The parent child relationship theory of stress, explains three domains of stress, namely, parents, child and relationships. The parenting component of this theory incorporates mood states, family belief systems, child development, gender, family history and the parent's unique experiences. A combination of parental factors will have a significant influence on how parents interact as well as deal with stress related issues. The child domain includes stress factors related to the child's behaviour such as challenging behaviour and non compliance. The relationship domain focuses on the quality of the parent-child relationship. This theory postulates that stress experienced in either the parent domain, child domain or parent-child domain can lead to negative effects on other domains. Furthermore, a reduction in any of the domains can contribute to positive effects in the other domains (Deater-Deckard, 2004). According to this theory if there are changes in the parenting domain, there is an increased possibility that this would influence the child and parent-child domain. Each domain has the potential of impacting each other according to this theoretical viewpoint, so the child's behaviour difficulties may increase at the same time as having a knock on effect in the parent-child domain. Conversely, should the family experience a stress reduction in any one of the domains, other areas would respond accordingly and improve (Deater-Deckard, 2004).

It is helpful to understand a general theory of stress that can be conceptualised to understand how stress develops. The interaction with the environment can play a significant part in the development of stress. Lazarus' theory of stress appraisal and coping (1984) highlights the interaction and relationship between the person and their respective environment as significant contributing factors to the development of stress. This theory postulates various processes. Perception by the individual that an event is stressful or not is

the key to understanding the first process. According to this theory, if the individual does not perceive an event as potentially stressful by designation it will not be stressful for them. The next process happens when the individual engages in a cognitive appraisal of the situation. Cognitive appraisal of a potential stressor helps the individual to assess if a stressor should be avoided or not. The last process involves the use of coping mechanisms to decrease the impact of a negative stressor.

2.7 Normalisation

Prevailing societal attitudes impact people from an early age. Negative and biased attitudes towards people with learning disabilities are formed from strong cultural influences. A negative attitude towards people with learning disabilities has devastating consequences. Pervasive social and cultural norms, standards and expectations often lead to the creation of negative attitudes. Vash (2001) argues that the most dominant negative attitudes are those that define and influence entire cultures. Segregated institutions for people with disabilities in the United States and United Kingdom are declining as a result of disability rights legislation. Attitudes are developed and perceptions shaped by the language we use towards people with disabilities. Words about disability have been influenced by the political, medical and legal professions. Pementel (1981) argued that language should be accurate and represent an individual accordingly. One of the most important aspects is that language should emphasize the person rather than the disability.

Less than a century ago, the majority of people with learning disabilities did not reach adulthood. Children died from complications as a result of their disability. Those children, who did survive, were often admitted to institutional settings such as large asylums and psychiatric hospitals. The institutional structures remained during the first four decades of the 20th century. Some children remained with their families, sometimes hidden away from

society. In those days children were often removed from their families on the advice of their doctors who had the parents well being in mind by relieving them of the burden of care. People with disabilities were often treated as second class citizens who were not entitled to the rights and opportunities that others enjoyed (Hutchinson & McGill, 1992). The negative ramifications of differential treatment started to gain increasing recognition, and in response the term normalisation was developed. During the 1960's the normalisation principal became a concept which greatly influenced and characterized the work and services responsible for people with disabilities in Sweden. Scandinavia was one of the first countries to develop a model of normalisation (Grunewald, 1986; Nirje, 1970). The principle of normalisation was developed in Scandinavia during the 1960's by Bengt Nirje. Nirje (1976) outlined components of disability as the medical and physical condition of the individual, the living conditions, daily routines, economic status, prevailing social attitudes and the identity of the person. Nirje (1976) advocated for people with disabilities to have daily routines, access to ordinary housing and usual life opportunities.

Wolf Wolfensburger presented principals of normalisation guided by a set of beliefs that of abandoning the stereotypes and ideologies of difference and replacing this with the principal of inclusion. Inclusion in this context refers primarily to all people being valued, accepted and respected regardless of ethnic and cultural backgrounds, socio-economic status, abilities, gender, age, beliefs and behaviours. Ainscow (2005) expands significantly on the term inclusion as a human rights and social justice principal which embodies values such as equity and fairness in society. The implementation of normalisation was the rallying plea on behalf of those with disabilities and the force behind the break down and execution of the deinstitutionalisation process. Normalisation has had a significant impact on the way services for people with disabilities have been shaped throughout Europe and America. This has led to new developments of the term disability, contributing to significant changes from a social as

well as educational perspective. One of the earliest attempts to provide improved lifestyles for people with disabilities is Wolf Wolfensberger's principle of Normalisation (Wolfensberger, 1972) which later evolved into social role valorisation (Wolfensberger, 1983; 1995; 2000). Normalisation involves the acceptance of people with disabilities, responding to these difficulties and offering the same conditions as are offered to others in society.

Normalisation and valorisation are both based on social role theory, which asserts that people define themselves and others based on what roles they occupy. Wolfensberger (1972) contends that individuals with disabilities have traditionally been allowed only marginal roles within society, consequently leading to their devaluation as individuals. Devalued members of society are more often than not economically poorer, often mistreated, and are not allowed opportunities. Wolfensberger (1983) argued that people with developmental disabilities were at risk of developing increased and significant social devaluation within institutional environments. Some environments would encourage staff to label people with disabilities as deviant or objects of pity, ridicule or sickness (Wolfensberger, 1987). Summarizing the normalisation principals, there appears to be the view that people with disabilities should have the right to live where non-disabled people live and live a normal life. Irrespective of the degree of disability the person should be seen as a worthy citizen and as such have a right to live in the community under "normal patterns of everyday life".

To summarize, based on the literature, it appears clear that negative attitudes towards people with disabilities do exist and represent barriers to their subsequent development. Negative attitudes towards disabilities are powerfully correlated with undesirable effects on the social, emotional, psychological and intellectual development. Attitudes towards people with disabilities are influenced by culture, schools and the language we use. Attitudes appear to be reliant upon socialisation and in order for inclusion to be successful people with

disabilities need to experience acceptance, and inclusion. Language is powerful, and reflects and shapes people's perception. Language used about people with disabilities has been influenced by the medical, legal and political fields. Language should give emphasis to the person rather than the disability. Parents often face additional stress, when having to deal with negative attitudes towards their children. Having an understanding of parental and child factors of stress, a theoretical view and historical account of how attitudes develop it is now important to understand how we measure stress.

2.8 Parental Stress Measurement

The Parenting Stress Index (PSI) is the most widely used measure of parental stress. The PSI was designed to be an instrument where the primary task would be to indentify parent child systems that were under stress or at risk of developing dysfunctional parenting behaviours. The PSI is a screening and diagnostic assessment technique. The PSI/short form (PSI/SF; Abidin, 1990) is a 36 item parent self report instrument designed to measure the relative magnitude of stress in a parent-child system and to identify the sources of stress. The PSI was originally designed for parents of children between the ages of two and twelve; it has been successfully used in studies of parents of older children with developmental disabilities (Cuskelly, Chant, & Hayes, 1998). The PSI measures situational characteristics that contribute to parental stress. The PSI includes such items as "My child makes more demands on me than most children." Parents rate each item on a 5 point Likert scale which range from one (strongly agree) to five (strongly disagree). The parenting stress index yields three major subscales, which include parental distress, parent child dysfunctional interactions and difficult child. Although the three factor solution was originally described for the 101 item long form of the PSI, it remains applicable to the short form (Abidin, 1990). The PSI/SF is correlated with the full length PSI instrument (r=.94), and 2 week test-retest reliability of the full length PSI with the PSI/SF is .95 (Abidin, 1990). Domains of stress include the subscales

adaptability; demandingness, mood, and distractibility, acceptability of child to parent and child's reinforcement of parent (Abidin, 1992). The design of the PSI child domain subscales acknowledges components in the experience of stress. Abidin (1992) highlights the importance of child characteristics, as well as the parental perceptions that enhance the clinical utility and validity of the PSI. The process of interpreting the results of the PSI incorporate global considerations of the overall stress score including the Child Domain subscale and Parent Domain scores. Webster-Stratton (1989) noted that the depression subscale of the PSI is associated with maltreatment and dysfunctional parenting.

2.9 Summary

   While evidence suggests that stress is influenced by a variety of factors, parental stress does not necessarily lead to family dysfunction. It is evident that there are diverse factors that are related to this complex phenomenon. Contextual and environmental factors explain much of the variance in parenting stress. Consistent with previous research several poignant theories of stress are discussed such as the daily hassles theory of parenting stress. The parenting daily hassles view focuses primarily on minor stressful events that can accumulate over longer periods of time. Social cognitive theory is examined and discussed and understood in context of parental belief systems and how they impact on parental stress. The chapter reviews normalisation theory, considers family as well as individual and environmental factors that contribute to stress. Finally measures of stress are discussed with a brief review of previous parental stress interventions.

Chapter 3: Short breaks

3. Introduction

Providing care for a child with a developmental disability takes a lot more commitment than caring for a child without developmental delays. As a result of the extra demands, families often rely on short breaks services to assist them in the caring role. Short breaks are not a new phenomenon; it emerged in the late 1960's with the move away from placing young people in institutions. One of the most important principles was the belief that the best place to care for a child with special needs is in the child's home and community. Families are well aware of the commitment and intensity of care necessary to look after a child with developmental disabilities. Short breaks are recognised as a statutory service to support parents with the care of their child. The UK Government has introduced a number of strategies and policies directed at enhancing the support to carers. The Carers Recognition and Services Act (Department of Health, 1995), clearly acknowledged carers rights and the need to have these addressed. Consequently Caring about Carers and the Carers and Disabled Children's Act was formed (Department of Health, 1998). The White paper *Valuing People* supported the view of the overall improvement of services for carers (Department of Health, 2000). Respite care, which is also recognised by the term 'short breaks', in that it is the provision of short-term relief to individuals who care for friends or family members who might otherwise require a permanent place in a care facility outside of their home. Short breaks has become the preferred term, partly due to the negative connotations of family carers in need of respite from their children and also because short breaks now encompass a much wider range of supports (Cramer & Carlin, 2008).

The term short breaks will be used throughout this research, with the exception of direct quotes from previous research studies where the term respite is used by study participants.

The term short breaks has a number of definitions such as any intervention designed to provide the family with a break from the caring role (Shaw et al., 2009). Likewise the term respite could be used for the person who has a learning disability, a short break at home, in the community or in a residential setting (Treneman, Corkery, Dowdney and Hammond, 1997).

Short breaks were designed for children with complex developmental disabilities to spend time in the company of peers and give family carers a break to allow young people the opportunity to have new experiences with a wider range of people outside the family. Diversity in the range of short breaks being offered to families with a child who has developmental disabilities is on the increase in the UK; these increases are struggling to meet the needs of the rising numbers of disabled children (Cramer & Carlin, 2008).

3.1 Support & perceptions of short breaks

Short break services provide support for the maintenance of the primary care giving relationship given the emotional, physical and financial consequences of caring for a child with developmental disabilities. Research has started to provide evidence about the beneficial effects of short break services, particularly for mothers (Bose, 1991; Botuck & Winsberg 1991; McGill, 1996). Botuck and Winsberg (1991) found that mothers were less stressed while using short breaks and had significantly more choices in terms of outside activities. Short breaks is the service that is most frequently requested by caregivers (Snyder and Keefe, 1985), but it is in critically low supply, unaffordable or inaccessible, no matter what the age or the disability of the person to who care is given (Neff, 2009). For those children with developmental disabilities, short breaks target at relieving the family of the caring role, providing specialised care while the families take a break. Short break services have been acknowledged as contributing in positive ways to family well being (McNally et al., 1999).

These services provide families and care givers the chance to catch up with basic family routines such as shopping, rest and day to day chores. Parents report significant relief from stress, when short breaks are offered (Olsen & Maslin-Prothero, 2001). According to Laverty and Reet (2001) short breaks allow parents therapeutic opportunities, quality time and improved quality of life for the family. Short break services are often perceived as a crisis intervention, as opposed to a network of services to support the family. Service providers in the UK support the view that short breaks should provide for the child's therapeutic needs in conjunction with the promotion of independence. Short breaks services have been developed with the goal of empowering family members by encouraging family capacities that support overall functioning. Parents often report that short breaks provide them with an opportunity to spend time with other family members and enhance the relationships between members (Sines, 1999).

Laverty and Reet (2000) document their views of respite as allowing therapeutic opportunities, quality time, and independence for the child and the family. Laverty and Reet (2000) advocate that family members feel supported as a result of using short break services. Various aspects around short breaks include making sure the child is engaged in therapeutic activities in conjunction with the promotion and enhancement of teaching independent daily living skills. These skills are seen as crucial to helping the child develop, as well as encouraging the ability to make new friends and the participation of normal childhood activities. The literature reviewed clearly illustrated the wide ranging effect caring for a child with developmental disabilities can have on the whole family unit. Without a break, parents are likely to become completely exhausted or even unwell, due to the constant physical, psychological and social demands of caring (Mitchell & Sloper, 2001; Olsen et al., 2001; Robinson et al., 2001; Cowen & Reed, 2002; Watson et al., 2002). Moreover, it has been recognised that the availability of short breaks can vary significantly and can be dependent on

social agencies. The benefits of short breaks to families should not be underestimated (Catherall & Iphofen, 2006). Mencap (2006) argues that families should be allowed frequent breaks, bearing in mind that these breaks are enjoyable for parents and more often than not for the young person with a disability.

3.2 Aiming high for disabled children

Families with disabled children face a constant struggle to access affordable and appropriate childcare. According to the Disability Discrimination Act (1995), a person is disabled if they have a physical or mental impairment that has a substantial and long term adverse effect on his or her ability to carry out normal day to day activities. The term disability is therefore used in this research to encompass all physical, mental or special educational needs. This definition encompasses the full spectrum of disabilities and includes sensory impairments, learning difficulties and impairments resulting from or consisting of mental illness. The definition encompasses hidden impairments such as dyslexia, autism, speech and language impairments where these substantially affect the child's ability to carry out normal day-to-day activities in the long term. The impacts of disabilities can be multiple and complex. This can influence mobility, ability to concentrate, learning, communication, manual dexterity, motor coordination, continence as well as the perception of danger. In order to meet the needs of children and prevent inequalities and to ensure the families lead fulfilling lives, effective, integrated and accessible services are required (DOH, 2000; 2001).

For many families, parenting children with complex developmental disabilities requires a bespoke package of integrated care. Across the spectrum children with disabilities often find it difficult to access leisure activities. There is an abundance of evidence in recent research that families with disabled children face considerable challenges when it comes to childcare. (Chan & Sigafoos, 2000; Robinson, Jackson & Townsley, 2001; McConkey & Adams, 2000;

Grant & Whittell, 2000). Some of these issues relate to poverty and childcare costs, lack of appropriate places and services as well as inadequate information available to families who have disabled children.

Statistics in the UK reveal that 29% of disabled children live in poverty. According to Mencap (2003) this percentage is as high as 55% of families with a disabled child living in poverty. One of the Governments strategies is to enable parents to work to end child poverty by 2020. The Sure Start 2005 report "Use of Childcare among Families with Children who have Special Educational Needs" (SEN) report that families who parent a disabled child are likely to be disadvantaged on a number of levels. These levels include an increased likelihood to be from families with lone parents, lower incomes, and a mother / father with low educational qualifications. A Contact a Family internet based survey investigated the financial costs for caring for a disabled child. This survey concluded that 89% of families parenting a child with disabilities found it more expensive to arrange for childcare, than in comparison to childcare for a non-disabled child. The 2002 'Contact a Family Childcare' survey produced interesting results, as out of 1870 respondents , 94% of families thought that it is more difficult to find appropriate childcare for disabled children and 90% stated that there was insufficient choice in childcare available. Furthermore 79% of families found it almost impossible to combine work with childcare. The Day-care Trusts 'Everyone Counts' (2004) research included parent focus groups with questionnaires around Britain. This revealed that many families felt that flexible and appropriate child care was not readily available. A total of 69% of parents of disabled children experienced significant difficulty finding appropriate childcare. The Day-care Trust's (2007) 'Childcare Costs' survey indicated that 13% of families parenting a child with a disability had an assigned disability officer. The 'Every Child Matters' Audit commission revealed that many families have to battle through a host of services to gain relevant information, then have to proceed through a

series of hurdles to gain access to support. Service provision is rarely based on the priorities and needs of the individual families. What is provided is often too little and too late to make the best possible improvement to their everyday lives. For example many families still miss out on their full entitlement to benefits because services don't pass on key information at the right time (Every Child Matters' Audit Commission, 2003).

Meeting the needs of families who parent disabled children is a priority. Supporting families is part of the overall Government's strategy to implement relevant changes by 2020. The Disability Discrimination Act (2005) added to previous disability legislation (Disability Discrimination Act (1995) and Special Education Needs and Disability Act (2001) has introduced a disability equality duty. This will ensure that the public sector, local Government and private sector, must initiate a disability equality scheme, with a clear plan of how they will promote equality of opportunity with the aim of developing positive attitudes to families who parent disabled children. Research evidence indicates that perceptions among families with disabled children are varied and that some feel there are not enough appropriate services for children with complex and developmental disabilities (Chan & Sigafoos, 2000).

The overall purpose of the 'Listening to parents of children with disabilities and special needs' research was to identify the perceptions of families parenting a child who is disabled. Clearly there seems to be an identified gap in childcare provision for disabled children, a great difficulty for parents to combine work and specialised care and considerable financial implications when looking after a special needs child (Baker et al., 2002; 2003; Crnic & Low, 2002; Deater-Deckard, 2005; Tomanik et al., 2004; Spratt, Macias, 2007). According to the Every Child Matters campaign around 770,000 (7%) of children in the UK are disabled; 29 % of disabled children live in poverty and many of them are currently facing multiple barriers. The overall educational attainment of disabled children is lower than that of non-disabled

children and less than 50% of schools have accessibility plans. In 2007, the government

published 'Aiming High for disabled children: Better support for families'. This was an in

depth report looking at how every disabled child can have the best possible start in life and

fulfil their potential and considering what support they and their families need to make this a

reality. The report focused on specific areas which included the following: Access and

empowerment, involving disabled children in developing services at a local level and using

their experiences and feedback to make services work more effectively. This report

highlighted the importance or responsive services and timely support, ensuring the right

services are available at the right times in children's lives, that services are developed around

the child and family with the assurance that services are delivered in a coordinated and

integrated way. One of the most important areas in this report was improving quality and

capacity, and the recognition that certain services can make a huge difference to families

lives such as short breaks.

3.3 Development of Welfare and Support Services

Children are entitled to over 40 substantive rights given to them by the United Nations

Convention on the Rights of the Child (United Nations General Assembly, 1989). These

include the right to express their views and the right to have these views taken into account,

including the right to freedom of expression. Children with complex developmental

disabilities and associated health needs generally need to spend a significant amount of time

away from home, as treatment needs are met. However they still have a right to a review at

regular and consistent intervals. As stated children have the right to care and special

protection. Children with developmental disabilities are classified among 'children in need'

under the Children Act (1989) and thus must be provided with support services. Disabled

children have an entitlement to different kinds of assistance that they may require in order to

fulfil both their civil and human rights. In addition, parents and carers also have a right to services according to the Carers and Disabled Children's Act (2000). Choice Protects (2000) acknowledges that caring for children with developmental disabilities can be a demanding experience, taxing both the physical and emotional capacities of the family. The formal recognition that children with developmental disabilities often have additional needs has been well supported in the literature available. Consequently, the families are entitled to support as well as an integrated service, listed in the Children's Act and the Chronically Sick and Disabled Persons Act (1970). In the Children's Act (1970) it is outlined that every local authority shall provide services designed to give children with developmental disabilities the opportunity to lead lives which are as normal as possible. It is also important to note that if a child is given a placement in the form of care outside their home (whether short-term respite care or longer-term services) the relevant authorities should ascertain [their] wishes and feelings and take these into account when making decisions (Children Act, Sections 20 (6), 22 (4) and (5).

3.4 Historical Perspective

Developing 'community care' for individuals who are elderly, mentally ill, physically disabled, or who have learning disabilities, has been part of the guiding principal of the Government in Britain since the 1950s (Holloway, 1990). During the 1950s, people with learning disabilities were placed in large institutions (Stalker & Robinson, 1994). Since this time respite care services were developed as a consequence of the recognition of the importance of the parental-child interaction and the shift from institutional care to community care (Hoare *et al*., 1998). The UK government identified the development of respite care services as one of the key objectives for effective service delivery. The government made positive commitments to support the families of children with complex developmental disabilities (Department of Health, 1989). The British government commissioned Sir Roy

Griffiths to provide a review of the way in which funds are used to support community care policies (Department of Health, 1989). In 1989, the paper *Caring for people* (Department of Health, 1989) was published in response to the Griffiths report (Griffiths, 1988). These changes established a framework for community care procedures and policies, which included a new funding structure for social care, in which money would be allocated to Primary Care Trusts specifically for enhancement of respite care services within the community. The Griffiths report also encouraged the development of day care, domiciliary and respite services to allow people to live as independently as possible in their own homes. Recognition of the parallel need for relief to families as well as support initiatives took precedence. Respite care for parents of children requiring complex care started to receive increased attention. Despite this development some measures that were not accepted included the overall protection of community care monies and the creation of a ministerial post within the Department of Health with specific responsibility for community care as well as respite care. The paper Caring for people (Department of Health, 1989) influenced the NHS and Community Care Act (1990), which gave local authorities the lead responsibility in assessing families' needs and setting up support and care, including the allocation of funds for respite care services. A significant part of the act was the provision of services for people at home, which constituted three types of service; domiciliary, day and respite services.

The Carers (Recognition of Services) Act (1995) then placed responsibility on local authorities to assess the needs of families in need of short breaks. Therefore families providing a significant amount of care on a regular basis are given the right to request an assessment from social services. Fruin (1998) found that implementations of the initiatives under this act were vague. This resulted in families not receiving enough information about their entitlements (Carers National Association, 1997). Research revealed that assessments were not always getting carried out; some carers were offered practical support, whilst others

were provided with almost nothing. Moreover, when the requisite assessments were undertaken, the carers reported that they were satisfied with both process and the results. Carers were entitled to an annual review regarding family needs, available services and a summary of the help they receive (Department of Health, 2000).

3.5 Changes to Policy

One way to help families with a child with a developmental disability is the provision of short break services (Robinson & Stalker, 1993). The British Government has made significant provision by providing £140 million, to increase the accessibility of short breaks for families and carers. This innovative development has moved away from the more traditional forms of respite care (Briggs & Askham, 1999). On the whole, the goal for short break provision is to improve the quality of life for those involved in caring (Weightman, 1999). Providing care for a child with a developmental disability can take considerably more commitment and resources than caring for a child without developmental delays. Over the last 25 years, a significant feature of the UK Government policy towards people with severe intellectual disability has seen a shift away from the traditional long-term institutional care approach, to practical care within the community (Thompson, 1993; Zealley, 1993). As a result of changes to this policy children with severe intellectual disabilities are more likely to remain within the family for their developmental years and early adult life. *Caring for people* (Department of Health, 1989) was published in direct response to the Griffiths report (Griffiths, 1988). This paper established a framework for specific changes to the community care procedures, including a new funding structure for social care. The paper specifically endorsed the development of day care, domiciliary and short break services. This was an in-depth report looking at how every disabled child should have the best possible start in life and is able to fulfil their potential. Areas of the report were prioritised in terms of access and

empowerment, responsiveness and timely support as well as improving the quality and capacity of respite care services. The report goes on to work towards achieving improved outcomes for disabled children. These outcomes specifically targeted areas such as improving communication, being healthy, being safe, making a positive contribution, increased ability to enjoy life and to achieve economic well-being.

Caring for people (DOH, 2009) influenced the NHS and Community Care Act (1990), which gave local authorities the primary responsibility of assessing people's needs and planning and providing care, including the allocation of funds for respite care. A core component of the act was the provision of services for people at home, which constituted three types of service; domiciliary care, day and respite care services. Despite the potential advantage of respite care, an important limitation seems to be the availability of resources which, is largely dependent on the priority allocated to the service by either the health or social services agencies (Robinson & Stalker, 1993).

3.6 Benefits of Short Breaks

Overall, the function of short break services in the research literature has been viewed as providing breaks for family carers. A qualitative investigation in the UK studied 36 families with children with developmental disabilities, and found that parental perceptions were similar in that they felt that the service was for themselves rather than their disabled child (Platts, Hughes, Lenehan, Morris and Flynn, 1995). Parents had similar ideas about short breaks, such as being fun, being able to provide a wide range of services which included therapeutic work, as well as providing a helpful information and professional support as required. Knight et al. (1993) conducted a meta-analysis of interventions for caregiver distress concluding that short breaks did have a positive impact however this effect was only moderate.

Children with developmental disabilities have benefited enormously from the advances in neonatal medicine and nursing care all of which are seen as contributory factors in the growth in the number of children who survive complex developmental conditions such as low birth weight, birth trauma and a variety of anomalies. A significant proportion of these children are at increased risk of having long term needs that will require innovative nursing responses. Stalker and Robinson (1994) noted that the majority of children enjoyed short breaks, including the variety of activities short breaks offer. Although most children appeared to enjoy short break stays, research in this area should be interpreted with caution as most data collected was via care staff and teachers and they may have misread the child's communication cues. Of particular importance is the need for parental respite, given the demands of caring for disabled children in the context of the family home. The perceived benefits of respite were discussed in small scale qualitative studies. Families reported renewed energy and more time for activities as positive outcomes after receiving respite support services. Families also reported negative outcomes in relation to feelings of guilt and embarrassment at having allowed their child to attend respite care services (Wilkie & Barr, 2008). In a more general sense most of the studies demonstrate that parents consider short breaks to be a benefit to their child. Gerard (1990) conducted a cross sectional postal survey in the UK with 253 family care givers of children with developmental disabilities. Families in this study had used short breaks services and were asked if they felt that the service improved the quality of life and whether this had an indeterminate effect. This study was conducted across three short break services and it was found that the quality of life was deemed to have improved for 81%, 90% and 63% in each respective service. Authors concluded that short breaks provide overwhelmingly positive effects on the quality of life. A Welsh study reviewed family based short breaks with 150 family carers of children with developmental disabilities (Swift, Grant & McGrath, 1991). Several benefits were listed which included

exposure to new stimuli and interests; increased social awareness and social skills, friendship making opportunities, growing independence from the family, and an overall increase in confidence. Postal surveys in a Canadian study, focused attention on the impact of short breaks in a children's hospice which included 65 parents (Davies, Colins, Steele, Cook, Brenner & Smith, 2004). A large percentage of parents (63%) stated that their child benefited extensively from using short breaks, mostly in the form of residential breaks. Families viewed short breaks as a place where their child could relax and unwind, enjoy themselves with novel activities such as taking part in outings and being part of an integrated social network. In Northern Ireland researchers conducted a thematic analysis of responses by 108 parents to open ended questions about the perceived benefits of short breaks for their child with developmental disabilities (McConkey et al., 2004). Benefits as perceived by the parents related to the opportunity to interact socially with others in a different environment (N=49). Other perceived benefits included enjoying the break, getting used to being away from home (N=11) and being able to get involved with social activities that they would not normally be able participate in at home (N=10). Various qualitative studies using Interpretative Phenomenological Analysis to assess the views of six parents who used short break services reported benefits such as opportunity to meet others outside the family and an increased opportunity to participate in leisure activities (Wilkie & Barr, 2008).

Overall, the target is consistent with the view of improving the quality of life for both carer and the cared persons (Lightbody & Gilhooly, 1998). Briggs and Askham (1999) argue the importance of innovative approaches to short breaks which stipulate that the service is more responsive and reasonably accessible. On a functional level respite care services could potentially offer a variety of support. This could include offering a child an opportunity for additional experiences outside the family home, offer support to carers, prevent family breakdown and possible rejection of a child and the avoidance of long term residential care

(Lindsay, Kohls & Collins,1993). To uphold and sustain the health of the primary caregiver, the child, and the entire family, respite care has been established as a key resource in the provision of this essential care. The needs of carers have become evident since the Carers Recognition & Service Act (1995). The literature indicates the provision of short breaks is the key to the Government's national strategy. The aim being to improve the quality of life of the carer rather than simply to keep them in a caring role. Short breaks are particularly important in overall care where services are poorly developed and carer stress can be higher. Providing care for children with developmental disabilities by members of the family at home is widely recognised as the optimal choice for the wellbeing of the child and family (Neufeld, Query & Drummond, 2001). However recognised breaks are viewed as essential in relieving parental stress and improving overall mental health. Providing care for children with developmental disabilities by members of the family at home is widely recognised as the optimal choice for the well being of the child and family (Neufeld, Query, & Drummond, 2001). However recognised breaks are viewed as essential in relieving parental stress and improving overall mental health.

The Government has made significant changes to its overall policies (Department of Health, 2000), making changes to short break provision, providing flexible, responsive and interactive services which include client involvement in design and evaluation of services. The demand for respite care is apparent; the literature indicates that it is difficult to establish the precise benefits using qualitative analysis. Studies consistently suggest that short breaks may benefit children with developmental disabilities by providing new experiences, social activities that would not otherwise be available to them and social interactional experiences with people outside the family (Chan & Sigafoos, 2000; Robinson et al., 2001; McConkey & Adams, 2000; Grant & Whittell, 2000). There is evidence to suggest that disabled children can benefit from making friends and that this process can also enhance greater independence

skills. There is some evidence to suggest that some disabled children find short breaks a negative experience, but overall it appears to be viewed as extremely positive (Chan & Sigafoos, 2000). There is consistent findings in the research relating to the overall perception of short breaks by parents as being largely beneficial which in turn enables families to continue caring for their disabled child at home with renewed energy after a much deserved break (Grant & Whittell, 2000).

3.7 Rationale for using Short Breaks

Short break services for parents with children who have a developmental disability requiring complex care has received increasing focus in the literature (Mitchell & Sloper, 2001; Olsen et al., 2001; Robinson et al., 2001; Cowen & Reed, 2002; Watson et al., 2002). Short break services that provide temporary child care and support to children with developmental disabilities are thought to be a critical component of formal social support interventions deemed necessary to promote healthy family functioning. Respite care services are part of a comprehensive approach to early intervention for children with developmental disabilities. Lack of child interaction and responsiveness, unusual behavioural patterns and excessive care giving demands have been associated with increased stress levels as well as depression in the parents of developmentally disabled children (Ammerman, Hersen, Van Hasselt, Lubetsky & Sieck, 1988; Beckman-Bell, 1981; Brinchmann, 1999; Patterson & Leonard, 1994; Snowdown, Cameron & Dunham, 1994). Researchers have reported that short breaks alleviate and in some cases prevent caregiver stress and mental exhaustion as well as improve social and peer related interaction for the child with developmental disabilities (Damiani, Rosenbaum, Swinton & Russel, 2004). There is growing evidence into the nature and significance of short breaks for carers and those for whom they look after. Much of the literature examines the impact on the carers' ability to care for children with developmental disabilities. Short breaks have been reported to have a positive impact on

family relations, social activities, emotional well being and in the alleviation of stress (Chan & Sigafoos, 2001). Short breaks may provide support for the care giver, allowing parents the time to attend to their personal care and social needs (Cohen, 1982; Joyce & Singer, 1983; Neufeld, Query & Drummond, 2001). Short break services may be used in a crisis acting as a source of immediate support (Treneman et al., 1997) which in turn may aid in overall family stability by decreasing higher stress levels (Cohen, 1982; Joyce & Singer, 1983; Joyce et al., 1993 Folden & Coffman, 1993; MacDonald & Callery, 2004). Short break services could additionally provide a learning opportunity for the child in terms of increased social interaction and skills based developments (Damiani et al., 2004). As previously stated the relationship of individual psychological stress with caring for a child with complex developmental disabilities is well documented (Hall, 1996; Kirk & Glendinning, 1998; Mitchell & Sloper, 2001; Olsen et al., 2001; Robinson et al., 2001; Cowen & Reed, 2002; Watson et al., 2002).

3.8 Parental Perceptions of Short Breaks

Hartrey and Wells (2003) used a phenomenological approach to look at the apparent benefits of respite care. Their study focused on short break service provision in Ireland for children with developmental disabilities. They explored the views of two mothers who had access to short breaks and considered, in particular, its personal significance for them as it related to their caring relationship with their children. For the two mothers in question, whilst some benefits of respite care applied to them, such as improved social activity, using respite care facilities and the concomitant experience of separation from their children led to feelings of guilt and seemed to bring about a level of emotional stress. The authors thus argued that providers of respite care services must consider how they can also provide support for the parents who use their facilities so that they come to view it as an element of caring for their child, which should hopefully alleviate any guilt.

Mencap (2003) published their report that was made up of testimonies from parents looking after a child or children with developmental disabilities. This report illustrated the importance parents had placed on using short break services. Mansell and Wilson (2009) studied the family's views of short breaks services accessible to them via their local authority. The authors argue that access to high quality, regular respite care has a positive impact on the caregiver's ability to carry out their caring role. Despite the varieties of short break services in the UK, the authors revealed interesting findings. Mansell and Wilson (2009) used a mixed method design, with questionaires as well as focus groups, providing a qualitative and quantitative study. Families were sent questionnaires that included a respite care section. The response rate was extremely low, and as a result focus groups were carried out with a proportion of the carers who had filled in the questionnaire. Some of the families reported that their needs in relation to respite care were not being fully met. These unmet needs were generally around a lack of information around the criteria for access to respite care services.

Although there are positive aspects that are associated with the caring role, such as self fulfilment (Lane, McKenna, Ryan & Fleming, 2000), there is a link between high levels of carer stress and parent's abilities to care for a child who has a developmental disability (Hearne & Dunne, 1992; Treneman et al., 1997; Hoare et al., 1998). Caring for a child with developmental disabilities can involve considerable amounts of lifting, feeding, toileting, bathing and dressing (Connaughton & O'Donovan, 1999). Such demands on the caregiver come with additional personal costs, which include feelings of social isolation and a reduction in contact with friends and family members. Subsequently feelings of exhaustion and stress are the main reasons parents or carers use respite care services within the community (Hoare et al., 1998).

It appears that parents liked the quality of care provided within the overall short breaks service context. Some disadvantages included lack of choice and minimal contact with non-disabled children (Minkes, 1994). It seems that the overall perception is that short break services provide temporary child care, support and referral services to families of children with developmental disabilities and are thought to be a critical component of formal social support interventions deemed necessary to promote healthy family functioning. The helpfulness of short breaks among families with a disabled child is somewhat indisputable. For example, Olsen and Maslin-Prothero (2000) completed a qualitative evaluation of short breaks service that was led by nurses and based in the homes of the families who had children under the age of five with complex health care needs. Qualitative interviews with families were used with those in receipt of respite care. The outcome of evaluation revealed some interesting findings; some parents reacted with mixed emotions regards respite care services. Parents who used the service underwent several dilemmas and problems with regard to the provision of home-based respite support to this group. In particular, parents pointed to the need for flexibility in this kind of service provision if these support needs are going to be met successfully. Several authors question the positive impact linked to short break services. Stalker (1990) evaluated a family based short break service and identified that some families withdrew from the process as they felt their children's absence from the home in itself created additional stress. Stalker & Robinson (1993) found some of the psychological benefits derived from short break services were insignificant and a small percentage of families admitted to feelings of blame or fault in using respite care. McNally et al. (1999) assessed several studies on the impact short breaks had on the social interface of families and activities of carers and concluded that only one study confirmed respite care improved social life. There appears to be different interpretations of the benefits of short breaks to carers and feelings around placing a child in respite care and having to deal with their return.

On the whole the provision of short breaks is seen as an important means of alleviating stress levels. Quantifiable results from research studies are limited. However, a review of short break services for children with learning and developmental disabilities concluded that service users expressed an overall satisfaction with respite care and reported a considerable relief from stress and mental exhaustion (Hoare et al., 1998). Most families agreed that there were sufficient criteria to justify the need for such services. However the literature informs us that the influence and the quality of life of carers as well as those in receipt of care are both negative and positive. Regardless of the recognised demand for short break services, a few studies suggest that some families are dissatisfied with the overall service, including support and general accessibility (Hollingsworth, 1992; McGill et al., 2006). The benefits of short break services and the disadvantages varied considerably depending on parental perceptions and in some cases professional perceptions. The parents reported little difference between benefits while mental health professionals perceived significant differences between homes based care than short breaks (McConkey & Adam, 1999).

Other studies have found that short break services have a lesser contribution to family well being, and it is a combination of factors that contribute to well being (Olsen & Maslin-Prothero, 2001). Insufficient access to care, troubles with long wait lists, and frequency were all cited as potential stumbling blocks (Treneman et al., 1997; Neufeld et al., 2001). Other parental concerns were the strict levels of eligibility requirements for various types of short break provision (Benedict & Farel, 2003). Other forms of frustration included minimal diversity in the various types of respite care offered and problems with availability (Campbell 1996; Floyd & Gallagher, 1997). Overall services must be flexible and responsive to users so that they feel confident about the care that they are provided with (Cotterill, Hayes, Flynn, & Sloper, 1997). Short break services will be most effective when it is planned to meet the

expressed needs in terms of accessibility, flexibility and location (Glendinning & Kirk, 2000; Laverty & Reet, 2001).

3.9 Children's Views

Over the last few the years the government has recognised the importance of consulting with children about their views. The Gillick ruling of 1984 campaigned that children should be consulted about decisions which affect their lives. The National Service Framework for Children, Every Child Matters as well as the United Nations Convention all support the view that children's views are paramount. Consulting developmentally disabled children about service provision is vital because more often than not these children have to undergo multiple assessments and medical interventions when compared to other children. Children with severe learning disabilities or extremely limited communication skills can communicate preference if they are asked in the correct way (DOH, 1991). Gaining the views of children with developmental disabilities remains inconsistent in the literature. Beresford (1997) found that some of the available research indicates that when consulting children it is important to start from the perspective that all children, regardless of their level of communicational skills or developmental disability, have their own unique perspective. It remains the responsibility of the assessor to source appropriate strategies to understand their views as well as have the relevant skills to listen (Beresford, 2004).

Several cross sectional surveys focused on the views of users of short breaks, others included users of different types of short breaks (Neufeld et al., 2001; Radcliffe & Turk, 2007; Shared Care Network, 2008). Other studies used mixed methods to review the user's experiences of short breaks (Davies et al., 2005; Swift et al., 1991; McConkey, 2008; Truesdale, 2000). Qualitative research that focused on the views of users was used in several studies pertaining to this current research (Smith, Caro & McKaig, 1988; Kelly, McColgan &

Scally, 2000; Hartrey & Wells, 2003; Eaton, 2008; Wilkie & Barr, 2008). Following Crisp et al. 's (2000) consultations carried out with children with developmental disabilities using short breaks, it was found that children wanted more choices about what they did at short breaks. Minkes et al. (1994) found similar results on a study conducted with thirty learning disabled children using three different short break centres. Marchant et al. (1999) confirmed these results and carried out a study that involved six residential short break centres involving interviews with seventy seven children with developmental disabilities all confirming that children wanted more choices whilst staying in short breaks.

Available research suggests that whilst on the whole disabled children report being happy at short breaks, not all children are comfortable having to leave home. Studies show that most young people with developmental disabilities enjoyed their respite care, and responded positively to the various activities offered (Stalker & Robinson, 1994). Stalker (1992) also found that children enjoyed using respite care. Interview studies carried out in the US (Damiani, Rosenbaum, Swinton, and Russell, 2003) revealed that 46% of carers of children with cerebral palsy in the sample had used short break services in the previous year. Families using respite care had used this more than once, which suggests that parents found this a useful service. It is possible that children also found this experience to be positive and beneficial (Minkes et al., 1994; Stalker & Robinson, 1994). Clearly the function of short breaks in most of the reviewed literature has focused on the impact on families' well being; less attention has been placed on the impact for the children themselves. An exploratory pilot study in Northern Ireland obtained the views of three children with intellectual disabilities regarding the use of short break services (Kelly, McColgan & Scally, 2000). The children gave positive images of their experiences of short breaks. Another study in Northern Ireland interviewed five children with disabilities, using short breaks and it was found that all the five children described positive experiences as well as being able to develop friendships. Some of

the children were not sure why they were using short break services, and others held the belief that their mothers did not like them being at home. Overall the negative comments were mostly around missing their families rather than the services provided. The study concluded with suggestions that children should be consulted prior to using short breaks and given more concrete explanations as to why they are using this service. The study concluded with parental interviews and the reported benefits included: socialisation (N=12); new environment or experiences (N=7) as well as enjoying a break (N=7). Around 22 families reported benefiting from this service such as: new activities (N=6); building relationships (N=6) and having the opportunity to socialise with others (N=5) (McConkey & Truesdale, 2000). Mixed methods research design in the UK included structured interviews with 20 young children with a confirmed diagnosis of autistic spectrum disorder and attention deficit hyperactivity disorder who were using respite care services. Young people's views ranged from positive and negative experiences of respite care (Thompson et al., 2009).

The research reveals a dearth of information regards the views of disabled children in receipt of short break services. The research does however suggest that in a general sense children do get pleasure from short breaks; however there are some children that are unhappy with this service provision. Several studies have employed objective measures of outcomes to explore this in more detail. Longitudinal studies in the USA measuring the impact of residential short breaks (N=39) and short term inpatient admission (N=44), used the Functional Ability Scales to determine child functioning at admission and discharge (Mullins et al., 2002). Overall child functioning improved on discharge in both services, despite the short break being less than seven days in total, without additional therapeutic interventions; ethical issues limited this study in terms of a control group. Bose (1991) in a study in the UK assessed 48 families involved with a link scheme and found no significant differences between those that used short breaks and those that did not, in relation to the number of

friends or social experiences the child had. There is limited research available that uses objective outcome measures to assess the impact of short breaks on children with developmental disabilities. Research that is available has not been able to provide an evidence based approach to improved outcomes.

3.9.1 Summary

Even children with severe learning disabilities or very limited expressive language can communicate their needs and wants. What is important is that they are asked in the correct way by professionals who can both recognise the needs of the child and have the clinical skills to remain engaged. The process of consulting young people with developmental disabilities regarding their views of short breaks should be a positive and empowering experience. Consulting children with developmental disabilities should be based on effective communication skills.

Chapter 4:   Methodology

4.1 Introduction

This chapter describes the design of the present study. The decisions made in selecting the design are discussed as well as data collection procedures, ethical considerations and participants. The main topic of this investigation is the ability to predict the level of stress reduction, as measured by the Parenting Stress Index, which short breaks may bring to parents. To focus on the research question it was resolute that attitudes and perceptions of short breaks are at best derived from the words of the participants and the implication they assign to their experience. The suitability of the proposed design for the present study is also supported by reference to the techniques employed in past studies and their demonstrable effectiveness in producing validated results. This research design follows a pragmatic approach. A pragmatic approach integrates multiple methods, diverse world views as well as unique assumptions all of which are gathered for analysis. Upon examining the methodologies, it was determined that a combination of a quantitative as well as a qualitative approach be used to provide a deeper, broader understanding of the research problem. Creswell (2008) outlines the mixed methods research design. The mixed methods design is a procedure for collecting, analysing and mixing both quantitative and qualitative research in a single study to better understand the research problem (Creswell, 2008).

A pure qualitative approach to the research problem would have provided an integrated portrayal and rationalisation of the processes which aimed at understanding the subjective experiences of short breaks. On the other hand the main topic of the investigation is the ability of responses to predict levels of stress before and after short breaks, as measured by the Parenting Stress Index (PSI). For that reason quantitative methods of research were explored as a means to gauge parental stress levels before and after using short breaks. This study attempts to draw conclusions regarding some of the common themes in parent's

subjective experiences in using residential short breaks for their disabled child. This study investigates the ability of responses to predict any changes in stress reduction as measured by the (PSI), before and after using short breaks. To summarize, quantitative data concentrates on measurable parental distress, whereas qualitative data reveals concrete benefits. The qualitative analysis has enabled a picture to emerge of how parents conceptualize and experience short breaks.

4.2 Quantitative and Qualitative Research Methods

Qualitative research is an investigative process based on distinct methodological traditions of inquiry that explore human and social interaction. Qualitative research makes important contributions to understanding human behaviour. Qualitative research has the distinct advantage of exploring and interpreting observations and words holistically in an attempt to discover themes and patterns of human phenomena (Smith & Osborn, 2003). The researcher aims to gather data, build a complex picture, analysing words as well as conducting the study in a natural setting. Qualitative research is a method that examines contemporary real-life situations and provides the basis for the application of ideas and methods (Patton, 2002). In comparison quantitative research methods develop knowledge through the collection, analysis and interpretation of data in numeric form. It was determined that a standardised questionnaire and rating scale instrument would provide useful pre and post study measures of parenting stress. A standardised questionnaire would provide useful before and after study measures of parenting stress that would broaden the qualitative data.

4.2.1 Summary

These methodologies were carefully considered and a combination of qualitative as well as quantitative approaches adopted. A mixed methods design provides a procedure for mixing both quantitative as well qualitative research methods in a single study in an attempt to

answer the research question. It was envisaged that this approach to the research question would provide a deeper, broader perceptive understanding as opposed to a single method. This methodology is often used in social science research. A qualitative approach on its own would have provided explanations of processes which sought to understand the parents experiences of using short break services. However the research question also explores how using short breaks might impact parental stress levels. Quantitative research methods were also used to assess the severity and changes to parental stress before and after using short breaks.

4.3 Research Design

This study was conducted using an embedded mixed methods research design. The research method involves the integration of both qualitative and quantitative data which is collected concurrently. This method was chosen in an effort to gain as comprehensive data set as possible. The mixed methods model was chosen because there are two parts to the research problem, one being the parent's perceptions in relation to personal experiences of short breaks and the other to investigate how short breaks impact parental stress levels. Quantitative data was collected using an established measuring instrument, the Parenting Stress Index discussed in chapter 3, while qualitative data was gathered by asking the participating parent to complete a semi structured interview. A purposive sample of participants was used in line with the IPA requirements to have a small homogenous sample. Semi-structured interviews were used which were transcribed verbatim and analysed using IPA (Smith & Osborn, 2003).

4.4 Paradigms of Qualitative Research

According to Creswell (1998) there are five paradigms of qualitative research design made up of traditions of enquiry, biography, case study, ethnography and phenomenology. These

paradigms consist of philosophical origins and an underlying theoretical framework. The purpose of these paradigms is to work more effectively with the specific genres of qualitative enquiry. In this process each paradigm has separate structures for sampling, data collection and the report of findings. Furthermore each paradigm has guidelines for conceptualisation of data.

4.5 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) is an approach to psychological qualitative research with an idiographic focus, in that it aims to offer insights into how an individual in a specific context makes sense of a given phenomenon. In most instances these phenomena relate to experiences of some personal significance (Smith & Osborne, 2003). IPA is consistent with the current research aims as it is directed at "exploring experience in its own terms, rather than attempting to reduce it to predefine or overly abstract categories" (Smith et al. 2009, pg 2). IPA is a reliable approach in that it balances phenomenological description with insightful interpretation. The overall aim of IPA is not in making untimely generalisations about larger populations, but rather to cautiously analyse data before drawing conclusions (Smith et al. 2009). IPA was chosen to assess the meanings parents had given to short breaks. In accordance with this approach the research attempts to get as close as possible to the experiences of parents using short breaks.

4.6 Semi Structured Interviews

Semi-structured interviews were conducted with parents over an eight month period. The purpose of the semi-structured interview was to ensure that parents were given a voice in their subjective experience of short breaks and to seek insight into the meanings that they give to this experience. Open ended questions allowed parents to describe and explain their perceptions and experiences in their own terms. The semi structured interview questions were

deemed explicit and specific enough to gather the information necessary for analysis across participants, at the same time being flexible enough for parents to describe their feelings about using short breaks. A review of the literature was carried out for the purpose of generating interview questions. This process allowed the investigator to explore parts of the literature that had not been previously addressed. The clinical experiences of the principal investigator in the role of a clinical psychologist contributed to the formulation of the interview questions. Semi-structured interview questions were then discussed and evaluated by the manager of the short break centre as well as Professor Jeremy Turk, Consultant Child Psychiatrist. Professionals contributing to the development of the semi structured interviews were selected on the basis of their individual experiences and contributions to children with developmental disabilities. The contributions were essential in developing open ended, non leading questions deemed important to allow families to respond freely. The semi structured interview questions were grouped in sections. These sections were subsequently arranged in an order that would encourage natural conversation and be adaptable and flexible enough should families prefer to complete interviews by phone or post. The following general themes included: (a) Advantages of using short breaks, (b) Disadvantages of using short breaks (c) General feeling about using short breaks, (d) Retrospective reasons for using short breaks (e) Short breaks decision making process, (f) Perceptions of network regarding short breaks. Some of the interview questions appeared general however the interview was only semi-structured as families were encouraged and supported to share their feelings about using short breaks.

Some of the data collected by interview did extend beyond the confines of the information targeted by the interview questions. Hill et al. (1997) highlights the importance of warm up questions related to background information about children with developmental disabilities. Families were given a choice of face to face interviews or by telephone. Telephone contact

was maintained with families in the form of a brief call enquiring about the well being of family members before the interview began. The majority of participants chose telephonic contact as the preferred method of interview. Interviews were transcribed by the researcher with additional support and guidance from the statistical team.

4.7 Parenting Stress Index

Quantitative data procedures involved the administration of the Parenting Stress Index (PSI-SF) before and after using short break services. Paired t tests were used to compare pre and (PSI) forms. The (PSI) was collected to provide a comprehensive context for parent's experiences of short breaks principally in terms of stress levels. The majority of parents returned the (PSI) by post. The PSI-SF is a brief short-self report measure designed to be administered in less than ten minutes suitable for parents of children aged one month to 12 years. Parents indicate their level of agreement with statements reflecting parenting experiences on a five point scale (strongly agree, agree, not sure, disagree, and strongly disagree). The 36 items contribute evenly to three subscales: Difficult child (stress results from behavioural characteristics of the child), Parent Distress (personal distress related directly to parenting) and Parent Child Dysfunction interactional patterns (parental views interactions with child negatively). Scores indicating the degree of experience in the role of parenting is assessed by summing the subscales (Abidin, 1995). Subscales between the 15th and 80th percentile are deemed within the typical range. The (PSI) short form is based on factor analysis of the full length parenting stress index, developed in response to requests for a shorter screening instrument to evaluate stress. Abidin (1995) found significant correlations between total stress scores on tests (r=.94).

4.7.1 Summary

A mixed methods research design has been formulated to capture real world experiences of parents who use short breaks. Qualitative methods have enabled parents to tell their individual experiences of using short breaks and this has guided the interpretation and meaning of this phenomenon. On the other hand quantitative methods assess estimates of the severity of parental stress levels. Data analysis using the IPA approach was used to make sense of the feelings and experiences of parents in relation to short breaks.

4.8 Selection Criteria

Study participants met the following inclusion criteria:

1. At least one child with developmental disability.

2. Participants use residential short breaks for 3 days or more.

3. The disability level of participants was determined as mild , moderate or severe

Exclusion from the study was dependent upon meeting any of the following:

1. If the allocated social worker or managers of the short break centres, were not in agreement for families to be contacted or if the placement was court ordered, as this would fall in the category of sample exclusion in order to maintain sample homogeneity.

2. The principal investigator and the families who knew each other. Preceding associations were discussed as to increase the probability that families would feel free to voice their views throughout the data collection phase.

3. The researcher works as a clinical psychologist it was advised that particular attention is drawn to the fact that some families may have felt or feel particularly obliged to take part in the study, and therefore concluded that this was grounds for valid exclusion.

4.9 Participants

Creswell (1998) states that in phenomenological research there is a narrow range of sampling strategies available due to the necessity of recruiting participants who have the experience of the phenomena. Participants in both the pre and post-testing were the same. Opportunistic selection was used in this process and determined by who responded to the leaflets sent out. Patton (1990) contends that purposeful sampling is an essential strategy in qualitative research. Following consultation with the senior managers of children's services, the researcher was given permission to send out questionnaires and leaflets to all families who currently use short break services. The children who use short breaks have varying levels of developmental disabilities that include, but are not limited to: mild, moderate and severe learning disabilities. The participants for this study were recruited from one short break centre in the London Borough of Sutton. Social workers and senior managers were consulted to list families eligible for the study. A detailed leaflet was sent home with the child. The leaflet included information about the purpose and aims of the study, describing what participation in the study involved. Families were assured of the confidentiality and anonymity of all data procedures and guaranteed that this study would not influence the service provision in any way. The parents that returned the letter also provided contact details as well as giving informed consent to partake in the study. Parents that returned the consent forms were contacted by telephone in order to arrange dates and times. During the telephone conversation parents were given the opportunity to ask any questions they might have and to withdraw from the study, if they decided to. Parents were also given the option of face to face interviews, telephone contact or returning the questionnaires by post. Participants consisted of 17 parents who used short breaks. Of which 16 families completed both measures. Four families did not complete the semi structured interviews. Participant characteristics and demographics are reported in the results chapter.

4.9.1 Procedure

Following the return of the consent forms, families were contacted by the researcher. Parents were given the opportunity to ask additional questions and to clarify what might be expected of them. The majority of families preferred to conduct the semi structured interviews by telephone, and the majority sent their completed parenting stress index forms by post. During contact the voluntary nature of participation was highlighted and the participants were assured they could withdraw from the study with no fear of negative repercussions for their child in receipt of short break services. Participant's confidentiality and anonymity were carefully protected throughout this process. The semi-structured interviews were conducted before the quantitative measures were administered, primarily to avoid responses being influenced by the topics addressed in the parenting stress index.

The majority of responses to the qualitative data were brief consisting of a few sentences. Telephone contact appeared less intrusive for parents, while on the other hand some families seemed to welcome the social contact. Over a period of 8 months, contact was informal with telephone calls lasting between ten and fifteen minutes. In addition to the qualitative data gathered by interview format, the family demographics were reviewed with the manager of the respective short break centres. The procedure for data collection is outlined in table one.

4.9.2 Scoring of Parenting Stress Index

Upon completion of the data collection procedures, all the semi structured interviews were checked for completion. The (PSI) forms were scored using the online scoring system. All demographic data were assigned a numeric value, in order to assist data entry and ensure data protection. Responses to the parenting stress index were scored using the parenting stress index software, which was consequently entered onto a spread sheet. Once the data had been entered into tables the (SPSS) statistical analyses began.

4.9.3 Data Analysis

Creswell (1998) confirms that according to the embedded model, quantitative and qualitative data should be reported separately. Thorne (2000) highlights the importance of analysis as an explicit step in conceptually interpreting the data set as a whole using specific analytic strategies to transform the data into a coherent depiction. In accordance with IPA's idiographic inclusion all semi structured interviews were analysed individually (Smith et al., 2009). The transcript was read several times and initial annotations were made in the margin together with exploratory comments which depicted the initial thoughts around the content of language as well as conceptual interrogative comments (Smith et al., 2009).

4.9.4 Emergent Themes

Analysis of the content was also explored to discover the nature and implications of the experiences of the participants. The qualitative data was analysed to isolate any variance among participants. Emergent themes were listed chronologically and then placed into clusters of related themes. Themes in responses to the semi structured interviews were compared among participants in the study with the aim of identifying commonalities and shared themes.

4.9.5 Analysis

Data was assessed and examined for certain words, phrases, ways of thinking, or patterns of behaviour that could be identified. The qualitative data was assessed and analysed using (IPA). Hsieh and Shannon (2005) state that content analysis is a subjective interpretation of data that uses a systematic progression of coding to identifying themes. Following data collected and analysed a composite description of the phenomenon experienced by parents

was evident. Creswell (1998) outlines the following process for analysis of phenomenological research:

a) The researcher begins with a full description of the participants experience of the phenomenon derived from the interviews.

b) The researcher then finds statements in the interview about how the participants are experiencing the phenomenon and moves towards developing emerging themes.

c) Statements in the transcripts are then grouped into units of meaning.

d) The researcher then seeks to find all possible meanings, commonalties and divergent perspectives.

e) The researcher then constructs an overall description of the essence of the experience of participants.

f) This process is followed for the researchers account and then for that of each of the participants in the study (pp. 147-150).

4.9.6 Quantitative analyses

The quantitative data was analysed using SSPS. An analysis of variance (ANOVA) was used to test for statistically significant mean differences among groups. The ANOVA was employed to determine differences in stress levels pre and post short break services. Participants were given the measures immediately before their child went into the residential short centre. The same participants were then asked to complete the measures directly after their child had received short break services. The variables included in this study were gender of child, age of parent, level of disability (mild, moderate or severe), duration of diagnosis, number of children at home, years of diagnosis, length of stay at respite care, education provision(special needs or main stream), parental marital status, and using short breaks in the past. On completion, the quantitative and qualitative data was assessed and examined and

points were noted. Pearson's product-moment correlation coefficients were calculated to determine the correlations between variables.

4.9.7 Summary

A mixed methods research design using a strategically embedded approach was implemented in this study. A combination of these research methods have provided a meaningful context from which to understand parents stress levels using short breaks. The qualitative and quantitative data have been examined in the data analysis phase of the study using an interpretative phenomenological analysis approach. Integrating the use of multiple research methods has strengthened the design, data collection and analysis thus enhancing the overall validity of the study.

4.9.8 Ethical Considerations

The study was conducted in accordance with the British Psychological Society code of conduct. All parents gave their written informed consent and were assured confidentiality, they were informed of their rights to withdraw at any stage of the study. All parents were offered a summary of the findings in due course. Ethical approval was awarded from the Ealing NHS Ethics committee. The study also required local authority collaboration. The NHS ethics committee also approved the research design, recruitment of participants, data collection processes and the data protection strategies put in place to protect the identities of parents. Throughout the planning and implementation of this research, cognisance of the fact that families that use short breaks do often experience high levels of stress. The study was therefore designed and formulated to gather information with minimal burden to the family. For example families were given the choice of either face to face interviews or by telephone. Families involved with this study were informed of the aims of the study and informed of what participation in the study would entail. The parents that indicated an interest in the study

posted their consent forms back to the mangers of the respective short break centres. Families were then contacted by the researcher to address any concerns or additional questions about the research. Families were identified by the managers and social workers of the respective short break centres. No records were kept of the families. The importance of data protection was highlighted in the research leaflet sent to the family. All forms returned to the short breaks centres were locked away by the manager of the short break centre until collection by the researcher. The managers and social workers were not given access to the data and they were not aware of the names of families that agreed to participate in the research. This data was only known to the researcher, finally once data was collected; it was coded and then shredded to comply with the data protection act. No information that could later serve to identify the families was recorded on any of the measuring instruments. Participants were assigned a code, written on the top of the measuring instruments. No record was kept of any names corresponding to the numbers assigned. Data collected was not shared with any other teams and the semi-structured interviews were scored and coded by the researcher. The researcher analysed the data on a secure NHS smart card protected PC.

4.9.9 Summary and reflexivity

The goal of this study was to explore and better define the impact on the level of benefit (principally in terms of stress levels) which short break care services offer to parents of children with developmental disabilities. The research design consisted of an interpretative phenomenological analysis of the personal narratives of parents using short breaks, in order to gain insight into the meanings they gave to their individual experiences. An embedded mixed methods research design was implemented, using a combination of qualitative and quantitative data. Yardley (2000) described reflexivity as the process of reflecting on the impact of the researcher, during the stages of research. It is well known that in qualitative research the influence of the researcher's belief system will to some extent, determine how

data is collected, managed and processed. It is extremely important for the researcher to include a description of these experiences and beliefs. The final part of this chapter is devoted to highlighting some of my own beliefs and experiences working as a clinical psychologist in South West London and St Georges NHS Trust UK. I qualified as a clinical psychologist at the University of the North West in South Africa. I completed my first BA degree at the Nelson Mandela Metropolitan University and went onto to complete an Honours degree at Vista University, Port Elizabeth. I then relocated to London in 2000 and started working at a local mental health team. I completed my statement of equivalence in clinical psychology in London. I have worked in the field of learning disabilities for 13 years, and am currently completing a top up Doctorate in counselling psychology City University London. I have consulted with various professionals and agencies in relation to the interpretation of my qualitative data and initial research proposal in order to ensure high standards of research. For the greater part of the last ten years I have had the privilege of working with families who have children with developmental disabilities. During this time families have told me of the immense and often life changing effects short breaks bring to families in need such services. I have been influenced by an integrative model of treatment for families that have children with developmental disabilities. I think that it is vital for families to receive a comprehensive psychological assessment and intervention that includes short breaks. Bearing in mind that there are very different settings in which professionals work, short breaks are, I believe a fundamental part of offering support.

My interest in short breaks, started many years ago as I learned of the positive benefits this brings to both child and parent. I have personally read countless articles in the London free Metro paper about parents that have given up due to the psychological stress associated with raising a child with developmental disabilities. My research is in part in response to these articles that I have read where parents have got to such a point in their lives that the only

option they could see was to end their own lives. I firmly believe that in many cases if the families had access to short breaks this would have alleviated such stress and possibly contributed to saving lives, as such I am convinced that short breaks are crucial in helping families cope.

5.1 Chapter Overview

This chapter presents six main super-ordinate themes which emerged from the Interpretative Phenomenological Analysis (IPA). These super-ordinate themes are deemed most relevant as they were cited most frequently by participants. Interpretative Phenomenological Analysis is concerned with how people make sense of their experiences: in this case, the themes describe how parents view and experience the short break service. The objective in analysing these themes is to provide a deeper understanding of parental experiences of using the short break service and to capture the real meaning of parental feelings. Each theme will be discussed in turn and illustrated with examples from the interview transcripts. IPA highlights the process of discovering such themes which is primarily based on the researcher being engaged with a double hermeneutic (Smith, Flowers & Larkin, 2009).

The first super-ordinate theme, *functional advantages to self,* explores the positive impacts and implications of using short breaks for parents. It is divided into four sub-themes: rest, being able to catch up on everyday tasks, being able to interact with others, and being able to spend quality time with family members.

The second super-ordinate theme, *functional advantages to family,* explores the impact that short breaks have on the family system. This is divided into three sub-themes: quality time spent with spouse and siblings, stress-free time, and the supportive role short breaks play within families.

The third super-ordinate theme, *maternal guilt*, relates to how parents make meaning out of taking their child to short breaks. This is divided into three sub-themes: guilt at separating

from the child, guilt at purposefully excluding the child from family events, and missing their child when they are on short breaks.

The fourth super-ordinate theme, *functional advantages to child*, explores parental perceptions about the benefits short breaks bring to their children, including increased opportunities for socialisation, opportunities to interact with the peer group, and easy access to different activities.

The fifth super-ordinate theme, *safety of the child*, explores factors related to the overall safety and well-being of the child while on short breaks.

The final super-ordinate theme, *approval of family and friends*, explores the influence family and friends have over the families' decisions to use short breaks. This is divided into sub-themes related to approval and disapproval of using short breaks, and the positive impact short breaks have on children and families. The themes discussed in the analysis are listed in Table 5.1 below.

Table 5.1 Summary of themes

Super-Ordinate Theme 1	Sub-Ordinate Theme	Theme
Functional advantages to self	Emotional meaning	Rest from caring role(s).
	Control	Able to catch up on everyday tasks.
	Socialisation	Opportunity to interact with others / increased social interaction for participants.
	Interaction	Spending quality time with family.
Super-Ordinate Theme 2	Sub-Ordinate Theme	Theme
Functional advantages to family	Perception	Supportive role of short breaks within families.
	Feelings	
	Attitudes	Sense of normalcy within family setting.

Super-Ordinate Theme 3	Sub-Ordinate Theme	Theme
Maternal guilt	Feelings Reaction Attitude towards self	Feelings of guilt at separation from child. Guilt at purposely excluding child from family events. Missing child while at short breaks.
Super-Ordinate Theme 4	Sub-Ordinate Theme	Theme
Functional advantages to child	Perception Feelings Emotional meaning	Perceived increase in socialisation opportunities for child. Opportunities to interact with peer group. Enhanced and easier access to different activities.
Super-Ordinate Theme 5	Sub-Ordinate Theme	Theme
Concern for the child	Separation from child Care Protection Maternal / Paternal sensitivity	Overall safety and well-being of child while at short breaks.
Super-Ordinate Theme 6	Sub-Ordinate Theme	Theme
Approval of family and friends	Trust acquired Perceptions	Approval and disapproval of using short breaks. Perceived positive impact of short breaks.

The identified themes are discussed below, illustrated throughout by participant responses. The objective throughout the analysis is to present an in-depth portrayal of the experiences of parents who make use of short breaks for their developmentally disabled child. The following provides a key with respect to the participants who were interviewed, and whose comments are quoted in the analysis which follows. In the quotations empty brackets (...) indicate that

material has been omitted. Participants are referred to by pseudonyms throughout this thesis. The source of each quotation is indicated by page and line reference numbers.

Table 5.2 Summary of participants

Participant Number	Gender	Marital Status	Pseudonym
1	Female	Married	Tracey
2	Female	Married	Leah
3	Female	Married	Sarah
4	Female	Married	Joan
5	Female	Married	Abigail
6	Female	Married	Mary
7	Female	Married	Katie
8	Female	Married	Louise
9	Female	Married	Karen
10	Female	Married	Pam
11	Female	Married	Helen
12	Female	Married	Jane
13	Female	Divorced	Tilly
14	Male	Married	Paul
15	Male	Divorced	Peter

5.2 Super-Ordinate Theme 1: *Functional Advantages to Self*

The first super-ordinate theme, *functional advantages to self*, appeared to be central to most of the participants' experiences of using short breaks. This theme aims to describe the views of parents in relation to using short breaks. Topics identified within this theme included having time off to do other things, opportunities to socialise, free time to engage in pleasurable activities, reading a book, having a bath and giving the whole family a break. Parents also cited being able to take a break from the emotional aspects of caring.

Participants were encouraged to discuss and explore the perceived benefits of using the short break service. Most participants said that the short break service offers vital respite to the service user, the carer and the family network. These observations were consistent with what was suggested in the literature. Also reflecting the findings from the literature review, participants in the interviews consistently mentioned the overall benefits to the family. For

the most part, participants felt that an important function of short breaks was to offer a supportive role in times of stress. Most participants reported feeling less stressed and able to think in much improved ways after a short break from caring. Short breaks appeared to enable participants to prepare themselves for when their child returned home. Generally, the functional benefits for the participants appeared to be clustered around family functioning and wellbeing. However, they were dependent on participants' subjective interpretations and feelings around placing their child in short break care. The narrative excerpts in this chapter are grouped according to various themes that have been identified, relating to the perceived advantages of using short breaks. The experiences associated with using short breaks described in the transcripts were incorporated into sub-ordinate themes, namely emotional meaning, control, socialisation and interaction.

5.2.1 Rest from the caring role

The first sub-ordinate theme to be identified within the super-ordinate theme of *functional advantages to self* was rest from the caring role. When participants were asked to consider what they liked best about using short breaks, the overall perception of short breaks as offering an opportunity to gain much needed rest emerged as a dominant and recurring theme. Throughout the transcripts there were many examples of the perceived benefits associated with rest while using short breaks.

Tracey and Joan described short breaks as giving them the opportunity to catch up on sleep and rest. Most participants had formed an idea of how short breaks improve their rest, including their sleep. A number of participants described feeling much happier; that the break had a direct impact on their daily lives by allowing them to catch up on things:

Tracey: '*Opportunity to get a good night sleep and some respite from the caring role.*'

(1.1) '*It is essential, short breaks give me time to recharge with some rest and*

recuperation. I get a proper night sleep and respite from the sheer exhaustion of caring.

Try to have a social life, going to the cinema or to a restaurant.' (1. 3-6)

Joan used the word extremely to convey the strength of her feelings about short breaks:

Joan: *'It gives my husband and me quality time to spend with our younger children. In addition I generally feel far more relaxed and energised.'* (4. 30-31) *'I find them extremely beneficial and could not manage without them.'* (4. 29-30) *'(…) a break from the caring and time to be a normal family.'* (4. 34)

The participants in this study defined the rest they got from using the short break service in a number of ways; these included being able to recharge their batteries, actual respite from the caring role and an overall feeling of being well supported by services. The majority of participants described feeling much more relaxed and in control of things after having a break. Abigail, Mary and Karen provided insights into how they saw themselves as benefiting from the service.

Abigail: *'Firstly it gives me and my family stress free time (...) we haven't had the time to do things in our house when our son is around.'* (5. 39-40) *'Life at home can be quite stressful, when you're with a child twenty four seven you need a break away.'* (5. 46-47)

Mary pointed out the importance of having a break from the caring role:

Mary: *'having a break and giving my son the independence of being way from home.'* (6. 58)

A number of participants commented on the way that short breaks impact upon daily life, simplifying everyday tasks and allowing them to catch up on chores:

Karen: *'having a few days of normal life and being able to catch up on sleep. Go out shopping, cinema, restaurants, theatre, seeing friends, watching TV and even do house work.'*(9. 78-79) *'When (...) is at home he is very demanding and has frequent fits of temper and aggression; even when he is behaving I am holding my breath on full alert for the next one (…) any sense of normality is impossible. '*(9. 80-85)

Karen reported feeling less stressed and overwhelmed and suggested that without short breaks she would not have coped:

Karen: *'Without short breaks I would have gone under, without a doubt. My other two children both also have disabilities but (...) dominates at home that their needs are often put on the back burner.'* (9. 91-93)

Paul and Jane also described the impact short breaks had in relation to rest as well as within the wider environmental context:

Paul: *'It is good for child and parent. It gives the child a break and helps them mix with other children with the same disabilities.'* (15. 143-144) *'My reasons are so I can have a break and rest while my child is in short breaks.'* (15. 149-150)

Jane: *'It gives me and my children a break. I can do things with my other children.'* (12. 115-116).

Tilly interpreted rest as having the time to attend to other commitments outside the caring role:

Tilly: *'It gives me time off to do other things, other commitments (…) gives me a break from caring.' (*13. 124-125)

Describing the amount of time and commitment it takes to look after her child, who has severe learning difficulties, Tilly stated that:

Tilly: '*I need a rest like at least twenty four hours rest from my daughter to recharge my batteries.*' (13. 128-129)

When asked about the demands caring for a developmentally disabled child places on parents, most participants indicated that short breaks help reduce parental stress, enhance personal rest and, in some cases, reduce the burden at home. The time out that short breaks provide for parents appears to be beneficial to the parent child-relationship and seems to help participants cope better with the demands placed on them. Although all the participants found short breaks helpful, individuals appear to be unique and diverse in their particular needs and strengths. Peter gave an open and honest account of how he feels about his own parenting skills and how his child's condition has impacted on his overall functioning.

Peter: '*My son's behaviour has escalated over time. I am so tired of caring for him twenty four hours a day; I need a break.*' (14. 138-139)

5.2.2 Able to catch up on everyday tasks

Participants described their individual experiences of short breaks, highlighting the value of this service. Family functioning can be adversely affected by stress, which may stem from a variety of sources. General responsibilities at home can contribute to parental stress: managing schedules and being involved in day to day tasks can all add to the pressure. One of the most recent developments in the conceptualisation and measurement of parenting stress is the daily hassles approach. Crnic and Greenberg (1990) formulated their model of stress based on parenting daily hassles, in which stress is understood within a minor event perspective, incorporating the day to day frustrations that accompany child rearing.

Parenting daily hassles are defined as the persistently occurring, repetitive, bothersome but unavoidable tasks that are involved in the parental context. The cumulative impact of these daily hassles may significantly impact upon both child and parent. Parenting daily hassles are not isolated events; rather they accumulate, leading to parental stress. According to Crnic and Acevedo (1995), daily hassles are not confined to any specific population group, as it is assumed that they are shared by all families regardless of demographic status. The experience of being able to catch up on everyday tasks appeared to be a major theme in the transcripts when participants were discussing the benefits of short breaks. Many participants, including Mary, Abigail, Pam and Karen, agreed that short breaks afforded them the opportunity of getting on with other simple, everyday tasks that they could not have done otherwise.

Mary highlighted that she is able to get on with other things whilst her child attends short breaks:

Mary: ' *We miss our son; however we get to do things we cannot do when he is around.'* (6. 63-64)

Pam, on the other hand, was concerned about practical tasks that she is not able to do if her child is at home:

Pam: *'gives me a rest (...) and to give me a chance to paint my house.'* (10. 108)

Karen highlighted the fact that getting chores done and running errands is extremely important:

Karen: *'Having a few days of normal life and being able to catch up on sleep (...) go out shopping, cinema, restaurants, theatre, seeing friends, watching TV (...) my sanity, the needs of (...) siblings getting chores done, errands shopping is impossible when (...) is around'* (9. 95-96)

while Abigail spoke of the alleviation of family stress and being able to get on with unavoidable day to day tasks:

> Abigail: '*Firstly it gives me and my family some stress free time, we can relax and catch up on things that we haven't had time to do when our son is around.*' (5. 39-40)

5.2.3 Increased social interaction for participants

A salient theme that emerged from the transcripts was the value participants placed on being able to socialise. From the descriptions it seemed that social interaction – both for themselves and for their disabled child – was a high priority for many. This was particularly true for those in receipt of longer stay short breaks, but participants taking advantage of short breaks also felt that these gave them and their children more opportunity to socialise. The theme of increased social interaction emerged, as the demands of caring may inadvertently restrict parents' social activities. Participants described the process of parenting a child with developmental disabilities as requiring constant supervision, especially if the child has additional emotional, behavioural and communication problems. Other participants highlighted the fact that caring for a child with a learning disability can involve lifting, feeding, toileting, bathing and dressing. The accounts given by participants indicated the high level of support many disabled children require, and that the associated personal costs for parents may include feelings of being isolated from others as well as reduced social contact with friends in the community.

For the most part, participants described experiencing stress on several levels, such as interpersonal isolation, anxiety and in some cases breakdown in the family network. Reflecting the findings from the literature review, the participants repeatedly mentioned the benefits of improved socialisation. They reported how good it felt to be able to interact with others, and that short breaks allowed them this opportunity. For the most part, participants

felt that it was much easier to organise social events when their child was on a short break. It appears that regular short breaks can relieve some of the social limitations placed on participants and their immediate family and give parents the opportunity to participate in social events that ordinarily would not be possible.

Karen and Tracey described that if they had not had short breaks they would not have managed to do day to day chores, and life would be very different:

Karen: '*go out shopping, cinema, restaurants, theatre, seeing friends.*' (9. 80-81)

Tracey highlighted the importance of her own socialisation:

Tracey: '*try to have some social life, going to the cinema or to a restaurant.*' (1.6)

while Katie highlighted how having to focus so much on one child influences social interaction within the family as a whole:

Katie: '*When my son is at (…) we have time for his brother, (…) there are limitations to what we can do.*' (7.65-67)

Katie also described her feelings about the importance of her son interacting with people outside the immediate family:

Katie: '*It does give him time to be with other people.*' (7.69-70)

5.2.4 Spending quality time with family

This theme aims to capture the sense of freedom participants experienced while using short breaks services for their disabled child. Spending quality time with the rest of the family was described as vital for keeping the family together, since the stress of raising a child with disabilities was seen as likely to exacerbate problems within family relationships. Family cohesion depends on the strength of the emotional bonds between family members. From the

participants' descriptions it seemed that family cohesion was perceived as an important aspect when faced with the demands of parenting a child with disabilities. Positive aspects of family cohesion and resilience were discussed and explored within this context. Spending quality time with family appeared to be an important way for participants to feel more relaxed and in control and was also seen as contributing in part to enhancing family cohesion. Most participants felt that short breaks afforded them the opportunity to spend quality time with all family members; in fact, the sense of having more time to spend with family members and siblings seemed to be the most important positive attribute to come out of using short breaks. Increased time with family meant a temporary change for the better in their situation.

Short breaks promise participants a break from the demands of the current situation and a breathing space to make their own choices. Some participants referred to having the time to spend with their spouse without having to worry all the time. The sacrifices entailed in caring were perceived in ambivalent terms, with some participants describing the cost to family life in general terms. Within this context, spending more time with partners was seen as helpful and beneficial to the overall well-being of the family. This was a powerful theme; participants repeatedly alluded to how short break interventions allowed them to spend quality time with others in their social network.

Sarah's account suggests that the short breaks are also beneficial for her other son:

Sarah: *'It gives me and my husband a break (...) my other son needs to have a break from his brother.'* (3. 18-20)

Her comments highlight the social limitations placed on parents and the relief that this service can potentially offer families – in Sarah's case, this was appreciated by her extended family:

Sarah: *'because of the demands my son's special needs put on the whole family and general exhaustion of me and my husband.'* (3. 27-28) *'They think it is very positive for us as a family.'* (3. 29)

Joan also discussed the importance of quality time and interaction with her younger children:

Joan: *'It gives me and my husband quality time to spend with our young children. In addition, I generally feel far more relaxed and energised.'* (4. 30-31)

And Abigail's comments showed that the family as a whole benefited from the opportunity to relax:

Abigail: *'Firstly it gives me and my family some stress free time, we can relax and catch up on things that we have not had time to do when our son is around.'* (5. 39 -40)

Abigail: *'my son (...) because we needed time to ourselves away from our son who can be very demanding.'* (5. 49 -50)

Mary recognised that her son's needs are changing and acknowledged that certain things are difficult without short break intervention:

Mary: *'It was an appropriate time for me; as my son gets older his needs are increasing. Him being away gives us a chance to spend more quality time with his siblings.'* (6. 60-62) *'My family thinks it's great (...) however, we get to do things we can't do when he is around.'* (6. 63-64)

Both Katie and Karen seemed to agree that spending time with others in the family is very important. Both found it difficult to cope without short break intervention and highlighted the functional advantages to the entire family system.

Katie: *'When my son is at (...) we have time for his brother alone, although he likes to be with his brother, there are limitations to what we can do as his brother tends to be choosy on a lot of things.'* (7 .65-67) *'(...) it gives us time with our other son and ourselves.'* (7. 71-72) *'It's beneficial to the whole family.'* (7. 73)

Karen described the needs of her other children:

Karen: *'Without short breaks I would have gone under, without a doubt. My other two children both also have disabilities but (...) dominates at home that their needs are often put on the back burner. My other two kids get a full time, full time mum when (...) is not around.'* (9. 91-94) *'the needs of (...) siblings.'* (9.95)

Karen: *'My other two children were on holiday with their grandfather this week so (...) is at (...) for three days. I was really able to recharge and our house felt silent.'* (9.97-99)

Jane and Peter also felt that time with their other children is extremely important, and that without short breaks this would not be possible. Participants identified the need for a break from constant care giving, needing to meet the demands of the other children in the family and limited social support as reasons for using short breaks. Most participants anticipated benefits both for themselves and their children. It was evident that parental expectations pertained to the enhancement of family well-being and that short breaks lived up to these expectations. Overall, this theme illustrates that short breaks are associated with increased independence and more opportunities to spend quality time with others in the family.

Jane: *'It gives me and my children a break. I can do things with my other children.'* (12. 115-116) *'It's very hard for me and my children to cope with him sometimes.'* (12. 122) *'My children are happy because we get to do things together.'* (12. 123)

Peter's account demonstrates the importance of interaction with others. Several participants felt that short breaks make a difference to everyone involved:

> Peter: '*give family a break my son loves interacting with others. Gives him added advantage of being with others, relieves family stress.*' (14. 132-133) ' *It's a good way to help family and child, we can play with things with other children, when my son is at respite care we can divide our parenting evenly as our son takes up all our time.*' (14.135-137)

> Paul: '*Short breaks have helped so many families, it's a great service. I think it's good for both parent and child. It gives the child a break and the parents a break so the parents have a rest too.*' (15. 145-148)

Peter and Paul's responses illustrate the far reaching effect caring for a child with developmental disabilities can have on the whole family unit. Without a break parents are likely to become completely exhausted or even unwell, due to the constant physical, psychological and social demands of caring. Participants appeared to experience short break provision as a service that allows therapeutic opportunities, quality time, independence and a break from the stressors and strains of parenting. Some participants felt that short breaks allowed them additional quality time and gave all family members the chance to live a fuller life. This theme also illustrates that short breaks enhance family empowerment and balance.

5.3 Super-Ordinate Theme 2: *Functional Advantages to Family*

The second super-ordinate theme, *functional advantages to family,* explores the impact that short breaks have on all family members. This is divided into two sub-ordinate themes; the perceived supportive role short breaks play in families, and how short breaks help create a sense of normalcy within the family. Response to stress was a prominent theme in the

transcripts. Participants identified various aspects of their child's behaviour as generating stress, such as their inability to adapt to new situations, and problems with mood and emotional stability, in addition to the overall difficulties presented by the daily challenge of meeting their child's needs. Beyond these child-related dimensions, other areas of stress were also identified in the transcripts: the social restrictions felt by parents and other health factors all played a contributing role.

5.3.1 Supportive role of short breaks

The super-ordinate theme of *functional advantages to family* centres on the supportive role played by short breaks. The majority of respondents concentrated on the fact that short breaks provided a break from the caring role, allowing them the opportunity to get on with things that they otherwise would not have been able to do. Other participants highlighted the sense of feeling like a normal family. Participants described a variety of factors such as repetitive parenting duties and cumulative, minor, daily parenting stressors that can lead to perceptions of inadequacy and difficulties in coping without short break intervention. For some participants it seemed that they generally struggled to respond in an appropriate way to their child's ever-increasing developmental needs and perceived short breaks as a clear support.

Abigail: *'Firstly it gives me and my family some stress free time, we can relax and catch up on things that we have not had time to do when our son is around.'*(5. 38) *'Life at home can get quite stressed when you're with a child twenty four hours a day and so does he as well (...) it is a change of scenery for him and again it gives the rest of the family some quality time.'* (5. 39-48)

Mary: *'Having a break from caring for my son and him having a break from home (...) it was an appropriate time for me as my son gets older, his needs are increasing (...) being away gives us a chance to spend more quality time with his siblings.'* (6. 58-62)

Katie: *'It gives us time with our other son and ourselves (...) there are limitations to what we can do.'* (7.65-67)

Some participants described feeling rested, having taken a break from the caring role:

Louise: *'I get rest and uninterrupted time (...) I need time to rest and to re-group and care for other family members.'* (8.77-78)

Karen described the supportive role that short breaks have in relation to day-to-day support:

Karen: '(...) *catch up on sleep (...) going out to restaurants (...) even doing house work (...) getting chores, errands and shopping is impossible when (...) is there (...) I was able to recharge my batteries.'* (9. 80-96)

Finally, Peter highlighted how demanding he found his role, caring for a disabled child, and how important this supportive intervention is:

Peter: *'My son's behaviour has escalated over time. I am so tired of caring for him twenty four hours a day (...) his care needs have got worse – we need the help.'* (14. 138-140)

5.3.2 Normalcy

The second sub-ordinate theme within the super-ordinate theme *functional advantages to family* is the sense of normalcy that some families feel short breaks offer them. This theme was powerfully expressed in the transcripts. It appears that short breaks are deemed important for bringing a sense of normality back into family life. The families' accounts suggest they find the interaction and responsiveness, unusual behavioural patterns and excessive care demands of their children stressful. For the most part, there was a real sense of parents struggling to cope in society with their child, and many participants described their sense of isolation from the outside world. On the other hand, short breaks provide a sense of normality

in their everyday lives. Feelings of social isolation and depression were also discussed in the context of the family trying to gain a sense of normalcy in their life. For many participants, disrupted sleep patterns lead to feelings of exhaustion and depression. Short breaks were perceived as offering a temporary solution to these problems. Participants stated that short breaks enable them to do the things that most people take for granted and described the service as a life support. The transcripts frequently show parents describing how short breaks allow them to attend to their own personal and social needs.

Karen described a set of challenging and complex situations, where she felt that being normal was impossible:

Karen: *'he is very demanding and has frequent fits of temper and aggression; even when he is behaving I am holding my breath on full alert for the next one, any sense of normality is impossible.'* (9. 80-85)

Joan highlighted the importance of short breaks in helping hers feel like a normal family.

Joan: *'I find them extremely beneficial and could not manage without them (…) a break from the caring role and time to be a normal family.'* (4.32-34)

5.4 Super-Ordinate Theme 3: *Maternal Guilt*

The third super-ordinate theme, *maternal guilt,* relates to how parents make emotional meaning out of taking their child to short breaks. This is divided into three sub-ordinate themes: guilt and the struggle to separate from the child, the guilt associated with purposely excluding the child from family events, and missing the child whilst they are on short breaks. A number of interviewees expressed concerns in relation to this aspect of short breaks. There were some general concerns about children not getting the opportunity to take advantage of short breaks. Two participants described experiencing emotional conflict when they used

short breaks, and generally, the experience evoked ambivalent emotions among most participants. Short breaks provided an opportunity for rest, but separating from their child in some cases left parents with feelings of guilt.

5.4.1 Guilt at separation

Some of the mothers' accounts of using short breaks reflected a clear theme of guilt. On the one hand, they agreed that short breaks brought them a much needed break from the demands of caring, but on the other, they felt guilty for sending their child away. For the most part, participants placed their child's need for a positive, enriched environment ahead of their own needs.

Sarah described having very ambivalent feelings about short breaks:

Sarah: *'that the needs of my child are such that this service should be necessary (...) leaving my child there when he would sometimes rather come back with me.'* (3. 21-22)

5.4.2 Guilt at excluding the child from the family

Other participants were concerned about leaving their child at short breaks while they had a good time with the rest of the family. Both Joan and Karen described having conflicting feelings about using short breaks for this reason:

Joan: *'We started when our son was 9 years old, after a horrendous holiday abroad (...) I always feel guilty about leaving our son and excluding him from some family activities.'* (4. 32-36)

Karen explained that although she wanted her son with her, she wanted to be able to get the rest she needs. Like other participants, she reported feeling mean at purposely excluding her child from family activities:

Karen: *'I feel guilty sometimes (...) is reluctant to go, and I really feel mean in making him go. I don't ever want him to feel rejected or unwanted at home but the sad reality is that home is much easier without him and I know he is settled and happy at (...), it's just before hand that he is protesting.'* (9. 86-90)

5.4.3 Missing the child

Several of the mothers admitted to having mixed feelings about the short breaks service simply because they missed their child when they were away:

Louise: *'I miss my son.' (8. 75)*

Katie: *'not actually a bad thing but we do miss or son when he is away.'* (7. 68)

Mary: *'missing my son for the time he is away, especially if he is in for two nights.'* (6. 54)

5.5 Super-Ordinate Theme 4: *Functional Advantages to Child*

The fourth super-ordinate theme, *functional advantages to child*, explores parental perceptions about short breaks relating to the child's socialisation opportunities. These include a perceived increase in socialisation, opportunities to interact with the peer group and easy access to different activities. Participants repeatedly described the social restrictions felt by families caring for a disabled child. Many perceived short breaks as an opportunity for their child to participate in social activities that would not be possible otherwise – to play with other children and enjoy increased peer interaction and social competence. Participants reported increases in self-esteem and self confidence in their children after using short breaks. Others described how short breaks helped to develop their child's communication skills, linking this with self-esteem.

5.5.1 Opportunities for socialisation and peer interaction

The first and second sub-ordinate themes within this super-ordinate theme centre on the opportunities short breaks offer children to socialise with others, and particularly to interact with their peers. A key feature within this theme was the perception that short breaks allowed children to learn pro-social skills and peer-mediated approaches. The development of social relationships was deemed an important component of children's overall development. Peer-related social competence, opportunities for developing friendships and participation in social interactions were all viewed as essential by most participants. Short breaks were generally viewed as supporting children with their overall communication skills, social skills and self-confidence. Participants also felt that their children would be at increased risk of being socially rejected and would not have the opportunities to engage in social interaction without short break intervention.

Most participants felt that short breaks helped their child mix with others. As may be expected, parents also appreciated the safety of short breaks:

Pam: *'a chance to stay with friends in a safe environment.'* (10. 104-105)

Abigail described how short breaks contributed to her son's well being:

Abigail: *'It gives my son a chance to have a break away from us, and he gets time with some friends, a bit like a sleep over.(…) I know he is being looked after and that he's safe, but enjoying himself as well.'* (5. 43-45)

For some, short breaks are an intervention that supports social group interaction and teaches the skills necessary for the enhancement of communication skills and peer-related social competence:

Leah: *'It helps the children mix with other people and other children and it gives them a break from home.'* (2. 11-12)

Others explained the importance of having time for themselves and being able to give more time and attention to siblings, allowing them to experience being put first. Katie also described how short breaks enable her son to have a good time with the staff and other children:

Katie: *'same as mentioned above, it gives us time with our other son and ourselves and for him to have fun with people.'* (7. 71-72)

and how they enable him to achieve a level of independence:

Katie: *'it does give him time away to be with other people besides us. It's like being independent in a way.'* (7. 71-72)

This sense that the child benefits from being able to mix with others outside the family was echoed by other participants:

Paul: *'It is good for both child and parent. It gives the child a break and helps them mix with other children with the same disabilities.'* (15. 143-144)

Peter: *'give family a break (...) gives (...) added advantage of being with others.'*(14. 132-133).

Thus, there seems to be strong evidence to suggest that short breaks are invaluable for children with disabilities. Short breaks are most often perceived by parents as offering their children the opportunity to increase social interaction, develop friendships and social competence, and enhance their overall social-emotional development.

5.5.2 Access to activities

There was a sense among parents that this intervention affords opportunities for peer-related social events that would not be easily available in the wider community:

Mary: *'My son gets a chance to experience a loving and caring environment. He has opportunities to access various activities. I can't afford to take him to socialise with other children.'* (6. 55-57)

From Sarah's description there was a sense that short breaks provide safety as well as being well managed:

Sarah: *'It gives me and my husband a break, my son enjoys going and it gives him a good social opportunity.'* (3. 18-20) *'(…) that the place my son goes to is excellently run, the staff are genuinely caring and there is a low turnover of staff as continuity of relationships is important.'* (3. 23-25)

5.6 Super-Ordinate Theme 5: *Safety of the Child*

The fifth super-ordinate theme, *safety of the child*, explores factors related to the overall safety and well-being of their child while at short breaks. The majority of participants could not find anything negative to say about short breaks. However, a few participants did express concern about their child's overall safety whilst staying at short breaks. The expertise of staff was central to participants' perception of short breaks as being a place of safety for their child.

There was a sense that disabled children living away from home were particularly vulnerable, and factors such as risk of being abused, poor feeding and inadequate toileting arrangements, the handling of challenging behaviour, and lack of emotional support were all discussed within this theme. Some expressed anxieties about possible lack of awareness amongst staff, lack of communication and consultation with the children, and the fact that their child in some cases lacked the verbal skills to tell others if things went wrong. Overall, however, the responses indicated that short breaks is regarded as a safe place with accessible

staff, that staff are believed to be reliable and well trained, and that positive steps are taken there to improve the communication skills of the children.

Tracey and Abigail were both particularly positive about their child's safety whilst at short breaks:

Tracey: *'it is essential (...) whilst knowing that my child is in a safe place and stimulating environment.'* (1. 3-4)

Abigail highlighted the importance of peer interaction but emphasised her belief that her child is safe at short breaks:

Abigail: *'It gives my son a chance to have a break away from us and he gets time with some of his friends a bit like a sleep over. I know that he is being looked after (...) he is safe, but enjoying himself as well.'* (5. 42-45)

Sarah's account also indicated her confidence that staff at short breaks are aware of her child's vulnerability and are well trained:

Sarah: *'that place my son goes to is excellently run, the staff are genuinely caring and there is a low turnover of staff as continuity of relationships is important.'* (3. 23-25)

On the other hand, some participants voiced their overall concerns about safety. Interestingly, Pam found that although there was only one isolated incident at short breaks, this had a great impact on her, significantly raising her concerns:

Pam: *'I had an incident where she was given the wrong medication.'* (10. 106)

5.7 Super-Ordinate Theme 6: *Approval of Family and Friends*

The final super-ordinate theme, *approval of family and friends*, aims to capture the influence family and friends have over the decision to use short breaks. This is divided into

sub-themes related to the approval and disapproval of family members, and the impact the extended family thinks short breaks have on children and their families.

5.7.1 Attitudes of family

Many participants described extended family and friends as playing a vital role in enabling and supporting their disabled child. Child-related factors such as level of disability or challenging behaviour were some of the reasons cited for extended families becoming involved. Some participants even expressed concerns around families becoming overly involved in child care arrangements, education, short break intervention, behaviour and other related issues. Many of the participants described the support shown by their family and friends for their use of the short break service:

Paul: *'My family and all my friends say that the short breaks is a very good idea and it helps lots of families with children with disabilities.'* (15. 152-153)

Mary: *'My family think it's great, (...) we get to do the things we can't do when he is around.'* (6. 63-64)

Sarah: *'They think it's very positive for us as a family.'* (3. 29)

Jane: *'My children are happy (...) because we get to do things together.'* (12. 122-123)

But other participants described members of their extended family as expressing very negative views regarding short breaks.

Peter: *'They are very negative because they don't understand what respite care is they think (...) the child will be abused, this is not true. They don't get involved so they don't understand.'* (14. 140-142)

Joan described how her family have made negative judgements about short breaks without offering any support themselves. However, family friends appear to have been much more supportive and collaborative:

> Joan: *'I don't think my family particularly like the fact that we use respite care but then none offer to help. (…) Friends are more understanding.'* (4. 37-38)

In Karen's case, her family were initially very negative about short breaks but over time they came to realise the functional advantages:

> Karen: *'(…) older so we have been using overnight respite for several years. In the early days my extended family had concerns and were a little critical about sending him away, however, they are now supportive (…).'* (9. 100-103)

Family and friends play a crucial role in supporting children with severe developmental disabilities. They most commonly become involved to help with challenging behaviour.

5.7.2 Perceived positive impact

The majority of respondents said that members of their extended family and their friends agreed that short breaks are a very positive service – one that gives them the opportunity to get on with things that they could not otherwise do. Abigail's extended family, for example, felt short breaks are a good intervention that helps her to relax:

> Abigail: *'Everyone agrees (…) it's a good idea for us and my son as they* [the extended family] *feel a lot more relaxed and my son has had a nice time.'* (5. 51-52)

Tracey's family see the importance of looking after one's personal health:

> Tracey: *'some (…) think it's a good idea as it means I can try and look after my health a bit more. Some feel I shouldn't need short breaks as my child is no trouble.'* (1. 9-10)

5.8 Quantitative Analysis

The data was gathered using the Parenting Stress Index short form questionnaire (Abidin, 1995), which measures parental distress. This is a standardised questionnaire which provides a measure of overall stress. It also contains three separate subscales. The first is the Parent Distress subscale (PD), which determines the anguish and distress a parent is experiencing in their role. PD also measures overall disappointments within the parenting role. The second is the Parent Child Dysfunctional Interaction (P – CDI) scale, which assesses parental perceptions that their child does not meet their expectations. This subscale also evaluates overall parental satisfaction with the parenting role. The third subscale, the Difficult Child (DC) subscale, focuses on assessing the specific behavioural characteristics of children that make them trouble-free or not easy to manage. High scores here suggest parents have significant problems helping their children learn to self-regulate their behaviour. Other data collected included: gender of parent, age of parent, number of children of the parent, gender of the child, age of child, diagnosis of child (mild, moderate, severe), behaviour (challenging and complex), primary diagnosis (behaviour, challenging, cerebral, physical, learning), years since diagnosis, length of stay at the short breaks (measured in days), and parental status (married, divorced).

The data was analysed using SPSS for Windows (version 17), and selective output from the analyses can be found in Appendix 1. To investigate any decrease in overall stress scores a paired samples t-test was conducted to compare scores pre- and post care. Similarly, separate paired samples t-tests were conducted for each of the subscales for pre- and post care data. To explore any relationship between length of stay and improvement in stress score a Spearman's rho correlation was used. For this a variable was computed which represented the improvement in total stress score. Moreover, to investigate any gender differences in the pre-

and post care scores a 2x2 mixed design ANOVA was implemented, using the factors time of measurement (pre-score, post score) and gender of child (male, female).

5.8.1 Participant characteristics

Families parenting a child with mild, moderate or severe learning disabilities in receipt of short breaks took part in this study. The sample of 15 families was obtained from a short break centre which supports 40 families in total; in other words, more than 35% of the families using the centre participated in this study. The overall mean age of parents was 39.53 years old (SD = 6.47, range = 30-55) and the mean age of children was 10.82 years old (SD=1.07, range = 9-12). The average length of stay for the children at the short breaks centre was 3.35 days (SD= 1.32, range= 2-7 days). The mean duration diagnosis was 6.59 years (SD= 2.76, range = 2-12 years).

Of the 15 families, the majority were married and had two children including one child with a confirmed diagnosis of mild, moderate or severe learning disabilities. The majority of children had been diagnosed with severe learning disabilities more than four years prior to the start of this study. See Tables 5.3 & 5.4 for summaries of the case study data.

Table 5.3 Parent demographics and sample statistics

	Gender of parent		Marriage status		Number of children		
	Male	Female	Married	Divorced	1	2	3 or more
N	2	13	12	3	2	8	5
% of total	13.33	86.67	80	20	13.33	53.33	33.33

Table 5.4 Child demographics and sample statistics

	Gender of child		Severity of disability			Years since diagnosis		
	Male	Female	Mild	Moderate	Severe	Less than	3-4	More than 4

					3			
N	5	10	1	3	11	3	5	7
% of total	33.33	66.67	6.67	20	73.33	20	33.33	46.67

5.9 Quantitative Results: Descriptive Statistics for Total Stress

Research question 1

What is the difference between pre- and post care test ratings of total parental stress, as measured by the (PSI)?

Pre- and post testing showed a significant reduction in total stress. Maximum total stress score was 180 and the minimum was 36. Figure 5.1 shows the mean parent pre- and post test scores on the total stress scale (PSI). Total stress scores are the sum of all the three subscales. From the figure below it is evident that participants measured clinically significant reductions in total stress over the period they were using short breaks. The difference between pre- (Mean (M)-112.53, Standard deviation (SD)-30.81) and post scores (M-104.87, SD-24.06) for total stress ($t(14) = 2.22$, $p < .05$) indicated a decrease of 7.66 points on average after a short stay.
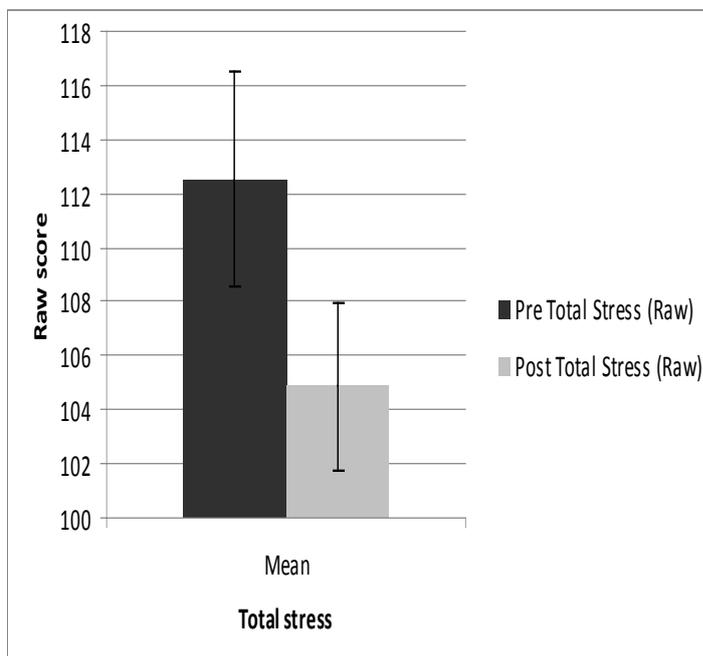
Figure 5.1 Mean scores for pre- and post total stress conditions with error bars (standard error of the mean).

Research question 2

What changes occur within the parental distress domain (personal distress related directly to parenting)?
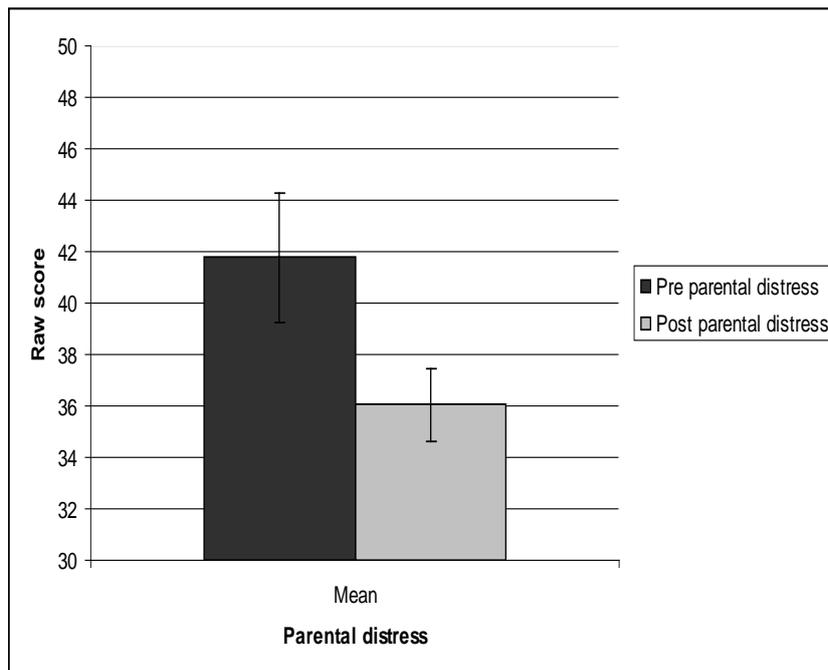
Figure 5.2 Parental Distress Subscale (PD), mean scores and standard error bars.

Figure 5.2 shows the mean parent pre- (M-41.76, SD-10.26) and post (M-36.06, SD-11.62) test scores on the Parental Distress subscale of the PSI. There was a significant reduction in parental distress scores between pre- and post care, as demonstrated by the paired samples t-test (t (16) =3.84, p<=.001). In other words, parental distress was significantly reduced (on average by 5.7 points) when the child engaged in the short break programme. The maximum score on the subscale was 60 and the minimum was 12.

Research question 3

What changes occur within the parent-child dysfunctional interaction domain?

Figure 5.3 shows the mean parent pre- and post test scores on the P-CDI subscale. The paired samples t-test (see Appendix 1) demonstrated no significant difference between pre- (M-34.29, SD- 9.37) and post (M-32.41, SD-6.53) scores on the P-CDI (t (16)=1.15, n.s.). The maximum score on the subscale was 60 and the minimum was 12.
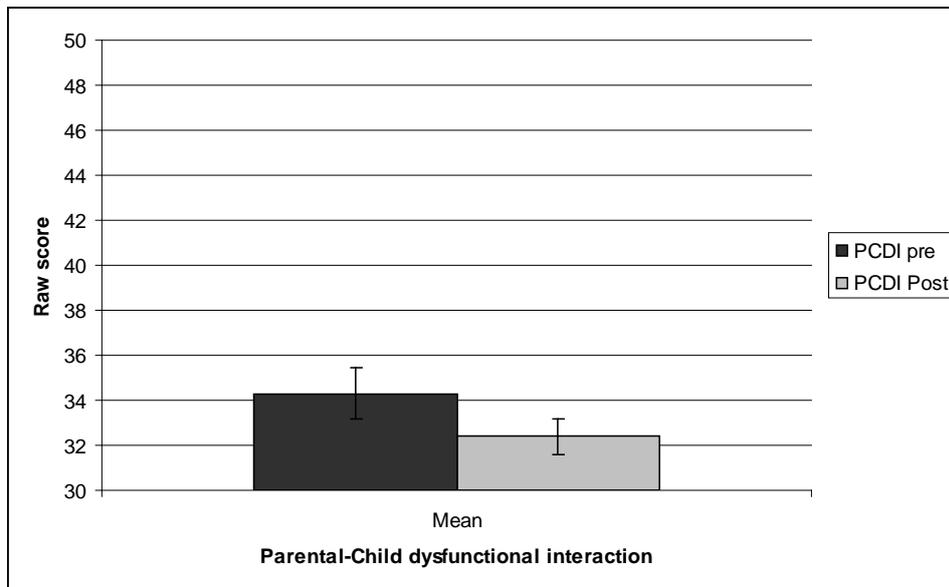
Figure 5.3 Parent-Child Dysfunctional Interaction (P-CDI), mean scores.

Research question 4

What changes occur within the difficult child domain?

Figure 5.4 shows the mean parent pre- (M-38.69, SD-12.50) and post (M-37.38, SD-9.39) test scores on the Difficult Child subscale of the PSI. The analysis indicates there were no significant reductions (t (15)1.10, n.s.). The maximum score on the subscale was 60 and the minimum was 12.
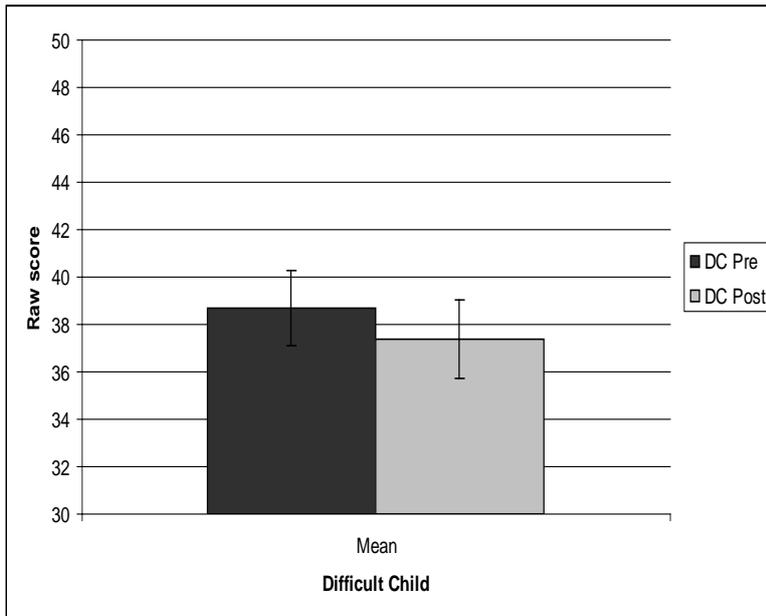
Figure 5.4 Difference between pre- and post Difficult Child scores (DC).

Research questions 5 & 6

Question 5: Is the total stress affected differently in males and females?

Analysis to see if gender has any effect upon the difference in pre- and post total stress scores demonstrated that time of measurement had a borderline significant main effect $(F(1,13)=4.68, p< 05)$, with the t-test showing an overall reduction in total stress (see Section 5.8). However, no main effect was observed from either the gender of child $(F<1)$, or the 'gender of child'*'time of measurement' interaction $(F<0.1)$.

Estimated Marginal Means of MEASURE_1
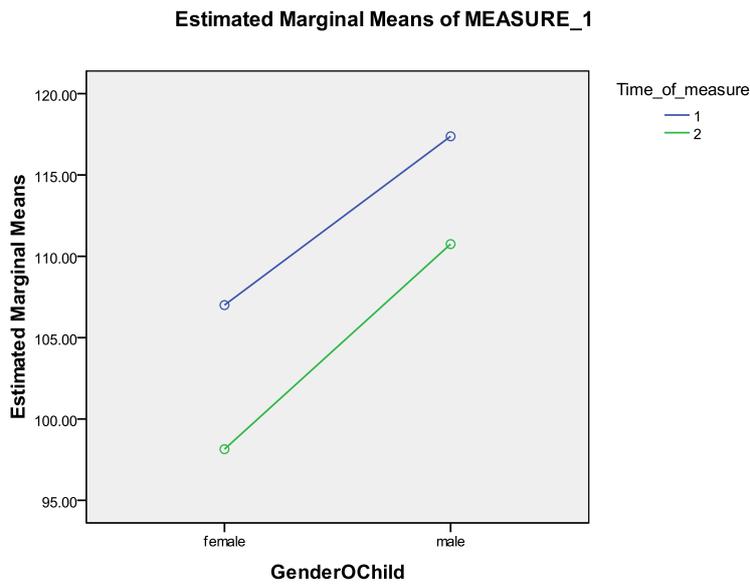
Figure 5.5 Effect of gender of child upon improvement in total stress score.

Question 6: What is the relationship between length of stay and improvement in total stress

score?

Analysis of the relationship between length of stay and improvement in total stress score,

using a Spearman's rho, demonstrated no significant correlation (rho=.23, n.s.).
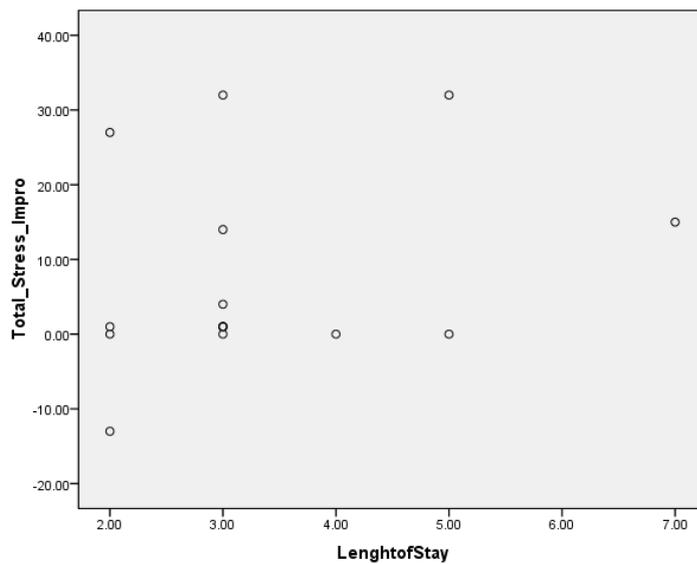
Figure 5.6 Scatterplot demonstrating the relationship between length of stay (measured in days) and improvement in total stress score (total pre- test score subtracted from total post test score).

Table 5.5 Improvement in total stress score descriptive statistics

		N	Mean	St. Deviation
Gender	**Male**	8	6.63	11.26
	Female	7	8.86	16.32
Diagnosis	**Severe**	10	7.8	13.89
	Not severe	5	7.4	13.85
Length of stay	**2**	4	3.75	16.76
	3	7	7.57	11.82
	4	1	0	0
	5	2	16	22.63
	7	1	15	0
	Total	15	7.67	13.38

5.10 Summary of Results Analysis

The aim of this study is to investigate any changes in parental stress levels following use of the short break service. The main question investigates whether there are any statistical differences between pre- and post test ratings of total parental stress. Scores reflect the sum of the three subscales which estimate parental distress (PD), stress associated with parent-child interactions (P-CDI), as well as stress arising from the child's behavioural characteristics (DC). Total stress scores are designed to provide an estimation of overall parental stress. Total stress scores exclude other life events and should only be interpreted as an indication of the stress levels associated with the parental role.

The study found that the sum of all three subscales (total stress) on the Parent Stress Index (PSI) reduced significantly over the short break intervention. Total stress scores prior to short breaks varied, but most parents scored above the 85th percentile. Although total stress levels reduced significantly, only two out of 15 parents indicated a significant reduction in stress levels specifically associated with the Difficult Child subscale. The Difficult Child subscale focuses on behavioural characteristics of children; these can include learned patterns of

behaviour, defiant outbursts or extremely demanding behaviour. Higher scores on this subscale suggest that the child has problems with the self regulation of behaviour. The majority of parents who scored higher on the Difficult Child subscale prior to short break intervention also scored higher on the total stress subscale.

The results of this investigation indicate that there is a significant reduction in total stress after using short breaks. They also indicate a significant reduction in parental distress scores after participants have used the short breaks service. However, no significant differences were found in the Parent-Child Dysfunctional Interaction (P-CDI) scores or in the Difficult Child subscale scores. Tests confirmed that short breaks are beneficial to parents across the measured domains. Further analysis to investigate any effect gender might have upon the difference between pre- and post care total scores demonstrated that time measurement had a borderline significant main effect, but that gender had no main effect. Further analysis investigated the relationship between length of stay and improvement in total stress score, and this demonstrated no significant correlation. The next section discusses the results of the current research in the context of the wider literature. The discussion chapter highlights the clinical implications and explores the limitations of the study. Future research is discussed as a way of encouraging further developments in the field of short breaks.

Chapter 6: Discussion

6.1 Overview

This chapter reflects the findings derived from the interviews and psychometric tests with the participants and considers the findings in the context of the relevant literature. Analysis of the themes consistent among parents will be explored, as well as the statistical outcomes to the parenting stress index. The primary aim of this study was to investigate psychological impact, in terms of stress, that short breaks have on parents using a combination of the parenting stress index tests and qualitative interviews. Parenting stress and short breaks are frequently described in the literature. However, few studies have investigated the link between them. This study involved an embedded mixed method design in order to capture the broader picture of short breaks on both levels. Quantitative data in this study concentrated on measurable parental distress, whereas qualitative data revealed parent's perceptions of short breaks. Qualitative analysis enabled a picture of how parents conceptualise residential short breaks. The purpose of this analysis was to identify and describe themes relating to parents thoughts and feelings regarding short breaks. This analysis identified six themes in total: functional advantages of short breaks to the child, functional advantages of short breaks to the self, functional advantages of short breaks to the family, negative emotions relating to short breaks, concerns over the child, and the general attitudes among family and friends about using short breaks. This next section will discuss how the themes derived from the findings of the study relate to the literature reviewed.

6.2 Discussion

The primary aim of this chapter is to consider the current findings in the context of the relevant literature. Analysis of the interview data led to six main themes: *functional advantages to self, family and child; maternal guilt; concern for the child and approval of*

family and friends. From a statistical perspective, the results of this study indicate a significant reduction in parental stress after parents have used the short break service. Key findings within these themes will be discussed with reference to the original questions that this research aimed to answer. These were:

1. Is there a reduction in parental stress following the use of short breaks as measured by the PSI (short form)?

2. Are there differences in the subscale scores pre and post short breaks, namely Difficult Child (DC), Parental Distress (PD) and Parent–Child Dysfunctional Interaction (P-CDI)?

3. What are the common themes in parents' subjective experiences of using short breaks?

As noted in previous chapters, short breaks for parents of children with developmental disabilities has received increased attention (Chan & Sigafoos, 2000; Robinson et al., 2001; McConkey & Adams, 2000; Grant & Whittell, 2000; McHugh, Saunders, & Reed, 2008), but the psychological impact that short breaks have on parents has received little attention. Evidence remains, however, that caring for a child with developmental disabilities requires absolute involvement, ranging from parental acceptance, refusing to give up, unique problem solving abilities, increased capacities to make informed decisions as well as commitment and support from local services. Furthermore, parenting a child with developmental disabilities is correlated with significant amounts of increased parental stress in relation to child behaviour problems (Blacher & McIntyre, 2006; Chan & Sigafoos, 2000; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower, Baker, & Blacher 2005; McHugh et al., 2008). In addition to these challenges, research has focused attention on the stresses imposed on families by the complex and demanding aspects of caring for a child with developmental disabilities (Egan & Walsh, 2001; Shearn & Todd, 2000). The amount of recognition of the role parental stress

has when parenting a child with developmental disabilities has increased over time (Blacher & Mcintyre, 2006; Dunn et al., 2001). Studies that demonstrate a strong link between the levels of developmental disability and parenting stress have found a significant correlation associated with child behaviour (Lecavalier et al., 2006). In addition to these challenges, there is an abundance of evidence that child behaviour problems are associated with parental stress (Eisenhower, Baker, & Blacher 2005; McHugh, Saunders, & Reed, 2008). Studies tend to highlight the negative aspects of raising a child with developmental disabilities, such as the impact on family esteem, draining the family's emotional resources and interfering with normal routines. These negative impacts can lead some parents to adopt negative coping skills and experience enhanced parental stress levels. There is increasing research available on the impact developmental disabilities have on overall family wellbeing (Eisenhower, Baker, & Blacher, 2005; Hastings & Brown, 2002; Hastings & Johnson, 2001). Determining the impact child behaviour has on parental stress is beyond the scope of this study. However, it is important to bear in mind that child behaviour has a significant influence on overall parental stress levels. Blacher and McIntyre (2006) highlighted the link between child behaviour and parental stress, which appeared even more significant than the level of the child's disability.

It was clear from the themes in this study that there are a host of meaningful aspects to parental experiences of using short break services. The significance of using short breaks has been previously identified (MacDonald & Callery, 2004). Parents in this study expected and discussed benefits for themselves as well as their children. MacDonald and Callery (2004) found that most parents report positive experiences of short breaks, which is consistent with the findings in this study. The functional advantages of short breaks included topics such as the opportunity to socialise with other children, including members of the staff. In addition, most parents agreed that short breaks offer their child a chance to take a break themselves

from everyday home life, which is similar to the findings of Glendinning & Kirk (2000), Laverty & Reet (2001), and Tarleton & Macaulay (2003). Wilkie and Barr (2008) conducted a small scale qualitative study about parental experiences of short breaks. The theme of rest also emerged as meaningful for most parents in relation to using short breaks.

This study revealed positive outcomes in that most parents reported renewed energy, reduced parental stress and having more time for other activities. Similar to reported studies, Crowe and Florez (2006) found that mothers with children with disabilities generally have less time available for socialising than mothers of children without disabilities. This may also explain why parents reported themselves to be more socially isolated. This was reflected within the current study, as parents discussed being much more able to interact with others including those outside the family network. In addition, parents repeatedly referred to their perceived feelings of social isolation. The views held by the majority of parents in this study were of a positive experience of short breaks, which is consistent with the findings of previous research. As discussed in previous chapters, short break services have been identified in the literature as a key support for families (Glendinning & Kirk, 2000; Laverty & Reet, 2001; Tarleton & Macaulay, 2003). Parents in this study described the direct advantages in terms of self, family and their child. Indirect advantages were also reflected to some extent within the theme of parent-child relationships and family relationships.

In terms of the perceived functional advantages of short breaks, most parents focused on a number of constructive aspects, including being able to have a break from the caring role, having added quality time with the other children in the family and the opportunity for an improved social life while their child is on a short break. Functional advantages to self also emerged as a particularly strong theme, evident in the accounts of all parents. These findings are consistent with similar studies of the perceived benefits to parents of using short breaks (Glendinning & Kirk, 2000; Laverty & Reet, 2001). Ashworth and Baker (2000)

conducted a study involving interviews with 23 caregivers in the London Borough of Lambeth; interviews were analysed using interpretative phenomenological analysis (IPA). The result of this study revealed that carers acknowledged problems with short breaks; however, they reported that the benefits far outweigh the problems identified.

Parents discussed the added advantage that a short break has on everyday family life. This study confirms the important contribution that short breaks offer to families. The primary value, as perceived by the parents, was to give them a period of respite and to spend time with other members in the family. Turnbull and Turnbull (1990) argue that the anguish of one family member reverberates among all members of the family. Krausz and Meszaros (2005) clarify the impact of raising a child with disabilities and how the entire family system is affected. Overall, the parents in this study reported significantly improved family relationships as well as having more competence in their parenting skills after using short breaks. As part of family wellbeing, there was suggestion within participants responses that for the most part short breaks provided essential time for the family to recover and regain strength. Other studies confirm this finding and have found that short breaks improve overall family functioning (Chan & Sigafoos, 2000; Robinson et al. 2001; McConkey & Adams, 2000; Grant & Whittell, 2000). Chan and Sigafoos (2000; 2001) also found that short breaks can prevent family breakdown.

Participants evaluated short breaks on many different levels, and the importance attributed to each of these varied. One parent in the study stated that short breaks provided a time to recharge their batteries and the opportunity to recuperate. Most participants agreed that taking time off with their spouse was imperative. Interestingly, parents in this research often made reference to time off as a distinct advantage. In addition, most parents seemed to feel that most of their time was spent trying to meet the needs of their disabled child and that, without

some respite from this, they never have time to reflect on their own lives. Within this context, parents felt they had much more time to complete everyday household tasks which the majority of parents perceived as beneficial and a positive experience. For some parents, periods of short breaks meant that they could escape the demands of caring, enhancement of overall coping strategies and engage in everyday things that most people take for granted. Sivberg (2002) carried out a quantitative study of 66 mothers of children with disabilities, concluding that coping strategies had a direct correlation with management of parental stress. Crnic and Greenberg (1990) formulated their model of stress based on parenting daily hassles, in which stress is understood within a minor event perspective that incorporates day-to-day frustrations that accompany child rearing. Parenting daily hassles are defined as persistently occurring, repetitive, bothersome, unavoidable tasks that are involved in a parental context. From this perspective, parents within this study perceived short breaks as providing them with the opportunity to get these everyday tasks completed. Most participants commented on the way short breaks impacted their daily lives, simplifying tasks and allowing them the time to catch up. Crnic and Acevedo (1995) found that daily hassles are not confined to any specific population group, and it is assumed that they are shared by all families regardless of demographic status. Based on this premise and the supporting literature, it seems plausible that parenting daily hassles can be linked to aspects of child as well as parent wellbeing. The majority of respondents reported short breaks as an essential service and felt that it was extremely supportive. It was also interesting to note that, in this study, most parents focused on the positive aspects of short breaks. However, there was little elaboration on the negative experiences of short breaks which would be interesting to explore.

When asked about the worst aspects about short breaks, most participants were loath to imply that the service was anything other than very good. Participants identified a number of

significant features that they valued in the service provision. One participant reported feelings of guilt when their child was away from home. Chan and Sigafoos (2001) also note that short breaks can increase parental stress, citing the effects of separation and arranging appropriate transport as some of the causal factors. Several respondents felt that receiving short breaks made the difference between the families being able to maintain ongoing provision and care for their child. However, for the most part the majority of participants wanted to make it very clear that they were all extremely appreciative for the service they received. Participants agreed that short breaks are a positive service, and similar findings are abundant in the literature (MacDonald & Callery, 2004).

Some parents reported feeling a sense of freedom after their child had been on a short break, and this appeared to be an important aspect of using these services. For some parents short breaks meant a temporary change in their personal situation for the better. In all cases, participants reported that they had developed a good relationship with their child. The majority of parents interviewed stated they would not have been able maintain the family unit if they had not had access to short breaks. Parents reported that they needed this service so that they could rest to alleviate the total exhaustion they often experienced. This finding is consistent with those of other studies related to short breaks (Wilkie & Barr 2008). Most parents agreed that short breaks offered them a chance to attend to their other children. Parents use of short breaks to combat exhaustion has been reported elsewhere (Olsen et al., 2001).

A few participants said that they required the time to be a "normal family again". Implicitly, therefore, their disabled child was not perceived as part of this replenishment. Normality was a highly prized asset in most responses. Ashworth and Baker (2000) confirmed this finding and found that short breaks did bring a feeling of normalcy to older parents. Parents valued short breaks as they helped them to appear normal. Normality to the

parents of children with complex needs shifted from a change in environment to being viewed as "normal" by people outside the family system. Many respondents could not find anything negative to say about short breaks, stating that everything about short breaks is good. The fact that it helped so many families led them to perceive it as a great service in their mind. Further focussed research would help in clarifying the reasons why parents feel so strongly about short break provision. It may be that parents were too afraid to say anything negative as they feared the service may be changed in some way.

Other parents reported having time to visit other places that were deemed unsuitable for their child with complex developmental needs because of issues such as mobility, accessibility, funding and transportation. Parents spoke of using short breaks to escape the routine of complex caring. This was a particularly strong theme for most participants and is confirmed in the recent findings (Blacher & McIntyre, 2006; Chan & Sigafoos, 2000; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower, Baker, & Blacher 2005; McHugh et al., 2008). Parents said they were able to engage in a range of normal activities and the feeling of increased family cohesiveness was derived from their sense of freedom, without the tedious planning required when parenting a child with special needs. Research suggests that parenting a child with developmental disabilities can impede the process of maintaining cohesive relationships. Family cohesion has also been known to be an important factor in coping with the demands of stress. Olson (2000) contends that families who fall within the connected or separated category tend to react to changes within the family in a much more constructive and positive way. From a broader perspective it appears that families that fall within the balanced range (connected and separated) are more likely to deal with stress successfully. Family cohesion has been cited in this study as a helpful family resource, and the opportunity on the part of parents to rest can positively increase this process.

Chan and Sigafoos (2001) found that in some cases short break access can increase parental stress levels. Factors such as the impact of separation from the family and the need to arrange specialised transport can potentially serve to exacerbate psychological stress. Some respondents reported feelings of guilt related to the use of short breaks, generally characterised as an emotional struggle they experienced between reasonable self-interest (i.e., being able to take a rest from daily care of the child) and concerns or other feelings of guilt (i.e., feeling guilty that they're sending the child away for care, missing their child, etc.). Some reported feeling mean and as they were forcing their child to go on short breaks, whereas others felt that they were purposefully excluding their child from family activities. Several concerns emerged around families not wanting to make their child feel rejected by taking them on short breaks.

Additionally, concerns for the child also emerged as a separate theme. These concerns, while less common, generally focused on the issue of safety for the child while on short breaks. Finally, opinions and attitudes expressed by family and friends regarding short breaks also emerged as a theme in this analysis. As would be expected, respondents noted that family and friends express both positive and negative opinions regarding the use of short breaks. The majority of respondents felt that short breaks were a very good idea for both the child and family. Within the participants accounts there were references to the importance of family approval for using short breaks.

This study examined the impact short breaks have on total parental stress in a sample of parents who have a child with developmental disabilities. The results of this study supported the main question. They confirm that there is a greater likelihood that parental stress levels will decrease for a group of parents with a child with developmental disabilities in receipt of short break services. The discussion has considered how the current findings relate to the research aims of exploring the parental experiences of using short breaks. It is evident from

these findings that for most participants, using short breaks is characterised by positive and meaningful experiences. This discussion will consider the findings related to the second research aim in relation to parental stress levels.

Results indicate that there was a statistically significant difference in total parental stress before and after using residential short breaks. The results of the current study contribute to the emerging evidence base regarding the functional advantages of short breaks principally in terms of stress reduction for those parenting a child with severe developmental disabilities. In addition, the exploratory results support the idea that parents benefitted principally in terms of an improvement in parent-child interactions when allowing their child to use short breaks. Furthermore, the set of research questions, that parental stress in all three subscales would decrease following a stay at short breaks, was supported on the parent distress and parent child interactions outcomes in this study. The subscale difficult child revealed no significant changes pre- and post-short break intervention. According to Abidin (1995), the total stress scores can potentially identify parents at risk of developing dysfunctional parental behaviours. The majority of participants in this study scored higher on the difficult child subscale. Higher scores on this subscale may be associated with children who exhibit qualities that are difficult for parent's to manage effectively, thereby increasing parental stress. The implications of this finding are that child characteristics are a major factor in contributing to parental stress. Previous research supports the idea that the child's problematic behavioural characteristics are associated with higher parental stress (Baker et al., 1997; Tomanik, Harris & Hawkins, 2004). Poehlmann, Clements, Abbeduto and Farsad (2005) achieved similar results in regards to children's behavioural problems that have a direct impact on parental stress. In the context of caring for a child with disabilities, overall family functioning is of significance, as difficult child behaviour can influence the family system is several ways. Difficult behaviours can disrupt the emotional bonding that exists

between family members and impact on family cohesion, which can in turn exacerbate parental stress levels. Family cohesion has also been known to be an important factor in coping with the demands of stress. Olson (2000) contends that families who fall within the connected or separated category tend to react to changes within the family in a much more constructive and positive way. From a broader perspective, it appears that families that fall within the balanced range (connected and separated) are more likely to deal with stress successfully. Family cohesion has been cited as a helpful family resource. From this perspective, higher levels of family cohesion could be easily influenced by fluctuating parental stress levels, which could ultimately be disadvantageous to family wellbeing. Research on family cohesion confirms that families that are more cohesive tend to react more positively to stress (Olson, 2000).

Barr (2008) conducted a small scale qualitative study of parental experiences of short breaks. The study revealed positive outcomes in that most parents reported renewed energy, reduced parental stress and having more time for other activities. This finding also supports previous research that short breaks decrease parental stress. Short break services have been identified in the literature as a key support for families (Tarleton & Macaulay, 2003). Although there is a paucity of research on the impact of short breaks on children themselves, research has identified the positive effects on parents. Chan and Sigafoos (2000; 2001) found that short breaks can also prevent family breakdown. Having short breaks in place for families can bring about positive outcomes for parents and in turn reduce parental stress. As discussed in previous chapters, correlation studies suggest that appropriate support from services such as short breaks is likely to decrease parental stress and can be useful to families with children who have developmental disabilities (Sloper & Turner, 1992). Laverty and Reets (2001) reported that short breaks allow quality time and the opportunity for all family members to live a rewarding life. They suggest that short breaks also aid in the enhancement

of family empowerment and balance. Family balance and empowerment could be important contributions to parental wellbeing and contribute to secondary gains from using short breaks.

In concurrence with other studies, research has examined how stress related symptoms whilst raising a child with disabilities directly affects how parents care for their children (Briggs-Gowan, Carter, Skuban & Horwitz, 2001; Innocenti, Huh & Boyce, 2002; Orr et al., 2003; Roach, Orsmond & Barratt, 2009). The literature suggests that the characteristics of the children themselves are also factors to consider, with the most consistent research finding being an association between higher levels of the various dimensions of parental stress (Floyd & Gallagher, 2007; Baker, McIntyre & Blacher, 2003). The findings in this study indicated that short breaks significantly reduce total parental stress. The correlations between effect of gender on improvement and time measurement in pre- and post-total stress score demonstrated no significant differences. It should be noted that this effect was not predicted and resulted from exploratory analyses that attempted to capitalise on the interactional effects of the variables. Overall, the findings in this study support the idea that short breaks reduce total parental stress. The findings of this study are consistent with previous research and also contribute to research in the area of parental stress as it relates to short breaks. This study demonstrated that there are functional advantages to using short breaks for families with children who have developmental disabilities. Although the present study may not be representative of the total population of children using short breaks, studying this population highlights the links between short breaks and reduced parental stress. The results of the present study do not challenge previous research but rather confirm the association.

6.3 Limitations

Though this study contributes to past research conducted with families who have a child with a disability, there are certain limitations to it. While the limitations do not invalidate the study results, they do serve as reminders to interpret the findings with caution. Many of these children were rated as having poor behaviour and parents rated themselves as stressed. At these extremes, a tendency to decrease in stress toward the mean is common. Several significant changes in parental stress before and after using short breaks were found. However, another possible explanation for these changes in stress levels is that some other event outside of the short break intervention affected the parents and influenced the changes in stress levels. Outside events could have affected how parents perceive their stress. All these possible errors and confounds make any conclusion that may be drawn from this study tentative, therefore limiting its ability to generalise the findings.

The research was conducted on the basis of a relatively small sample. The smaller sample size may have affected some of the results of this study, resulting in lower power and a smaller effect size. Future studies in this area may benefit from using incentives for parents to participate in the study. While a small sample size is not desirable, it was unavoidable due to the difficulty in gaining access to parents who use residential short breaks. There is a possibility that if there had been a larger sample and higher predictor of parental stress, changes may have been found. Information was only gathered for this study from parents who agreed to participate, and there is thus uncertainty regarding how closely the sample in this study matched all the parents using short breaks. During the semi-structured interviews there may have been an element of trying to please the interviewer in spite of written assurance to the contrary.

The national ethics committee deliberated the research proposal for 18 months, revising and reworking the original study proposal. After a successful final appeal, which was attended by Professor Jeremy Turk, the ethics team approved the study. During this appeal it

was felt that it would not be fair to parents to withhold short breaks for the sake of establishing a control group, and therefore no control group was instituted in this study. However, the statistics in this study would have been much stronger using a control group study design alongside an increased sample size. The number of parents that responded to the leaflets determined the sample size. It is hoped that further studies could make use of controls.

Conducting a three month follow up would also be an important addition to any future studies. This would allow the researcher to determine whether or not changes in parent stress are maintained over time. This may encourage future research. This study only examined the parental stress levels of parents before and after using short breaks. This study did not take into account the feelings and interpretations of the child and other family members. As the literature provides evidence for relationships between study variables and parental stress, with no other variables being examined in this study, this may limit the findings. Most parents opted for telephonic interviews. For the most part, the participants in this study had very little spare time as most of their days were occupied with parenting tasks. Opdenakker (2006) points out that telephone interviews are a versatile way of gathering data. Similarly, Sturges and Hanrahan (2004) found that qualitative telephone data have been described as rich, detailed and of much higher quality. Carr and Worth (2001) discuss some of the disadvantages of telephone interviews, such as a lack of visual cues and the potential for distraction by participants in their own environment. Other disadvantages include the fact that for the most part telephone interviews are in general much shorter than face-to-face interviews. Fontana and Frey (2005) highlight the importance of nonverbal interview data such as the emotional content which in turn contributes to the depth and overall quality of the data collection. Vital information communicated non-verbally is missing in a telephonic interview. Sturges and Hanrahan (2004) also found that telephone interviews can be much

shorter than face-to-face interviews, and the quantity of data is therefore at risk of being compromised. Patton (2002) describes the importance of rapport, indicating that any loss thereof may reduce the value of participant responses. Consequently, it may be much more difficult to create a good rapport on the phone than in face-to-face interviews. Sweet (2002) found that interviewing by telephone can ultimately limit good rapport because of a lack of nonverbal interaction. Nunkoosing (2005) draws attention to the fact that both researcher and participant are not visible to each other during a telephone interview, hence making it more of a challenge to detect any ambiguous data. However, in this study the majority of parents specifically requested telephonic interviews, and this issue was discussed in supervision. Most parents experienced excessive care giving demands and the general stress of caring for a child with extensive needs, which most found time consuming. This meant that they had very little time to attend interviews. Further studies should take the limitations of this study into consideration.

6.4 **Implications for application**

The results of this study contribute to the knowledge base related to families using short break services. Parental motivational levels remain exceptionally high around the psychological benefits of short breaks and it is hoped that this will be incorporated into the overall service development planning in the future. It is hoped that this study will promote and encourage future research, drawing practical conclusions about how best to meet the needs of parents who care for their disabled child. Health care professionals working with families should be made aware of the impact caring for a child with developmental disabilities has on parental stress. Based on the findings, professionals working with families may be more aware of overall stress patterns. Additionally, parents may benefit from exploring these difficult feelings with a professional therapist. Given these difficult challenges, there are practical steps the managers of short breaks could take to improve

practice. This could be achieved by the short break centres offering a referral directory that could facilitate parent communication, thereby encouraging the dissemination of information about short breaks. In the school setting, it may helpful for school staff to be aware of the stress levels of parents and be more aware of their emotional reactions to their child on a day-to-day basis. Local parenting support groups could be provided to promote family understanding, together with psycho-educational sessions to help families develop ways to overcome stress. This study provides a contribution to an understanding of short breaks and their benefits. Searches of the literature indicate that there is a paucity of research into the psychological benefits principally in terms of stress reduction. Although the study used a relatively small sample size, which included mixed diagnosis of mild, moderate and severe learning disabilities, the findings do contribute to an overall understanding of the psychological benefits short breaks brings to parents. More longitudinal research needs to be conducted to examine the stress levels of parents raising a child with a disability over time. It would be interesting to study the correlation between stress levels in parents over time in order to better understand specific stressful periods or critical times in raising a child with a disability. Additional research is needed to study the levels of stress of parents who do not have a child with a disability as compared to parents who do.

6.5 **Future Research**

Primarily, the current study demonstrates a need for further research to broaden an empirical understanding of parental experiences of using short breaks. The findings of this study provide a basis for a larger study which could explore parental stress levels and a national level within the UK. Service providers should inform families of the increased beneficial effect short breaks has as well as encourage health care providers to increase information provision to families. There are several implications for health care workers involved in providing care to families, such as being aware that short breaks have different

meanings to parents. A number of issues have been identified to inform practice and overall service delivery. There are substantial gaps in the literature regarding the preparation procedures prior to families engaging in short break services. Preparing children and their families for short breaks should be viewed as an essential process. There are further gaps in the literature relating to families that have chosen not to use short breaks services, and understanding the reasons for this would help to ensure that short breaks are available and accessible to all children with developmental disabilities. The provision of acceptable and appropriate short breaks depend on careful assessment of the meanings parents attached to this service, and are eventually tabled into the short break allocations. The study expands research on parents with children who have developmental disabilities. Short break service providers should attempt to promote more family and community involvement to foster healthy attitudes by caregivers towards receiving short breaks. Families should attempt to understand and feel empowered to assess supports to help maintain their own physical and mental health. Future researchers should look more closely at parental stress levels for those parenting a child with developmental disabilities. Research could continue to investigate the moderating and mediating variables linked to parental stress levels. It is hoped that the experiences of parents using short breaks may be considered in planning short break services.

6.6 Conclusions

From the numerous discussions with parents and the emerging themes in the qualitative analysis, it is clear that raising a child with developmental disabilities can be a challenging task. There is substantial evidence that the challenges faced by parents and the ways in which they manage stress may vary from family to family. There are many possible explanations for the higher stress levels associated with parenting. The findings of this research indicate that short breaks provide meaningful experiences for parents. The level of the child's disability and the features that are often associated with a developmental delay such as impulsivity,

hyperactive behaviour as well as complex behaviour all play a role. While any conclusions that can be drawn from this study are tentative, this study lends itself to support the research question that short breaks clearly reduce parental stress levels. The overall experience for parents in terms of their feelings towards short breaks in general was overwhelmingly positive. For the most part, parents were presented with complex challenges associated with parenting a developmentally disabled child. On the whole, the majority of parents described functional advantages to self, family and child. Similar responses were present in other studies conducted by Neff (2009) and Olsen & Maslin-Prothero (2001) as well as Chan & Sigafoos (2000).

This study revealed that short breaks need to be flexible enough to meet the needs of both parent and child. This study has highlighted key areas, and further research should consider the most appropriate way to evaluate short breaks from the perspective of the parents as well as the child. As stated in the literature, short breaks are perceived as important for overall family wellbeing (Chan & Sigafoos, 2000; Robinson, Jackson & Townsley, 2001; McConkey & Adams, 2000; Grant & Whittell, 2000). Reported perceptions of the use of short breaks were varied. This study holds important information to any parent considering using short breaks for the first time. It seems clear that supporting parents can have a positive impact on all concerned within the family system. The current study focused directly on parenting stress levels and attempted to measure any changes before and after using short break services. The present study found a significant reduction in overall parental stress during the short break period. Exploration into the impact of children's developmental disabilities on parents' mental health should be actively encouraged. This may have clinical relevance for therapeutic interventions for parents at risk of high stress levels. Overall, the findings suggest that short breaks are useful to families in ameliorating parental stress. The statistical evidence from this study provided support to suggest that this line of research is promising. Identification of

some of the factors that cause stress may in turn lead to serve as protective factors for parents. This study could help to increase our theoretical understanding of how parents cope as well as improve clinical best practice with families. As part of delivering the Every Child Matters programme, local authorities have a strategic role to play in the overall development of support to all parents in their area. The study may provide useful guidance to each local authority in order to develop an integrated approach to the delivery of services for parents, which includes those parenting a child with any level of disability.

References

Abidin, R. (1990). Parenting Stress Index. Charlottesville, VA: *Paediatric Psychology Press*.

Abidin, R. (1992). The determinants of parenting behaviour. *Journal of Clinical Child Psychology*, *21*, 407-410.

Abidin, R. (1995). Parenting Stress Index (Eds.), Florida: Psychological Assessment Resources.

Aiming High for Young People: A ten year strategy for positive activities 2007, HM Treasury and the Department of Children, Schools and Families.

Aiming High for Disabled Children: Better support for families 2007, HM Treasury the Department of Children, Schools and Families.

Ainge, D.J. (1995). A comparison on couples views on caring for their child with intellectual disability. *Australia & New Zealand Journal of Developmental Disabilities*, *20*, 175-188.

Ainscow, M. (1999). Inclusion. Paper presented at address to staff at the centre for Inclusion: Perth, Western Australia.

Ammerman, R. T., Hersen, M., Van Hasselt, V. B., Lubetsky, M. J., & Sieck, W. R. (1994). Maltreatment in psychiatrically hospitalized children and adolescents with developmental disabilities: Prevalence and correlates. *Journal of the American Academy of Child and Adolescent Psychiatry*, *33* (4), 560-570.

Ammerman, R. T. (1998). Abuse and neglect of children with disabilities (letter to the editor). *Child Abuse & Neglect*, 22 (7), 660-663.

Ashworth, M., Baker, A.H. (2000). Time and space: Carers' views about respite care. *Health and Social Care in the Community*, *8* (1), 40-54.

Bailey, D. B., & Roberts, J. (*2007). Maternal Depression and Developmental Disability: Research Critique. Mental Retardation Developmental Disability Res Rev, 13:* 300-310.

Baker *B. L.,* Blacher J., Crnic K. A. & Edelbrook *C. (2002) Behaviour problems and parenting stress in families of three year old children with and without developmental delays.* American Journal of Mental Retardation *107, 400-444.*

Baker, B.L., McIntyre, L.L., Blacher, J. et al. (2003). Preschool children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disabilities Res, 47:* 200-210.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioural change. *Psychological Review*, *84*, 190-200.

Bandura, A., Adams, N.E., & Beyer, J. (1977). Cognitive processes mediating behavioural change. *Journal of Personality and Social Psychology*, *35*, 120-130.

Bandura, A., & Schunk, D. H. (1981). Cultivating competence, self- efficacy and intrinsic interest through proximal self-motivation. *Journal of Personality and Social Psychology*, *41*, 500-580.

Bandura, A. (1982). Self-efficacy in human agency. *American Psychologist*, *37*, 120-140.

Bandura, A. (1986a). Social foundations of thought and action: A social cognitive theory. Englewood, Cliffs, NJ: Prentice-Hall.

Bandura, A. (1986b). The explanatory and predictive scope of self-efficacy theory. *Journal of Social and Clinical Psychology*, *4* (3), 350-360.

Bandura, A. (1986). Social foundation of thought and action: A social cognitive theory. Engelwood Cliffs, N.J. Prentice-Hall.

Bandura, A. (1993). Perceived self-efficacy in cognitive development and functioning. *Educational Psychol.*, *28*, 100-140.

Barnett, W.S. & Boyce, G.C. (1995). Effects of children with Down syndrome on parents activities. *American Journal of Mental Retardation*, *100*, 110-125.

Barlow, J., Coren, E., & Steward – Brown, S. (2002). Meta-analysis of the effectiveness of parenting programmes in improving maternal psychosocial health. *British Journal of General Practice*, 52, 200- 233.

Beckman-Bell, P. (1981). Child-related stress in families of handicapped children. *Topics in Early Childhood Special Education*, 1 (3), 40- 50.

Belchic, J.K. (1995). Stress, social support, and sense of parenting competence: A comparison of mothers and fathers of children with autism, down syndrome, and normal development across the family life cycle. Dissertation Abstracts International, *57*, 2.

Belsky, J. (2006). Early child care and early child development: Major findings of the NICHD study of early child care. *European Journal of Developmental Psychology*, *3* (1), 90-98.

Beckman, P. J. (2001). Comparison of mothers and fathers perceptions of the effect of young children with and without disabilities. *British Journal on Mental Retardation 95*, 585-595.

Beck, A., Hastings, R. P., & Daley, D. (2004). Pro social and behaviour problems independently predict maternal stress. *Journal of Intellectual & Developmental Disability* 29, 330-320.

Benedict, R. E. & Farel, A. M. (2003). Identifying children in need of ancillary services enabling services: a population approach. *Social Science and Medicine*, *57*, 2030-2043.

Beresford, B. (1997). Personal accounts: involving disabled children in research. London: The Stationary Office.

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child Care, Health and Development*, 30, 6, 500-580.

Bigras, Marc, LaFreniere, Peter J., & Dumas, Jean E. (1996). Discriminate Validity of the Parent and Child Scales of the Parenting Stress Index. *Early Education & Development*, *72*, 160-170.

Blacher, J., & Baker B. L. (1994). Out of home placement for children with retardation: Family decision making and satisfaction. *Family Relations*, *43*, 10 – 12.

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual and Developmental Disabilities, 50*, 180 – 198.

Borough of Poole. (2010). *Respite Care for Children with Disabilities*. Retrieved March 9, 2010, from Children and Young People's Integrated Services: http://www.poole.gov.uk/children_integrated/services/ref:S464ACB6916B6B/aka:Respite+Care+for+Children+with+Disabilities/

Bose, R. (1991). The effect of a family support scheme on mental health of mothers caring for children with mental handicaps. *Research, Policy and Planning 9*, 3 -6.

Botuck, S., & Winsberg, B. (1991). Effects of respite care on mothers of school age and adult children with severe disabilities. *Mental Retardation 29*, 40 – 6.

Briggs, K., & Askham, J. (1999). The Needs of People with Dementia and Those Who Care for Them*: A Review of the literature*. Alzheimer's Society, London.

Briggs-Gowan, M., Carter, A., Skuban, E., & Horwitz, S. (2001). Prevalence of social emotional and behavioural problems in a community sample of one and two year old children*. Journal of the American Academy of Child and Adolescent Psychiatry 40*, 811-880.

Brinchmann, B. S. (1999). When the home becomes a prison: Living with a severely disabled child. *Nursing Ethics*, *6* (2), 130 – 143.

Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and non disabled boys: Adaption and spousal support. *Developmental Psychology*, *24*, 440-450.

Bromley, B., & Blacher, J. (1989). Factors delaying out of home placements of children with severe handicaps. American Journal of Mental Retardation, *94*, 284-291.

Bruns, E. J., & Burchard, J. D. (2000). Impact of respite care services for families with children experiencing emotional and behavioural problems. Children's services: *Social Policy, Research, and Practice*, *3*, 40-60.

Carers National Association. (1997). *Still battling? The Carers Act one year on.* London: CNA.

Carr, A. (2006). The Handbook of Child and Adolescent Clinical Psychology. 4th edition. London: Routledge.

Carr, E. C., & Worth, A. (2001). The use of the telephone interview for research. Journal of Research in Nursing, 6, 500-512.

Catherall, C. & Iphofen, R. (2006). Living with a disability*, Learning Disability Practice 9* (5): 10-30.

Campell, H. (1996). Inter agency assessment of respite care needs of families with children with special needs in Fife. *Public Health, 110*, 150- 154.

Chan, J. B., & Sigafoos, J. (2000). A Review of Child and Family Characteristics Related to the Use of Respite Care in Developmental Disability Services. *Child and Youth Care Forum* , 27 - 37.

Chan, J. B. & Sigafoos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children? *Child and Youth Care Forum*, *30*, 250-261.

Cochran, M. M., & Brassard J. A. (2009). Child development and personal social networks. *Child Development 50*, 600-615.

Cohen, S. (1982). Supporting families through respite care. *Rehabilitation literature*, *43*, 7-10.

Cole, D. A. (1986). Out of home placement and family adaption: A theoretical framework. *American Journal of Deficiency 91*, 220-230.

Coleman, P.K., & Karraker, K.H. (1997). Self-efficacy and parenting quality: Findings and future applications. Developmental Review, *18*, 47-85.

Connaughton, O., & O'Donovan O. (1999). Families coping with physical disability – the need for shared care. *Irish Social Worker 17,* 15 – 16.

Cotterill, L., Hayes, L., Flynn, M., & Sloper, P. (1997). Reviewing respite services: some lessons from the literature. *Disability and Society , 12* (5), 775 - 788.

Cowen, P. S., & Reed, D. A. (2002). Effects Of Respite Care for Children with Developmental Disabilities: Evaluation of an Intervention for At Risk Families. *Public Health Nursing* , 272 - 283.

Cox, C. (1996). Findings From a Statewide Program of Respite Care: A Comparison of Service Users, Stoppers, and Nonusers. *The Gerontologist* , 511 - 517.

Cramer, H. & Carlin, J. (2008). Family-based short breaks respite for disabled children: Results from the fourth national survey. *British Journal of Social Work*, *38*, 1000-1060.

Creswell, J. W. (1998). Qualitative inquiry and research design: choosing among five traditions. Thousand Oaks, CA: Sage.

Creswell, J. W. (2008). Educational research: Planning, conducting and evaluating quantitative and qualitative research. 3rd edition. New Jersey: Pearson Education.

Crisp, A., Marchant, R. & Jones, M. (2000). Quite like home: Young people's views about residential respite care services in Kent. Brighton: Triangle.

Critchley, C.R., & Sanson, A. V. (2006). Is parent disciplinary behaviour enduring or situational? A multilevel modelling investigation of individual and contextual influences on power assertive and inductive reasoning behaviours. *Journal of Applied Developmental Psychology*, *27*, 300 -320.

Crnic, K. A., & Greenberg, M. T. (1990). Minor parenting stresses with young children. *Child Development*, *61*, 1600-1637.

Crnic, K. A., & Booth, C. L. (1991). Mothers and fathers perception of daily hassles of parenting across early childhood. *Journal of Marriage and Family*, *53*, 1000-1040.

Crnic, K. A., & Acevedo, M. (1995). Everyday stress in parenting. In M. H. Bornstein (Ed.), Handbook of Parenting: 1st edition. (pp. 277-297). Mahwah NJ: Lawrence Erlbaum Associates.

Crnic, K., & low, Christine (2002). Everyday stress and parenting. In M. H. Bornstein (Ed.), Handbook of parenting: Vol. 5. Practical issues in parenting (2nd ed., pp. 240-250). Mahway, NJ: Lawrence Erlbaum Associates.

Crnic, K. A., Gaze, C., & Hoffmann, C. (2005). Cumulative parenting stress across the preschool period: Relations to maternal parenting and child behaviour at age five. Infant and Child Development, *14*, 100-129.

Crowe, T.K., & Florez, S. I. (2006). Time use of mothers with school aged children: A continuing impact. *The American Journal of Occupational Therapy*, *60* (2), 190- 199.

Cubanski, J., & Kline, J. (2002). In Pursuit of Long-Term Care: Ensuring Access,Coverage, Quality. *Issue Brief 1* (7).

Cuskelly, M., Chant, D., & Hayes, A. (1998). Behaviour problems in the siblings of children with Down Syndrome: Association with family responsibilities and parental stress. *International Journal of Disability, Development, and Education*, *45*, 295-311.

Damiani, G., Rosenbaum, P., Swinton, M., & Russell, D. (2004). Frequency and determinants of formal respite service use among caregivers of children with cerebral palsy in Ontario. *Child: Health, Care and Development , 30* (1), 77 - 86.

Davies, B., Collins, J. B., Steele, R., Cook, K., Brenner, A. & Smith, S. (2005). Children's perspectives of a paediatric hospice program. *Journal of Palliative Care*, *21*, 250-259.

Deater-Deckard, K. (2005). Parenting stress and children's development: Introduction to the special issue. *Infant and Child Development*, *14*, 110-113.

Deater-Deckard, K. (2004). Parenting stress. New Haven, CT: Yale University Press.

Department of Health. (1970). *The Chronically Sick and Disabled Persons Act*. London: The Stationery Office.

Department of Health. (1989). *Caring for people.* London: The Stationery Office.

Department of Health. (1989). *The Children Act.* The Stationery Office: London.

Department of Health. (1991). *The Children Act* Guidance and Regulations: Volume 6 Children with Disabilities. London: HMSO

Department of Health. (1995). The Carer's Recognition and Services Act. HMSO, London, UK.

Department of Health. (1998). *Removing Barriers for Disabled Children Act: Inspection of services to disabled children and their families* . London: Department of Health.

Department of Health. (1998). Partnership in Action (New Opportunities for Joint Working Between Health and Social Services – A Discussion. Department of Health, London, UK.

Department of Health. (1999). *The National Strategy for Carers.* London: The Stationery Office.

Department for Education and Skills. (1999). *Children and Families.* London: The Stationery Office.

Department for Education and Skills. (2000). *Choice Protects.* London: The Stationery Office.

Department of Health . (2000). *Carers and Disabled Children Act* . London: The Stationery Office.

Department of Health. (2001). Valuing People Whit Paper. The Stationary Office, London, UK.

Department for Children, Schools and Families. (2003). *Independent Reviewing Officers Draft Guidance*. London: The Stationery Office.

Department for Children, Schools and Families. (2006). *Working Together to Safeguard Children* . London: The Stationery Office.

Department for Children, Schools and Families. (2010). *National quality framework for the Common Assessment Framework (CAF) process.* London: The Stationery Office.

Dobson, B., Middleton, S., & Beardsworth, A. (2001). *The Impact of Childhood Disability on Family Life*. York Publishing Services, York.

Downey, G., Coyne, J. C. (1990). Children of depressed parents: an integrative review: *Psychology Bulletin, 108*: 40-60.

Duff, G. (1992). Respite Choice. *Nursing Times , 88* (33), 65 - 66.

Duis, S. S., Summers, M., & Summers, C. R. (2007). Parent versus child stress in diverse family types: an ecological approach. Topics in Early Childhood Special Education, *17*, 53-73.

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, *37*, 30-50.

Dunst, C. J., Trivette, C. M., & Deal, A. (1998). Enabling and empowering families: *Principals and guidelines for practice.* Cambridge, MA: Brookline Books.

Dunst, C. J., & Trivette, C. M. (2006). Looking beyond the parent-child dyad for the determinants of maternal styles of interaction. *Infant Mental Health Journal 7*, 60-80.

Eaton, N. (2008). I don't know how we coped before: a study of respite care for children in the home and hospice. *J Clin Nurs*, *17*, 3000-3204.

Egan, J., & Walsh, P. N. (2001). Sources of stress among adult siblings of Irish people with intellectual disability. Irish *Journal of Psychology*, 22: 20-28.

Eisenhower, A. S., Baker, B. L. & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behavioural problems and maternal well being. *Journal of Intellectual Disability Research 49*, 600-650.

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research, 47*, 300-387.

Enfield, S. L., & Tonge, J. (2002). Manual for the Development Behaviour Checklist: Primary Carer Version (DBC-P) and teacher version (DBC-T) 2nd edition Melbourne: Monash University Centre for the Developmental Psychiatry and Psychology.

Feldman, M. A., & Werner, S.E. (2002). Collateral effects of behavioural parent training on families of children with developmental disablties adn behaviour disorders. *Behavioural Interventions 17*: 69 -73.

Fleischmann, A. (2005). The hero's story of autism. Autism, *9* (3), 290-315.

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations: Interdisciplinary Journal of Applied Family Studies , 46* (4), 359 - 371.

Floyd, F. J., & Gallagher E. M. (2007). Parental stress, care demands and use of support services for school age children with disabilities and behaviour problems. *Family Relations*, *46*, 300- 370.

Folden, S. L., & Coffman, S. (1983). Respite care for families of children with disabilities. *Journal of Paediatric Health Care*, *7*, 100- 109.

Fontana, A., & Frey, J. (2005). The interview: From neutral stance to political involvement. In The Sage handbook of qualitative research (3rd ed., pp 600-700). Thousand Oaks, CA: Sage.

Framework for the Assessment of Children in Need and their Families 2000, Department of Health.

Frude, N. (1992). Understanding Family Problems: A Psychological Approach. Chichester: John Wiley.

Fruin, D. (1998). *A Matter of Chance for Carers? Inspection of Local Authority Support for Carers.* Social Services Inspectorate. London: Department of Health Social Care Group.

Garvidia-Payne, S., & Hudson, A. (2002). Behavioural supports for parents of children with an intellectual disability and problem behaviours: An overview of the literature. *Journal of Intellectual Developmental Disability*, *27*, 29-49.

Geall, R., & Host, N. (1991). Sharing the caring. *Respite Care for Children and Families.* London: National Children's homes.

Gerard, K. (1990). Determining the contribution of residential respite care to the quality of life of children with severe learning difficulties. Child: Care, Health and Development, *16*, 177-180.

Glendinning, C., & Kirk, S. (2000). High-tech care: high-skilled parents. *Paediatric Nursing* , *12*, 24- 6.

Glidden, L.M., Jobe, B.M. (2006). The longitudinal course of depression in adoptive and birth mothers of children with intellectual disabilities. *J Policy Practical Intellectual Disabilities, 3*, 135-140.

Glidden, L.M., & Schoolcraft, S.A. (2003). Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research*, *47*, 200- 240.

Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: the relevance of gender, family composition and the life span. *J Appl Res Intellect Disabilities*, *13*: 250 – 270.

Griffiths, R. (1988). *Community Care: Agenda for Action.* London: The Stationery Office.

Grunewald, K. (1986). The intellectually handicapped in Sweden new legislation in a bid for normalisation, *Current Sweden*, *345*, 1-9.

Hall, S. (1996). An exploration of parental perception of the nature and level of support needed to care for their child with special needs. *Journal of Advanced Nursing*, *24*, 500-519.

Halpern, P.L. (1985). Respite care and family functioning in families with retarded children. *Health and Social Work, 10,* 130 – 140.

Hartrey, L., & Wells, J. S. (2003). The meaning of respite care to mothers of children with learning disabilities: two Irish case studies. *Journal of Psychiatric and Mental Health Nursing , 10*, 335 - 342.

Hassal, R., Rose J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, *49*, 400-405.

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young children with autism. Journal *of Autism and Developmental Disorders 31*, 300-335.

Hastings, R.P., & Brown, T. (2002). Behavioural problems of children with autism, parental self efficacy, and mental health. *American Journal of Mental Retardation*, *1000*, 220-230.

Hastings, R. P., Kovshoff H., Brown T., Ward N. J., Espinoza F. D., & Remington B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. Autism: *The International Journal of Research and Practice 9*, 300-390.

Hastings, R.P., Daley, D., Burns, C., et al. (2006). Maternal stress and expressed emotion: cross sectional and longitudinal relationships with behavioural problems of children with intellectual disabilities. *Journal of Mental Retardation, 111*: 40-50.

Hauser-Cram, P., Warfield M. E., Shonkoff J. P., & Krauss, M. W. (2001). Children with disabilities. Monographs of the Society of Research in Child Development *66*, 266, 1-100.

Hayes, N. (2000). Doing psychological research: gathering and analysing data. Buckingham, Open University Press.

Hayden, M. F., & Heller, T. (1997). Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation, 35* (5), 364 - 372.

Hearne, M,. & Dunne J. (1992). *Home Sharing: An Evaluation of Family based Respite Care.* Jay Lee Printers, Galaway.

Hendriks, A. H. C, DeMoor, J. M. H., Oud, J. H. L., & Savelberg, M. H. W. (2000). Perceived changes in well-being of parents with a child in a therapeutic toddler class. *Research in Developmental Disabilities, 21*, 400-450.

Hill, C. E., Thompson, B. J., & Williams, E. N. (1992). A goal to conducting consensual qualitative research. *The Counselling Psychologist*, *25*, 500- 560.

Hirst, M. (2004). Hearts and Minds: The Health Effects of Caring. Research summary. Carers Scotland.

Hoare, P., Harris, M., Jackson, P., & Kerely, S. (1998). A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research 42*, 200-224.

Hollingsworth, J. (1992). Service needs for children with disabilities and their families. *Journal of Paediatric Child Health*, *28*, 280- 286.

Holloway, F. (1990). Caring for People: a critical review of British Government policy for the community care of the mentally ill. *Psychiatric Bulletin* , 641 - 645.

Hutchinson, P., & McGill, J. (1992). Leisure, integration and community. Concord, Ontario: Leisurability Publications.

Hsieh, H.F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. Qualitative health research, *15* (9), 1200-1240.

Innocenti, M. S., Huh, K., & Boyce, G. C. (2002). Families of children with disabilities: normative data and other considerations on parenting stress. Topics in Early Childhood Special Education, *12*, 400-427.

Janssen, C.G.C., Schuengel, C., & Stolk, J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: A stressful attachment model. *Journal of Intellectual Disability Research*, *46*, 440-450.

Johnston, C., & Mash, E.J. (2001). Families of children with attention deficit hyperactivity disorder: Review and recommendations for future research. Clinical Child and Family Psychology Review, *4* (3), 180-200.

Johnston, C., Hessl, D., Blasey, C., Eliez, S., Erba, H., Dyer-Friedman, J., et al. (2003). Factors associated with parenting stress in mothers of children with fragile X syndrome.

Joyce, K., Singer, M., & Isralowitz, R. (1983). Impact of respite care on parent's perceptions of quality of life. *Mental Retardation*, *21*, 150-153.

Judd, D. (1994). Give sorrow words – working with a dying child. 2nd edition. Whurr Publishers: London.

Karp, N., & Bradley, V. (1991). Family support. *Children Today, 20,* (2), 20 -30.

Kelleher, J. (2001). Family Based Respite - the experience for children and adults with learning disabilities in St Michael's House. *Irish Social Worker , 19*, 19 - 21.

Kelly, B., McColgan, M., & Scally, M. (2000). A chance to say: involving children who have learning disabilities in a pilot study on family support services. *Journal of Learning Disabilities*, *4*, 110-126.

Keller, D., & Honig, A. (2004). Maternal and paternal stress in families with school aged children with disabilities. *American Journal of Orthopsychiatry*, *74*, (3), 330-340.

Kirk, S. & Glendinning, C. (1998). Trends in community care and patient participation: implications for the role of informal carers and community nurses in the United Kingdom. *Journal of Advanced Nursing*, *28*, 370-379.

Knap, J. (2005). Raising a child with autism: The impact on the quality of marital relationships. Dissertation Abstracts International. *The Sciences and Engineering, 65*, 1.

Knight, B. G., Lutzky, S.M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: recommendations for future research. *Gerontologist, 33*, (2), 200- 220.

Knussen, C., & Sloper, P. (1992). Stress in families of children with disability: a review of risk and resistance factors. Journal of Mental Health, *1*, 240-256.

Kobe, F.H., Rojahn, J., L Schroeder, S. R. (1991). Predictors of urgency of out of home placement needs. *Mental Retardation, 29,* 230-328.

Krauss, M. W. (2003). Child-related and parenting stress: similarities and differences between mothers and fathers of children with disabilities. British Journal on Mental Retardation, *97*, 390-400.

Lane, P., McKenna H. P., Ryan A., & Fleming, P. (2000). *Listening to the Voice of Carers:* An Exploration of the Health and Social Care Needs of Informed Carers of Older People. South Eastern Health Board, Kilkenny.

Lalvani, P. (2008). Mothers of children with Down Syndrome: Constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities, 46,* 430-440.

Laverty, H., Reet, M. (2001). Planning care for children in respite settings. Kingsley, London.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behavioural problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disabilities, 50*, 100-180.

Lightbody, P., & Gilhooly, M. (1998). The continuing quest for predictors of breakdown of family care of elderly people with dementia. In Marshall, M., ed. *State of the Art in Dementia Care*. Centre for Policy on Ageing, London, *200*, 14.

Lindsay, M., Kohls, M., & Collins, J. (1993). *The Patchwork Quilt*: *A Study of Respite Care Services in Scotland*. Scottish Office, Edinburgh.

Llewellyn, G., Dunn, P., Fante, M., Turnball, L., & Grace, R. (1999). Family factors influencing out-of-home placement decisions. *Journal of Intellectual Disability Research, 43*, 218-230.

MacDonald, H., & Gallery, P. (2004). Different meanings of respite: a study of parents, nurses and social workers caring for children with complex needs. *Child: Care, Health and Development, 30*, 270 – 280.

Mahoney, G., O'Sullivan, P., & Robinson, C. (1992). The family environments of children with disabilities: Diverse but not so different. *Topics in Early Childhood Special Education*, *12*, 300 – 400.

Mansell, I., & Wilson, C. (2009). Current perceptions of respite care: experiences of family and informal carers of people with a learning disability. *Journal of Intellectual Disabilities*, *13* (4), 255 - 267.

Marchant, R., & Page, M. (1993). Bridging the Gap: Child Protection Work with Children with Multiple Disabilities. London: NSPCC.

Martin, C. A., & Colbert, K. K., (1997). Parenting children with special needs. *In Parenting: A life span perspective* (pp 250-270) New York: McGraw Hill.

McConkey, R., & Adams, L. (2000). Matching short break services for children with learning disabilities to family needs and preferences. *Child: Care, Health and Development*, *26* (5), 429 - 444.

McConkey, R., Truesdale, M. & Conliffe, C. (2004). The features of short break residential services valued by families who have children with multiple disabilities. *Journal of Social Work*, *4*, 60-70.

McConkey, R. (2008). Developing services for children and young people with complex physical healthcare needs: Proposals for the development of short breaks provision. Report for the Department of Health, Social Services and Public Safety. Institute of Nursing, University of Ulster, Ulster.

McGill, P. (1996). Summer holiday respite provision for the families of children and young people with learning disabilities. *Child: Care, Health & Development*, *22* (3), 203 - 212.

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers and young people with developmental disabilities and challenging behaviours. *Child: Care, Health and Development*, *32*, 150-160.

McGrath, P (2006). Psycho-social issues in Childhood Autism Rehabilitation: A Review. International Journal of Psychosocial Rehabilitation, *11*, (1), 28-36.

McGrother, C. W., Hauck, A., & Bhaumik, S. (1996). Community care for adults with learning disability and their carers: Needs and outcomes from the Leicestershire register. *Journal of Intellectual Disability Research*, *40,* (2), 183 - 190.

McNally, S., Ben-Shlomo, Y., & Newman, S. (1999). The effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation*, 21, (1), 1 - 14.

McCubbin, H. I., & Figley, C.R. (1983). *Stress and the family*: Volume1: Coping with normative transitions. New York: Brunner Mazel.

McCubbin, H. L., McCubbiin, M. A., Thompson, A. I., & Thompson, E. A. (1995). Resiliency in ethnic minority families: Native and immigrant families (pp. 3-40). Madison, WI: Centre for Excellence in family studies.

Mencap, (2003). Breaking point: Report on caring without a Break for Children and Adults with Severe and Profound Learning Disability. London: Mencap.

Mencap, (2006). Breaking point: Families Still Need a Break. Report on the Continuing Problem of Caring without a Break for Children and Adults with Severe and Profound Learning Disability. London: Mencap.

Minkes, J. (1994). Consulting the children: interviews with children using residential respite care services. *Disability and Society*, *9*, 1, 40-54.

Mitchell, W., & Sloper, P. (2001). Quality in services for disabled children and their families what can theory, policy and research on children's and parents views tell us? *Children and Society*, *15*, 235-251.

Mores, D., Koegel, R. L., Schreibman, L., & Loos, L. M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological reports, 71*, 1111-1130.

Mog, B. (1998). *Disabled children: Directions for their future.* London: Department of Health.

Morgan, J., Robinson, D., & Aldridge, J. (2002). Parenting stress and externalizing child behaviour. *Child and Family Social Work*, *7*, 200-221.

Mullins, L.L., Aniol, K., & Boyd, M.L. (2002). The influence of respite care on psychological distress in parents of children with developmental disabilities: A longitudinal Study. Children's services: social policy, research and practice, *5*, (2), 120-130.

Mulsow, M., Caldera, Y. M., Pursley, M., Reifman, A., & Huston, A. C. (2002). Multilevel factors influencing maternal stress during the first three years. Journal of Marriage and Family, *64*, 900-950.

National Service Framework for Children, Young People and Maternity Services: Standard 8. (2004). Department of Health.

National Service Framework for Children, Young People and Maternity Services: Children and Young People who are ill (2007), Department of Health and Department for Education and Skills.

Neff, J. M. (2009). Respite Care: An Essential Yet Unmet Need for Families With Children With Special Health Care Needs . *Archives of Pediatric and Adolescent Medicine* , *1,* 89 - 90.

Nelson, A.M. (2002). A metasynthesis: mothering other-than-normal children. Qualitative Health Research *12*, 500- 520.

Neufeld, S. M., Query, B., & Drummond, J. E. (2001). Respite care users who have children with chronic conditions: Are they getting a break? *Journal of Paediatric Nursing ,* 16, (4), 234 - 244.

Nirje, B. (1976). The normalisation principle implications and comments. *Journal of Mental Subnormality*, *16*, 60- 67.

Nunkoosing, K. (2005). The problems with interviews. Qualitative Health Research, *15*, 600-701.

Olsen, R., & Maslin-Prothero, P. (2001). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation. *Journal of Advanced Nursing ,* *34* (5), 603 - 610.

Olson, D. H. (2000). Circumplex Model of Marital and Family Systems. *Journal of Family Therapy*, *22*, 140-150.

Ong, L., Chandran, V., & Peng, R. (1999). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation. *Journal of Advanced Nursing, 34,* 603-608.

Opdemakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research.

Orr, R. R., Cameron, S. J., Dobson, L. A., & Day, D. M. (2003). Age-related changes in stress experienced by families with a child who has developmental delays. Mental Retardation, *31*, 171-6.

Orsmond, G. I. (2005). Assessing interpersonal and family distress and threats to confident parenting in the context of early intervention. In: the Development Systems Approach to Early Intervention (ed. M. J Guralnick) 185-213. Brookes, Baltimore, MD Oxford.

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parental stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 38,* 1000-1100.

Parliament of the United Kingdom. (1990). *The NHS and Community Care Act.* London: The Stationery Office.

Parliament, (1995). *Disability Discrimination Act.* London: HMSO.

Parliament of the United Kingdom, (1995). *The Carers (Recognition and Services) Act .* London: The Stationery Office.

Patterson, J. M., & Leonard, B. J. (1994). Care giving and children. In Kahana, E., Biegel, D. E., & M. L. Wykle (Eds.). Family Care giving Across the Lifespan. Thousand Oaks, CA: Sage Publications.

Patton, M. Q. (2002). Qualitative research and evaluation methods. 3rd edition. Thousand Oaks, CA: Sage.

Pelchat, D., & Lefebvre, H. (2004). A Holistic intervention programme for families with a child with a disability. *Journal of Advanced Nursing, 48,* 120- 129.

Pementel, R. (1981). Tilting at Windmills. CA: Governors' Committee for the employment of disabled persons.

Platts, H., Hughes, J., Lenehan, C., Morris, S. & Flynn, M. (1995). We miss her when she goes away: respite services for children with learning difficulties and additional health needs. National Development Team, Manchester.

Phelps, J. L., Belsky, J., & Crinic, K. A. (1998). Earned security, daily stress and parenting: A comparison of the five alternative models. *Development and Psychopathology*, *10*, 20- 30.

Poehklmann, J., Clements, M., Abbeduto, L., & Farsad, V. (2005). Family experiences associated with a child's diagnosis of Fragile X or Down Syndrome: Evidence for disruption and resilience. Mental Retardation, *43*, 200-260.

Pollock, N., Law, M., King, S., & Rosenbaum, P. (2001). *Respite Services: A Critical Review of the Literature*. Retrieved March 9, 2010, from Can Child Centre for Disability Research: http://www.canchild.ca/en/canchildresources/respiteservices.asp

Prewett, B. (1999). Short-Term Break, Long-Term Benefit: Using family-based short breaks for disabled children and adults. *JUSSR/Community Care magazine* .

Radcliffe, J. J. L., & Turk, V. (2007). Distress in children with learning disabilities at a respite unit: perspectives on their experiences. British Journal of Learning Disabilities, *36*, 90-99.

Raina, PP., O' Donnel, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russel, D., et al. (2005). The health and well being of caregivers of children with cerebral palsy. *Paediatrics*, *115*, 600-610.

Risdall, D., Singer, G.H.S. (2004). Marital adjustment in parents of children with disabilities: a historical view and meta-analysis. Res Pract Persons Severe Disabilities, *29,* 90-100.

Roach, M. A., Orsmond, G. L., & Barratt, M. S. (2009). Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. British Journal on Mental Retardation, *100*, 422-436.

Robinson, C., Jackson, P. & Townsley, R. (2001) .Short breaks for families caring for a disabled child with complex health needs. *Child and Family Social Work*, *6*, 60 -76.

Robinson, C., & Stalker, K. (1993). Patterns of provision of respite care and the Children Act. British *Journal of Social Work 23*, 40- 60.

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, *10*, 60-80.

Saddler, A. L., Hillman, S. B., & Benjamins, D. (1993). The influence of disabling condition visibility on family functioning. *Journal of Paediatric Psychology*, *18*, 400-430.

Schalock, R. L., Luckasson, R. A., Shogren, K. A., Borthwick-Duffy, S., Bradley, V., Buntinx, W. H., et al. (2007). The renaming of mental retardation: understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities, 45,* (2), 100-109.

Seltzer, M.M., Greenberg, J.S., Floyd, F.J., et al. (2001). Life course impacts on parenting a child with a disability. *Am J Ment Retard, 106*, 260-270.

Shared Care Network (2008) breaking down the barriers: How short breaks are helping families of children with autism to be more like other families. Shared Care Network, Bristol.

Shared Care Network, (2010). *About short breaks: Be the big difference*. Retrieved March 9, 2010, from Shared care network: The short breaks charity: http://www.sharedcarenetwork.org.uk/content/-1860956361725

Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health and perceived expertise of assistance upon stress anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability, 22*, 10- 19.

Shaw, C., McNamara, R., Abrams, A., Cannings-John, R., Hood, K., Longo, M., Myles, S., O' Mahoney, S., Roe, B., & Williams, k. (2009). *Systemic Review of Respite Care in the Frail and Elderly*. Report for the Health Technology Assessment Programme. London.

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: the perspective of mothers of children with intellectual disabilities. *Journal of Applied Intellectual Disability*, *13*, 109.

Sines, D. (1999). Identifying the need for respite care for people with learning disabilities in Northern Ireland. J Learn Disabilities Nursing Health Social Care, *3*, 80 – 85.

Shin,J., Nhan, N. V., Crittenden, K. S., Flory, H. T. D. M., & Ladinsky, J. (2006). Parenting stress of mothers and fathers of young children with cognitive delays in Vietnam. *Journal of Intellectual Disability Research, 50*, 700-746.

Singer, L., & Farkas, K. J. (1989). The impact of infant disability on maternal perception of stress. Family Relations, *38*, 400-443.

Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities, Am J *Ment Retard, 111*, 150-160.

Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. Child: *Care, Health and Development, 18*, 250-270.

Smith, J. A., Flowers, P. & larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory Method and Research.* London: Sage.

Smith, J. A. & Osborne, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.) *Qualitative Psychology: A practical guide to research methods. London, Sage.*

Smith ,T. B., Oliver, M. N. L., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. American Journal of Orthopsychiatric Association, *71*, 250-260.

Smith, M. J., Caro, F. G., & McKaig, K. (1988). The role of home care service in family care developmentally disabled children: an exploratory study. *Home Health Care Services Quarterly*, *9*, 110-130.

Spratt, E., Saylor, C, & Macias, M. (2007). Assessing parenting stress in multiple samples of children with special needs. *Families, Systems, & Health, 25,* 400-420.

Snyder, B., & Keefe, K. (1985). The unmet needs of family caregivers for frail and disabled adults. *Social Work in Health Care , 10 ,* (3), 1 - 14.

Social Care Institute for Excellence. (2004). SCIE research briefing 5: Short breaks (respite care) for children with learning disabilities. Available online at http://www.scie.org.uk/publications/briefings/briefing05/index.asp [last accessed 25/03/2010]

Snowdon, A. W., Cameron, S., & Dunham, K. (1994). Relationships between stress, coping resources, and satisfaction with family functioning in families of children with disabilities. *Canadian Journal of Nursing Research*, *26*, (3), 60-70.

Spratt, E. G., & Macias, M. M. (2007). Assessing parenting stress in multiple samples of children with special needs (CSN). Preview. *Families, Systems & Health* 25, 400-449.

Stalker, K. (1990). *Share the care: an Evaluation of Family Based Respite Care Services*. Jessica Kingsley Publishers, London.

Stalker, K. (1992). An Overview of Short Term Care Services for People with Learning Difficulties. *Social Services Research , 41*, 25 - 30.

Stalker, K., & Robinson C. (1993). Parents views of different respite services. *Mental Handicap Research, 7*, 97 – 117.

Stalker, K. Robinson, C. (1994). Parents views of different respite services. *Mental Handicap Research, 7, 2, 90 -100.*

Stoneman, Z. (2007). Disability research methodology: current issues and future challenges. In S. L. Odom. R.H. Horner, M. E. Snell., & J. Blacher, (eds), *Handbook of Developmental Disabilities.* New York: Guildford Press.

Stores, R., Stores, G., Fellows, B., & Buckley, S. (1998). Daytime behaviour problems and maternal stress in children with Down's syndrome, their siblings and non-intellectually

disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research*, *42*, 220-230.

Strauss, A., & Corbin, J. (1994). Grounded Theory Methodology: an overview . In N. K. Denzin., & Y. S. Lincoln (eds.) Handbook of qualitative research (pp. 200-250). Thousand Oaks, CA: Sage.

Strohm, K. (2002). *Siblings*: Brothers and sisters of children with special needs. Kent Town SA: Wakefield Press.

Sturges, J.E., & Hanrahan, K.J. (2004). Comparing telephone and face to face qualitative interviewing: A research note. Qualitative Research, *4*, 100 – 110.

Sweet, L. (2002). Telephone interviewing: Is it compatible with interpretative phenomenological research? Contemporary Nurse, *12*, 50 – 60.

Swift, P., Grant, G., & McGrath, M. (1991). Parent's views of different respite care services. Mental Handicap Research, *7*, 90-117.

Taanila, A., & Jarvelin, M., & Kokkonen, J. (1999). Cohesion and parents social relations in families with a child with disablity or chronic illness. *International Journal of Rehabilitation Research*, *22*, 100-103.

Tarleton, B., & Macaulay, F. (2003). Better for break? Short break services for children and teenagers with autistic spectrum disorders and their families. York: Shared Care Network.

Thompson, D., Whitmarsh, J., Southern, L., Brewster, S., & Emira, M. (2009). Access the leisure activities: the perceptions of children and young people with Autistic Spectrum Disorder or ADHD and their parents/ carers. Centre for Development & Applied Research in Education, University of Wolverhampton, Wolverhampton.

Thompson, D. (1993). *Learning Disabilities: The Fundamental Facts*. Mental Health Foundation, London.

Thompson, A. (2002). Mothers perceptions of respite care. MSW Thesis. University of Manitoba.

Thorne, S. (2000). Data analysis in qualitative research. Evidenced based nursing, *3,* (3), 60 - 70.

Tomanik, J. Y., Washington, O.G.M. & Hawkins, J. (2004). The relationship between behaviour exhibited by children with autism and maternal stress. *Journal of Intellectual Developmental Disability, 29*, 10-20.

Treneman, M., Corkery, A., Dowdney, L., & Hammond, J. (1997). Respite care needs – met and unmet: assessment of needs for children with disability. *Developmental Medicine and Child Neurology, 39, 550 - 554.*

The Audit Commission. (1986). *Making a Reality of Community Care.* London: The Stationery Office.

Treneman, M., Corkery, A., Dowdney, L., & Hammond, J. (1997). Respite care needs – met and unmet: assessment of needs for children with disability. *Developmental Medicine and Child Neurology , 39,* (8), 548 - 553.

United Nations General Assembly. (1989). *Convention on the rights of the child*. Available online at http://www.cirp.org/library/ethics/UN-convention/

Valuing People: A New Strategy of Learning Disability for the 21 st Century, 2001 (White Paper), Department of Health.

Vash, C. L., (2001). Disability attitudes for all latitudes. Journal of Rehabilitation, *67*, (1), 30-40.

Watson, D., Townsley, R., & Abbott, D. (2002). Exploring multi-agency working in services to disabled children with complex healthcare needs and their families. *Journal of Clinical Nursing*, *11*, 360-376.

Webster-Stratton, C. (1989). The relationship of marital support, conflict and divorce to parent perceptions, behaviours and childhood conduct problems. *Journal of Marriage and the Family*, *56*, 900-904.

Weightman, G. (1999). A Real Break: A Guidebook for Good *Practice in the Provision of Short term Breaks as a Support for Care in the Community*: DOH, London.

WHO. (2001). International classification of functioning, disability and health. Geneva: WHO.

Wilkie, B., & Barr, O. (2008). The experiences of Parents of Children with and Intellectual Disability Who Use Respite Care Services, *Learning Disability Practice, 11,* (4), 29- 32.

Wikler, K (1981). Chronic stressors of families of mentally retarded children. Family Relations, 30, 281-288.

Witt, W.P., Riley, A.W., Coiro, M.J. (2003). Childhood functional status, family stressors, and psycho-social adjustment among school aged children with disabilities in the United States, *Arch Paediatric Adolescent Med, 157*, 679-690.

Wolfensburger, W. (1972). Normalisation: The principle of normalisation in human services. Toronto: National Institute on Mental Retardation.

Wolfensburger, W. (1983). Social role valorization: A proposed new term for the principle of normalisation. Mental Retardation, *21*, (6), 200-230.

Wolfensburger ,W. (1995). An "if this, then that" formulation of decisions related to social role valorization as a better way of interpreting it to people. Mental Retardation, *33*, (3), 159-169.

Wolfensburger, W. (2000). A brief overview of social role valorization. Mental Retardation, *38*,(2), 100-120.

Working Together to Safeguard Children 2006, Section 11.27: Abuse of disabled children. Department of Education and Skills.

Yantizi, N.M., Rosendberg, M.W., & NcKeever, P. (2007). Getting out of the house: challenges mothers face when their children have long-term special needs. *Health and Social Care in the Community, 15, 40 – 50.*

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*, 200-220.

York, L., & Bricknell, S. (2004). *Children with disabilities in Australia*. Canberra: Australian Institute of Health and Welfare.

Zealley, A. (1993). Mental retardation. In: *Companion to Psychiatric Studies*, 5th edn (eds R. Kendall & A. Zealley), pp. 617-47. Churchill Livingstone, Edinburgh.

<p style="text-align: center;">**Case Study**</p>

1.1 Introduction

Challenging behaviour may be a means of communication. Severely challenging behaviour refers to behaviour of such intensity, frequency and duration that the physical safety of others is compromised (Emerson et al., 1988). Review of the literature on challenging behaviour indicates how broad this topic is (Emerson et al., 1988; Qureshi 1994). Young people with developmental disabilities often have communicational difficulties and may display challenging behaviour as a way of communicating specific needs. Daniel was referred to clinical psychology for an assessment of his challenging behaviour with the view of offering behavioural strategies and support. Daniel is a 13 year old boy with a diagnosis of Fragile X syndrome and severe learning disability and autism (ICD - 10 criteria). Daniel lives with his mother and two brothers aged 18 and 21. Father left home shortly after Daniel was born. Daniel was referred by school staff to the local child and adolescent mental health services, because of his complex and challenging behaviour both at school and at home. Daniel is well below in educational achievements as well as having poor organizational skills. These concerns were persisting despite his having a full time classroom assistant. The clinical psychology team was asked to offer a psychological intervention to help Daniel with the difficulties identified in the core assessment and progress notes recorded on the NHS system of clinical notes. Functional assessment was considered the treatment choice in being able to provide a behavioural management support system, tailored to Daniel's specific and unique needs.

1.2 Presenting Problems

Daniel's mother raised concerns about her son's challenging behaviour at home, particularly when he lashes out without provocation. Daniel often hits his brother; and when in a rage will throw things around the house. Daniel has also become progressively more aggressive towards older males. The family are equally concerned about the aggressive behaviour that Daniel shows towards his peers. Daniel will often present as tearful and unhappy. Daniel has also been exhibiting marked obsessional behaviour and has serious difficulties in his social relationships. School report him having no friends and that he often antagonized his peers. A diagnosis of autism (ICD-10 criteria) was made on the basis that Daniel's longstanding and persisting multiple qualitative impairments in social functioning, language and communication, imagination and ritualistic/ obsessional tendencies. Daniel's mother reported that although the intensity of some of the behaviour has improved over time, his aggressive behaviour is still problematic, enduring, complex and interfering with their lives. Daniel's mother also is concerned that he swears, spits, and constantly provokes those around him. Furthermore, the school management team is also concerned about Daniel's head banging against furniture.

1.3 Goals for therapy

The main goals for therapy were to help reduce the challenging and complex behaviours and provide strategies to support Daniel at school and home.

1.4 Assessment of daily living skills

Daniel is relatively independent with using the toilet and is able to dress himself with adult support. Daniel requires assistance with having a bath and brushing his teeth. Daniel needs constant supervision, both inside and outside of the home environment. He has a lack of danger awareness, such as road safety and safety in the kitchen. Daniel will walk onto the road without being aware of traffic and has put his hands on hot stoves.

1.5 Social skills

Daniel has severe delays in his social and communication skills, he finds forming and maintaining relationships extremely challenging. Daniel does have a good attachment with his family members and shows empathy towards them. This is particularly evident by the relationship he has with his mother who he shows eagerness and excitement when she is around. Daniel is able to play with other children, with adult support and supervision.

1.6 Communicational skills

Daniel has severely disordered speech and language skills. He is however able to communicate his basic needs by using single words but lacks the motivation to communicate with others. Daniel is able to understand basic instructions at school and benefits from using visual aids and contextual cues. It appears that Daniel is not motivated to communicate, for example he tends to sit at the computer and wait for someone to turn it on rather than make a request for this. At home he will take his mother's hand and lead her to a desired activity. At home Daniel responds well to a visual timetable and uses the Picture Exchange System (PECS) in a competent manner. Daniel has limited comprehension and usually understands one instruction at a time.

1.7 Functional behavioural assessment

When a young person's behaviour has been identified as complex and challenging, it is essential that a rationale is first provided as to exactly why it is challenging. It is also important to consider the degree of intent that may lie behind the behaviour. Challenging behaviour in people with severe learning disabilities is not necessarily deliberate or planned. Challenging behaviour in young people with disabilities may also be in response to situations in need as some may simply be behaving automatically in ways which have been successful in the past. Despite developments in the research literature on functional assessment of aggressive behaviour, a large body of research is available of its application to clinical practice with young people with severe developmental disabilities. Based on LaVigna et al.'s (1989) organisational frame work, a package of non-aversive interventions was introduced. Functional analysis may provide some evidence of the causes of Daniel's behaviour. Neef and Peterson (2007) state that a functional behavioural assessment is designed to obtain information related to the specific function, or purpose that behaviour serves for a person. Functional assessment is the process of collecting information, using different procedures, in order to develop and test hypotheses about the function of behaviour. The method selected drew on methodology of functional analysis (La Vigna & Donellan, 1986). Kiernan (1973)

notes that when undertaking a functional analysis, the clinician should analyse the specific behaviour as influenced by certain events (antecedents) followed by consequential events. The antecedents and consequences must be empirically demonstrated. The task of functional analysis is to explore the function the particular behaviour serves as well as identifying the environmental reinforces which maintain it. A comprehensive functional assessment is a system that involves various stages of assessment. Although the literature frequently uses the terms functional behavioural assessment and functional analysis synonymously, the two psychological interventions describe different activities (Cone, 1997). The goal of functional assessment is to identify environmental variables that contribute to the occurrence of challenging behaviour, in such a way that their influence may be reduced or removed. Functional assessment is therefore the process of collecting information, implementing different procedures in order to develop test hypotheses about the specific function of behaviour. Cone (1997) outlines three phases of the functional assessment, which involves a descriptive phase, interpretative phase and verification phase. There are several components that should be covered in a comprehensive functional assessment interview. The information should be gathered related to all problem behaviours by the client and not isolated to the most challenging. An operational description of behaviours needs to include a topography, frequency, duration, severity and impact. Information related to Daniel's environment and daily schedule that may have influenced behaviour was gathered. Other events such as medication, physiological discomfort, sleeping cycles, eating routines and general day activities were included in this assessment.

1.8 Intervention – school

Despite a lack of abundant research that clearly supports the effectiveness of conducting functional analysis in school based settings, the literature provides evidence that this is encouraged (Kates-McElrath et al., 2007). The purpose was to observe Daniel's behaviour at school, see how he interacts with others in the classroom and to note how his teachers interact and support Daniel. One of the primary goals was to assess how Daniel responds to structure and predictability and what system of communication is in place at school. As discussed the past few months have been challenging as Daniel's behaviour at home has deteriorated with instances of aggression towards his family, shouting, swearing, and throwing objects. His behaviour at home over this time has remained in a state of change with his family generally continuing to implement well researched strategies agreed and discussed at child and adolescent mental health services. Daniels complex behaviour at home has caused significant problems. After several multidisciplinary meetings with the team, it was agreed that a school observation would help assess Daniel's responses to behavioural strategies within the class room environment.

Main Observations at school

Daniel demonstrated a willingness to learn in class, and to participate in the activities, with expert guidance and prompting from the experienced school teaching staff. Daniel looks for and responds to the attention he receives in class in a positive way. However if he does not

receive 'positive' attention he makes bids for 'negative' attention. This is not at all an unusual pattern, although the amount of attention Daniel needs in order to feel noticed appears to be higher than most of the other children in his class. However his drive to obtain social responsiveness might also be viewed as a 'magic key' to directing his efforts and his learning. The school observation suggested that when Daniel's remarks are responded to with eye contact and clear interest or appreciation, his motivation to cooperate with the task in hand increases significantly. Sometimes Daniel expresses affection towards staff and children in a physical manner that can evolve into behaviour that hurts others. Currently Daniel is not being given clearly differential responses to these behaviours that might enable him to monitor them better. It may be that staff have come to expect aggressive behaviour and, also, that there is uncertainty about where to draw the line regarding physical contact generally. However it is important that Daniel is taught to differentiate between physical behaviour that is 'friendly' and 'unfriendly', through initial discussion, clear guidelines, consistent sanctions for 'unfriendly' actions, and consistent positive reinforcement of 'friendly' actions. Some of Daniel's behaviour appears oppositional especially when given an instruction. During the class times, some of the staff ignored his opposition finding this a useful tactic. (During the observation Daniel returned to class of his own accord). Daniel can work with enthusiasm for 30 minutes but at the end of this period not have fully completed the task set.

Summary & Therapeutic input for school team

Daniel's difficult behaviours at school appear to be his search for attention. Several meetings were arranged with the school team to feedback on the clinical observations made for Daniel as well as offering the school practical suggestions. Clearly Daniel struggled with understanding boundaries and with self-organisation skills. A suggested plan for encouraging positive behaviours as well as anticipating and preventing more complex behaviours was introduced in conjunction with the functional analysis outcomes. The suggested plan for encouraging positive behaviours as well as anticipating and preventing complex behaviours was introduced to the school management team. It was recommended that instructions are presented slowly, less frequently, and only once eye contact has been made.

Some flexibility within the school system was discussed, taking into account for example the length of Daniel's sentences as compared to those of his classmates, to encourage a feeling of pride and maintain enthusiasm for learning, in place of finishing with an experience of producing poorer work in a rush to complete the allotted task. It was advised that motivation, cooperation and self-esteem can be developed through working for a specific reward. As the power of this reinforcement is considerably lessened when the chosen reward is unavailable, a 'free' choice that is limited to a few, previously agreed options is usually the best option. It is generally conceded that behavioural difficulties need to be seen and managed in context, that it is not constructive for behaviours that occur in one setting to be sanctioned in another setting. It is therefore important to implement strategies to help Daniel improve his behaviour at school at school, and not to involve his family except in terms of agreeing strategies employed at school and for the purpose of informing. The informing of parents should be done in as neutral a manner as possible

Asking for part-cooperation (e.g. put your hand up) and then praising Daniel's action and moving on, rather than asking for the expected sequence of actions (e.g. put hand up, ask for something, include "please") is more likely to secure future cooperation. It was observed that when Daniel is praised for a specific action rather than for being 'good', he is more likely to do more of that behaviour. Suggested plan for encouraging positive behaviours and anticipating, preventing and managing Daniel's more difficult behaviours were summarized as follows:

1. Approach new situations with the expectation of positive behaviour. Try not to anticipate for example that he might kick, or to suggest you might need to remove him from the situation at school.

2. Spend time clarifying with Daniel the difference between friendly and unfriendly touching.

3. Positive reinforcement of friendly gestures by showing approval and discouraging unfriendly behaviours.

4. Record a few manageable rules and hang up a chart where Daniel's attention can easily be drawn to it, (e.g. No hitting, no biting, no scratching, no kicking – i.e. no hurting). Explain that this is about helping him to learn how to be friendly, make better friends and for everyone to be pleased with him.

5. Clarify with Daniel the sanction to be imposed for breaking a rule on his chart. If the behaviour is very frequent it may be realistic to agree a certain number of mistakes in a certain period of time before the sanction is imposed, or you might decide that one particular type of behaviour should carry an immediate sanction. Each period of time should begin afresh, e.g. so that the afternoon session is not tarnished by the morning session. Gradually a fewer number of 'smudges' will carry the sanction.

6. Respond immediately to a breaking of a rule with a short "no" and reminder of the rule, unless the sanction needs to be imposed immediately. Do this consistently. Give no further attention, i.e. don't talk to him about what he did or ask him for an explanation.

7. Respond with eye contact and interest to whatever Daniel says, except for shouting and rudeness, which should be responded to by withdrawing eye contact.

8. Make great efforts to look for Daniel doing or saying something positive and remark positively and with a smile to him. Lots of this will eventually develop a self-concept of someone who cooperates and is appreciated for doing this.

9. Make eye contact prior to issuing an instruction.

10. Ensure Daniels experiences success in reducing his difficult behaviours by making the initial goals easily attainable and then moving gradually further (e.g. picking up *one* thing he has thrown, refraining from touching another child for *20 seconds* at circle time, putting his hand *half-way* up). Praise him with a smile and a specific phrase (e.g. "You put the green book back", "You kept your hands on your knees") for achieving these partial goals.

11. If you can anticipate a difficult situation, try to distract before it develops.

12. Make a 'Friendship Diary ': simple drawings and cartoon bubbles showing daily examples of other people being friendly to Daniel and he being friendly to them (e.g. sharing, saying positive things, waiting for a turn, saying sorry). Try to find at least one interaction a day to record.

13. Be mindful of the context of the behaviour, especially so that a 'bad' session does not spill over into a new and different situation.

14. Expect times when things don't go as planned and try to see these as blips on the way rather than signs of a downward spiral.

1.9 Functional Assessment

Problem Behaviour:

At the initial assessment, Daniel's mother identified two types of problem behaviours including aggressive behaviour and throwing objects around when distressed and angry. Tracey reported the aggressive behaviour is most problematic.

Aggressive behaviour:

Tracey described the aggressive behaviours as throwing things around at home, hitting, kicking, scratching and spitting. Daniel has been known to provoke his siblings. Daniel has difficulty sharing toys and can become distressed if others interrupt his play time. Daniel will stamp his feet in protest and can become very frustrated if things don't go as he had planned at home and school. When Daniel is very upset he will also stand in front of the TV so that no one else can see. Daniel has difficulty understanding the needs of others and struggles to communicate his needs at school. Daniel will use these behaviours when he is not allowed to watch TV. Daniel tends to become frustrated if he is hungry or bored. Tracey however said that it is often difficult to gauge when Daniel is hungry. Triggers can therefore include switching channels on any of the TV's in the home and switching the computer off. Other triggers occur if changes in the home environment are made such as things being moved, or if

siblings get additional attention at home. This behaviour occurs on Saturday mornings, often when Daniel has mistaken this for a week day.

Intensity:

Tracey reports that Daniel has caused injury to others and also to himself. Family rated these behaviours 8/10 on intensity. However, they indicated that the intensity of some of these behaviours is less severe when the family is present.

Duration:

Tracey reported that Daniel's challenging and aggressive behaviour occurs very quickly, and he will display the behaviour until he gets what he wants. When he is having a tantrum and throwing objects around the house the behaviour lasts about 10-15 minutes before he calms down or is taken through time out strategies.

Frequency:

Tracey reported that in a typical day, Daniel will display these behaviours at least 3 times. They are less prominent first thing in the morning and before he goes to sleep at night. They are also less likely to occur if Daniel has had a very active day at school or after he has had a meal.

Onset:

Daniel's mother reported that the aggressive and challenging behaviours began about 6 years ago, around the time of first contact with services, at the time of diagnosis there were no identifiable triggers the family were aware of.

Response to Behaviour:

Aggressive behaviour: At home when Daniel shows aggressive behaviour towards others, it's usually in response to something he wants to do and can't do at the time. Tracey responds by taking Daniel away from the situation and also by distraction. Daniel responds very well to his mother and will usually listen to her. Tracey will take Daniel out to the garden, which has proven to be an effective distraction technique. Daniel will either throw himself on the floor or stamp his feet on the floor, until he has calmed down. If he does not calm down after a few minutes, Tracey will use incentives such as telling Daniel he will be able to watch TV, or go into the garden if he calms down. Once he calms down he usually apologises by saying sorry or by crying.

Antecedent analysis:

General trigger factors to behaviour

Tracey reports that if Daniel is not feeling well, the aggressive and challenging behaviour is typically worse. It is possible that some of Daniel's additional needs and the fact that he is

approaching adolescence, may make him uncomfortable which may lead to an increase in problem behaviours.

Communication:

Daniel has limited verbal communication and has few single words. He is able to ask for a drink, or if he wants to go to the toilet. Tracey reports that Daniel is able to use sentence strips with PECS with up to 5 symbols and can ask for items like, biscuits and water. Daniel is able to initiate some social interaction and communication to get things he wants. Sometimes he pulls or leads to the supervising adult. He uses some signing including 'sorry' which he displays by hugging his mother and saying sorry. Daniel will also pat his mother and tell her he "loves her". The PECS system and other behavioural management strategies have been used very successfully and it was noted that Daniel responds much more positively to visual rather than verbal instructions. Daniel's communication has improved a lot over the last year and he is talking a lot more, and is able to make himself understood.

Antecedent analysis:

Specific trigger factors to behaviour

Daniel's days at school are predictable with routine and lots of structure. However during the weekends there is not as much structure in place and this is where a lot of the problems arise. Ms Daniel reports that Daniel will display challenging behaviour if there is a sudden change in routine without warning. He often gets up on a Saturday morning thinking that it is school time. Daniel also likes to have control of his home environment and will display aggressive behaviour towards both his family if he can't get his own way. Daniel's aggressive behaviour increases in the presence of his younger brother Ricky whom he frequently targets. He is also likely to display aggressive behaviour towards his family if he can't watch TV on his terms. He tends to become upset when his sibling engages in interactive play and is left out.

Consequence Analysis:

From the data collected from the interview with the family and school, clinical notes on RIO, overview of the core assessment and clinical observations within the LD mini team, it appears that Daniel's aggressive behaviour is multi-functional and that it is reinforced by different outcomes.

1. Daniel's aggressive behaviour sometimes allows him to access tangible items such as preferred activities going into the garden and watching TV.

2. Daniel has difficulty in waiting for things he wants. For example, when taking turns he will use aggressive behaviour to intimidate his siblings and gaining access more quickly.

3. Daniel's aggressive behaviour also appears to have the function of demand avoidance or escape from situations he dislikes and finds aversive e.g. siblings crying.

4. Daniel's behaviour is also an indicator that he prefers structure and routine, and he uses his aggressive outbursts to maintain his preferred routine in the home environment. For example, he will display aggressive behaviour if there are any sudden changes in the home, such as switching over the TV channel or changes to the predicted routines in place.

5. Daniel's aggressive behaviour also suggests that he prefers playing on his own rather than with others and will actively seek being on his own. This may make it difficult for Daniel to share toys or TV time. This may also account for him leaving the room when others are around, which is consistent with his interactions in the home environment.

6. There is also a strong likelihood that the aggressive behaviour may be an indicator of Daniel feeling unwell or fed up because his behaviour is reported to increase at these times.

1.10 Summary

Daniel has limited means of communication and it is likely that the aggressive behaviour has become an effective method of communication and allows him to have some control over activities he likes in his environment. I thought it would be important to refer Daniel for a follow up clinical psychology review in the future, should the levels of aggression remain unchanged. The main driving force behind Daniel's difficult behaviours at school and home appears to be his search for attention. Other components include difficulties with understanding boundaries and with organising himself and a desire for independence. Daniel has many very positive qualities including his social interest and his motivation to learn. A suggested plan for encouraging positive behaviours and anticipating, preventing and managing his more difficult behaviours has been formulated in the next section.

A behavioural approach in this intervention included the spell framework, structure, positive approaches, empathy and low arousal, linking this approach to the behaviour support plan (see below). The main focus was to try and increase communication patterns for Daniel. It appears that Daniel would benefit from the use of more advanced visual timetables, set up to help him maintain consistency across all environments. This visual timetable was seen as a useful way to reinforce agreed upon goals in conjunction with reminders. The implementation of an adapted rewards chart to help Daniel with the target behaviours was introduced in the latter part of this psychological intervention. The following behavioural support plan was suggested as a means of supporting Daniel at home and school:

1.11 Behavioural Support Plan

Understanding of behaviours	Attempt to attract attention or maintain attention
	Attempt to get a particular object/ activity / TV
	Attempt to escape from a situation
	Difficulty focussing and maintaining focus of attention on task at home

	Distractibility and impulsivity at home
	Difficulty calming down after becoming upset
	Difficulty coping with unexpected change
Description of behaviours	Refusing to comply with request
	Raises his voice occasionally
	Running around
	Running away
	Jumping up and down
	Throwing self on the floor
	Making verbal threats to siblings
	Banging or kicking furniture and equipment
	Throwing equipment
	Aggression towards other children (Hitting, kicking, pulling, sitting on, pushing, pulling hair)
	Aggression towards staff (hitting, kicking, biting)
Strengths	Appreciation of adult attention, interaction and praise
	Liking for other children
	Interest in learning
	Sense of humour
	Positive response to recent behavioural intervention at home
	Compassionate and kind & Caring
Target behaviours	Non-compliance with reasonable requests.
	Aggression towards siblings and adults.
Aims	For Daniel to cooperate in an improved way.
	For Daniel to reduce aggressive behaviour towards others.
	For Daniel to behave appropriately towards adults and

	children.
Strategies	1. The provision of frequent short periods of adult attention not contingent on difficult behaviour.
	2. Immediate attention for compliant and positive behaviour.
	3. Minimal attention for difficult behaviours, i.e. one short instruction and *no* quiet talking to, *no* face to face or body contact with adult.
	4. No other 'rewards' for challenging behaviours, i.e. No 'soft play', and he needs to complete *some aspect* of a task refused.
	5. Clear visual system to help with 'waiting' and 'turn-taking' – implemented in advance.
	6. The expectations of a particular situation being made explicit to him through clear and simple verbal instructions accompanied by a clear visual reinforcement.
	7. Easily attainable initial goals - very gradually extended and visually reinforced (as above). Immediate, visually reinforced acknowledgement for every step of the task. *(E.g. sticker and/or praise for each of the above periods successfully completed).*
	8. A jointly agreed reward for completion of task/meeting expectations.
	9. Provision of this reward on completion of whole task/meeting expectations. *(E.g. special 'treat' chosen once a certain number of stickers earned).*
	10. Preparation and visual reminders in advance of changes at school and home.
	11. Friendship diary with simple drawings and cartoon bubbles showing daily examples of friendly behaviours towards and from Daniel (e.g. sharing, giving compliments, waiting for turn). To be discussed at school network meeting.

1.12 Discussion

In the literature on functional assessment, aggression and challenging behaviour have emerged as the most commonly investigated topographical classes of behaviour. This functional analysis described in this case study led to the introduction of a package of interventions which were intended to improve behaviour both at school and home. Daniel's aggressive behaviours decreased and initially remained relatively low at home and school. There are several possible explanations for this positive outcome. For the most part Daniel's difficulties were understood from the detailed functional analysis assessment. The functional assessment understanding of the aggressive behaviour and the positive outcomes suggest that

the initial formulation was broadly correct. Since Daniel's aggressive behaviour was only evaluated before and after treatment, it is therefore not possible to be entirely sure that changes in his behaviour reflected the interventions as opposed to coincidental events. Arguably the assessment and treatment of Daniel was relatively straightforward. During this process it was possible to identify provisional meaning for some of Daniel's aggressive behaviour. Daniel also had additional problems with sensory and gross motor impairments, complex behavioural difficulties as well as a biological syndrome which accompanied his diagnosis of severe learning disabilities. Previous studies highlight the importance of functionally based interventions with young people with severe developmental disabilities across settings such as school and home.

Reflection

The intervention was reasonably successful; however it is important to bear in mind that functional assessment is an intervention and the recognition that challenging behaviour can occur for very complex reasons. For some young people the reasons of complex behaviours can remain unclear even after a thorough functional assessment. It is often assumed that because a young person has severe learning disabilities, they have cognitive deficits and therefore cannot benefit from other evidences based psychological interventions. This misconception is particularly the case concerning the implementation of relaxation and imagery based interventions for young people with severe developmental disabilities. It is important to recognise that young people regarded as profoundly impacted by their disabilities, with no speech and a limited understanding of what others are saying to them, clearly show skills at both the recognition of increased arousal and taking concrete steps to avoid loss of control. Daniel was clearly able to demonstrate these skills by walking away from certain situations at school and home and increasing his body movements. It is important to include self-control skills and recognize existing ones.

In my view young people with severe learning disabilities are able to able to learn relaxation exercises as well as imagery exercises. Unfortunately it was beyond the scope of this current psychological intervention to offer relaxation exercises; however it would be important to offer a follow - up intervention that would include this. Since Daniel's challenging behaviour was only evaluated before and after treatment, it is not possible to be sure that changes in behaviour reflected the interventions rather than other extraneous events. At the conclusion of the functional assessment process, one should have a clearer understanding of the variables that maintain behaviour. However I think that over time, Daniel may be able to learn to identify certain emotions which will help him with the challenges he faces. It appears that Daniel lacks the motivation to communicate in certain situations, despite having the ability to verbalise a number of single words, he will only use this as a very last resort. Daniel will revert to challenging behaviour before he will articulate or communicate what is wrong and those around him often do not understand. I think that this intervention could have provided a focussed approach exploring alternative methods of communication. In hindsight I think that Daniel may benefit from regular speech and language input at school level. I also think that a referral to music therapy would be beneficial for Daniel, to help improve and find new and improved ways to communicate his needs.

Concluding thoughts

The purpose of the clinical intervention was partly achieved and it has enabled Daniel to access the support he needs within the school environment. Young people with disabilities lack key resources and are often stigmatized and devalued. The actual quality of life is an important aspect of overall functioning within society. It appears that young people with severe developmental disabilities are more often than not identified and associated with having problematic behaviour. Indeed a problem for one person is not always a problem for another person. It is very important to consider the degree of intent that may lie behind the behaviour. Challenging behaviour is not necessarily deliberate or planned; some young people behave in certain ways that have been successful in the past. Not all young people with severe developmental disabilities display problematic behaviour as this stigma could add to the burden. Young people with severe developmental challenges need a lot of support and therefore their lives are under constant scrutiny. Young people are often observed, and a lot of what they do is written down and shared with others in the network. The more time one focuses on individual behaviour, the more problematic behaviour one is likely to observe. Professionalizing a set of observed behaviours we are implying that the assessment identifies and assumes the correct areas of change required.   Usually the assessment targets individual changes, however just because the assessment supports changes in the young person, it should not simply suggest that is the only cause of the identified problem. There are many other factors involved that should be included in the assessment, so that the young person is not labelled and categorized.

References

Cone, J.D. (1997). Issues in functional analysis in behavioural assessment. Behavioural Research and Therapy *35*, 250-260.

Emerson, E., Cummings, R., Barrett, S., Hughes, H., McCool, C. & Toogood, A (1988). Challenging behaviour and community services: Who are the people who challenge services? Mental Handicap, 16, 16-19.

Kates-McElrath, K., Agnew, M., Axelrod, S., & Bloh, C. L. (2007). Identification of behavioural function in public schools and a clarification of terms. Behavioural Interventions *22*, 40-50.

Kiernan, C. G. (1973). Functional Analysis. In Assessment for learning in the Mentally Handicapped, Mittler, P. (Ed.) London: Churchill Livingstone.

LaVigna, G. W. & Donnellan, A. M. (1986). Alternatives to Punishment: Solving behaviour problems with non-aversive strategies. New York: Irvington Publishers.

Murphy, G., Oliver, C., Corbett, J., Crayton, L., Hales, J., Head, D. & Hall, S. (1993). Epidemiology characteristics of people with severe self-injury and initial treatment outcome. Clevedon: BILD Publications.

Neef, N. A., & Peterson, S. M. (2007). Functional behavioural assessment. In J. O. Cooper, T. E. Heron & Heward (Eds.). Applied Behavioural Analysis (pp. 501-519). Columbus, Ohio: Pearson.

The need to include the client:

2.1 Introduction

This final component of the thesis examines the limitations of functional assessment as well as highlighting the importance of keeping the child included and involved in the therapeutic process. The aim of this review is to explore the current uses of functional assessment with young people who have developmental disabilities. This section will review the empirical literature examining applications of functional assessment. The effectiveness of functional assessment will be discussed along with the limitations of the research. The term 'challenging behaviour' has become distorted from its original meaning, and has come to be misused as a diagnostic label. The main focus is on clinical theory and the practice of psychology, highlighting specific models for the assessment and management of challenging behaviour using a functional assessment approach. Functional assessment is a process of defining specific events in the environment that are able to predict and maintain problem behaviours (O Neil et al 1997). Functional analysis systematically tests hypotheses by manipulating the specific events that are thought to be associated with problematic behaviour (Hanley, Iwata, & McCord, 2003). More often than not various attempts to define challenging behaviour for the purposes of research have shifted focus towards a diagnostic label. Clements (1997) described challenging behaviour as behaviour that is unacceptable by social standards, imposing or threatening to oneself or others. Emerson et al (1988) state that challenging behaviour refers behaviour that could place others in jeopardy or behaviour that limits specific access to community services.

This means that young people have the potential of being labelled and the behaviour often gets used in a general sense within the functional analysis process. A large number of people with developmental disabilities engage in various forms of complex often challenging

behaviour, which have been considered unsettling and disruptive (Sigafoos, Arthur, & O'
Reilly, 2003). Holden and Gitlesen (2006) state that the overall prevalence of challenging
behaviour is around fifteen percent among people with developmental disabilities. Published
accounts of functional assessment outcomes have enhanced the outcome validity (Asmus et
al., 2004; Iwata, Pace et al., 1994). Didden (2007) summarised the existing epidemiological
literature on people with developmental disabilities and found that they show evidence of
increased problem behaviour as compared to people without disabilities. Research in the
assessment of problematic behaviour clearly supports functional assessment that identifies
contingencies and reinforcements that maintain problematic behaviour (Carr et al., 2000).
The fundamental unifying principle is to improve the quality of life for people whose
behaviour challenges others. Effective change is based on understanding the reasons for
problematic behaviour. This section summarises the processes and findings of the literature
regarding functional assessment. This follows an extensive scrutiny of the broader literature
as well as including a meta-analysis of research on functional assessment. Critical features of
effective interventions are summarised as well as the professional developmental needs.

When a young person's behaviour has been identified as challenging it is important that a
clear rationale is formulated of the behaviour in question. Challenging behaviour is not
necessarily deliberate or planned. There is a multiplicity of biological, environmental and
psychological factors that often cannot be easily conceptualised within functional analysis.
Elsek and Greenhalgh (2001) argue that traditional approaches need to be replaced with more
dynamic, emergent and creative approaches to clinical care. Functional assessment has been
carried out across various environments with relative success (Hanley, Iwata, & McCord,
2003). Correlation studies confirm positive outcomes using a functional assessment approach
to complex behaviour (Scotti, Evans, & Meyer, 1991; Didden, Duker, & Korzillius, 1997;
Ager, O'May, 2001). It is common practice for functional assessment to be generalised to

other interventions. However the evidence supports the use of this approach with challenging behaviour however where possible the management of challenging and complex behaviour should also follow an aetiological rationale. In varied situations of need, some young people with developmental disabilities may behave in ways that are positively or negatively reinforced. When considering an alternative to problematic behaviour a goal may be to replace a current behaviour. Changing problematic behaviour appears to be most effective if the motivation behind the behaviour can be precisely determined. When the motivation is determined and the need that the young person is trying to fill is ascertained, a relevant behavioural strategy can be implemented. Although understanding complex behaviour in young people with developmental disabilities is still restricted, attention for the topic in both research and clinical practice is rapidly increasing (Lang, O'Reilly, Machalicek, Lancioni, Rispoli, & Chan, 2008). Although functional assessment is a well-researched and experimentally accurate way to complete behavioural assessments to identify variables that influence behaviour it is not always conclusive. Challenging behaviour and its management can be complicated when working with children with developmental disabilities. A functional assessment is one way of assessing the motivation behind problematic behaviour and is essentially the application of a scientific method of examining behaviour. The majority of research into the understanding of complex and challenging behaviour as primary method of behavioural assessment has generally taken a functional perspective (Hanley, Iwata & McCord, 2003). Experimental research on challenging and complex behaviour has usually focused on learning disabilities, with the aim of providing an assessment and treatment procedures.

Three broad categories are involved in functional assessment these include environmental, social and physiological factors (Gresham, McIntyre, Olson –Tinker, Dolstra, McLaughlin & Van, 2004). Gardner and Sovner (1994) note that environmental factors include the

interference of day to day routines or common actions. Social interaction could include factors such as too much or too little interaction, challenging interactions with others, medication changes, possibility of pain, or sleep deprivation. All of these factors are taken into consideration when preparing a detailed functional assessment (Gresham et al., 2004). It is important to note that the impact of the consequences of these factors has a strong associated link with increased problematic and challenging behaviour. Most studies report a mixed or complex pattern of findings. Kern, Hilt and Gresham (2004) found that functional analysis allows for the discovery of the function of the problematic behaviour however the process also requires descriptive analysis that provides information about naturally occurring events. A considerable body of evidence suggests that descriptive analysis may not be useful for the overall identification of behaviour function and can therefore be viewed as a criticism (Kern et al., 2004).

Information gathered should aim to establish the rate of recurrence of the behaviour, evaluate different hypothesis, predict when the behaviour will occur and define the overall purpose or function that the behaviour serves the young person. Information about the young person should be gathered from a variety of sources. These sources include self-reports, interviews with the carers and family and direct clinical observations. Closely aligned to this approach is the behavioural modification framework which is primarily based on the systematic analysis and application of reinforcement. Shaping is the procedure by which new responses are acquired and positive, active ones strengthened. The assessment of complex, challenging behaviour using a functional assessment approach can aid in the identification of alternative behaviours that will produce desirable consequences. Therefore the client is actively encouraged to use alternative behaviours in settings that would usually elicit difficult behaviour. Functional investigation outcomes may vary as a function of response effort.

A comprehensive well-planned functional assessment may provide useful insights into the causes of behaviour and which should, in theory, provide an objective, individually tailored support plan. However another criticism is that the process can make faulty assumptions about specific variables in different environments. Before conducting a functional assessment, it is crucial to have a clear concise definition of the problematic behaviour (Winborn, Wacker, Richman, Asmus & Geier, 2001). Additional factors that may be part of a detailed functional assessment include a young person's overall communication abilities and their individual approach to learning. The use of standardised assessment tools supports the accurate measurement of target behaviour. The information gathered should ultimately aim to provide and establish a baseline of behaviour thereby establishing the properties involved in challenging behaviour, as well as understanding the intensity and duration of behaviour. The aim should also be to develop and evaluate an alternative hypothesis relating to the overall function the behaviour serves within a given environment. Other objectives in this process include trying to define the meaning that this behaviour serves.

In summary, a functional assessment is a systematic and scientifically evidenced based approach of studying behaviour. Several criticisms have been raised which include making erroneous assumptions about the variables of influence across different environments. More specifically the study of behaviour in relation to where it happens, when it happens and what happens can often not be the only explanation to problematic behaviour. A well-designed assessment plan and functional assessment would identify the contextual factors that contribute to challenging behaviour. Functional assessment can be a constructive process that can increase understanding of complex behaviour. It follows that this may enable clinicians to make changes that could ultimately reduce challenging and complex behaviour. This approach could support the young person in finding alternatives to using challenging behaviour.

2.2 Functional assessment: its application and limitations

A well-designed functional assessment should identify the contextual factors that contribute to behaviour (Gresham et al., 2004). The purpose is used to understand the specific structure and function of challenging, complex and enduring behaviour in order to be able to provide alternatives. One of the major criticisms of functional analysis is that the assessment setting may influence the final results of functional analysis in some cases (Harding, Wacker, Berg, Barretto, & Ringdahl, 2005). An overall criticism of the studies reviewed is the lack of discussion of developmental issues when using functional analysis. A functional assessment provides qualitative and quantitative information on behaviour alongside detailed information on the antecedents and consequences of the behaviour in question. Newcomer and Lewis (2004) found that research on the assessment and treatment of challenging behaviour supports the use of functional analysis to identify contingencies of reinforcement that contribute to problematic behaviour. Critical reviews of functional assessment reveal that the process can be undifferentiated. Several reasons for this could be that the problematic behaviour is maintained by a source of reinforcement that was not included in the initial process. Furthermore during functional analysis the behaviour under investigation may have under the control of an outside event not linked to the assessment setting (Hanley, Iwata, & McChord, 2003). Tiger, Hanley and Bessette (2006) also found that the presence of particular stimuli may impact the results producing differentiated or undifferentiated outcomes. Several studies reveal that in some cases reinforces not included in the functional assessment process can maintain problem behaviour (McChord, Iwata, Galensky, Ellingson, & Thompson, 2001). Didden (2007) in their meta-analysis of empirical studies concluded that functional analysis made a positive contribution to treatment outcomes. Carr and Durand (1985) found that challenging behaviour invariably serves four main functions: these functions include gaining attention for the young person, enabling escape from certain demands, tangible reinforcement

and sensory stimulation. A comprehensive functional assessment provides the clinician with a guide to shape the therapeutic intervention. Based on this premise, if we understand challenging and complex behaviour as a reaction to the interaction between variables and the immediate environment, we can therefore apply this to help define the targets for intervention.

2.3 Functional assessment Questionnaires

O'Neill et al., (1997) initiate their work which begins with an in-depth interview that includes:

- The description of behaviours

- The description of ecological factors

- A clear definition of the antecedents or predictors of behaviour

- The identification of the consequences

- Defining the efficiency of the undesirable behaviour

- A detailed account of any functional alternatives the person may have in their daily repertoire of behaviours

- An assessment of overall communication skills

- What factors have worked for the person

- What factors have not worked for the person

- An assessment of the reinforcement factors

- Historical account of problematic behaviours

- The development of summary statements.

2.4 Functional assessment of problem behaviour

When a young person's behaviour has been identified as challenging, it is important that a rationale is first provided as to why the behaviour has been labelled in this way. It is equally important to consider the degree of intent that underlies the behaviour. A detailed functional assessment may provide certain answers about the causes of behaviour. A functional assessment interview is a type of clinical questioning that seeks to identify the function of the challenging behaviour. The aims of the functional assessment interview are to provide a wide-ranging account of the behaviour, the situation in which it occurs and the environmental variables responsible for its maintenance. The first step is to carefully observe and precisely describe the behaviour that the young person is exhibiting, including the events in the environment before and after the behaviour occurs.

2.5 Application and Outcomes

Functional assessment has been applied to a wide range of problematic behaviours (Iwata, Pace, Dorsey, Zarcone, Vollmer, & Smith, 1994), and has been used effectively with a broad range of problem behaviours including attention from others, access to tangible items and challenging complex behaviour. In part, functional assessment methodology focuses on the identification of specific variables that influence the occurrence of problem behaviour. Outcomes of functional assessment identified that challenging behaviour appears to be maintained by identifiable reinforcement contingencies (Asmus, Ringdahl, Sellers, Call, Andelman, & Wacker, 2004; Derby, Wacker, Sasso, Steege, Northup, & Cigrand 2003; Iwata, Pace, et al, 1994). Newcomer and Lewis (2004) found that the treatment of problematic behaviour relies on the functional assessment to identify patterns of reinforcement that appear to maintain behaviour. Functional assessment involves ongoing clinical observations across different settings to help identify some of the triggers to behaviours, seeks to determine the motivation behind problematic behaviour and has several important benefits to clinical best practice. Herzinger and Campbell (2007) found that

treatments primarily based on functional analysis were more successful than other functional assessment methodologies.

2.6 Benefits of functional assessment and empirical support

Functional assessment has been applied to various population groups including young people and adults with developmental disabilities. This process has been conducted across various environmental settings (Hanley et al., 2003). Effective behavioural changes are based on the premise of understanding the reasons for complex behaviour. Some of the common features of the population groups where this intervention has been used tend to have impaired verbal repertoires. Functional assessment and its application have been applied to complex behaviour which includes self–injury (Iwata, Pace, Dorsey et al., 1994) and non-compliant behaviours (Wilder, Harris, Reagan & Rasey, 2007). However Carr et al (1999) contends that the success rates for complex and challenging behaviour interventions increased significantly when based on a functional assessment prior to treatment.

2.7 Limitations of functional assessment

Epidemiological studies have recognised that some forms of challenging behaviour have been under-represented in the functional analysis literature. Behaviours such as repetitive pestering, inappropriate sexual behaviour and running away are frequently occurring behaviours that have been seldom discussed in the functional analysis literature (Emerson et al., 2001; Hanley et al., 2003). It appears that young people who engage in certain behaviours are not referred for functional analysis. Effective behavioural change is based on understanding the reasons for complex and challenging behaviour. Functional assessment often relies heavily on labelling and classifying behavioural outcomes. According to O'Reilly (1996) functional assessment fails to identify maintaining contingencies because uncharacteristic behaviour is often sporadic in appearance.

2.8 Conclusions

This review has outlined a method of using functional assessment within psychology, and has pointed out some of the principles that underpin the process of carrying out effective functional analysis. It is important to bear in mind that the criticism around informed consent and confidentiality to all assessment procedures and are not unique to functional assessment. Common themes identified in the review include the benefits of this approach, empirical evidence and application to challenging behaviour. It seems clear that positive interventions implemented in a variety of environments now direct the literature. The most appropriate outcomes seem to occur when interventions are not driven by medication, the use of restraints or intrusiveness. Functional assessment lends itself to a sensitive, socially responsible and ethical approach to helping young people overcome the challenges they face. Alongside functional analysis other interventions are recommended and increasingly common in the published literature. It is important to be attuned to changes in manifestations of worry and anxiety. Many young people with developmental disabilities often display specific cues, such as words, images and sounds in an attempt to signal their personal distress. They may have immense difficulties trying to express themselves and this may be reflected in their behaviour, such as refusal to participate in events, withdrawal or manifesting challenging and complex behaviour. A significant amount of research has been conducted about functional analysis and its application to young people with developmental disabilities. Most often, only the negative and adverse outcomes are reported in the literature. In the last two decades the UK government has recognized the importance of consulting young people with developmental disabilities about their views. The United Nations Convention on the rights of the child and the Children's act (1989) highlight the importance of taking into consideration the views of children. Young people with severe developmental disabilities and limited expressive language are able to communicate preferences if they are asked in the right way

by professionals who understand their needs and have the relevant skills to listen. It appears that the validity of information obtained from young people with developmental disabilities and their perceived competence has been one reason for failing to take their views into consideration. An important starting place would be an assumption that regardless of the level of developmental disability, all people have their own unique way of communicating. The overall responsibility would be on being able to discover appropriate ways to understand the needs of this client group.

2.9 Ethical considerations

Any form of psychological intervention should bear in mind the moral and ethical considerations (Lewis, 2002). Before embarking on a functional assessment, all efforts to gain consent from the young person should be attempted. A clear record of how the young person has been approached prior to the functional analysis process would ensure on-going clinical best practice. Lindsay (2000) states that research with young people with developmental disabilities poses the same ethical questions around consent to participation. In other words, is the child included meaningfully in the decision making process? Generally the voices of young people with developmental disabilities have been largely absent in the research literature to date. There appears to be a lack of provision for supporting participation in the process of undergoing functional assessments. The meagre scope of dissemination of this process has been heavily criticised. Fortunately there is growing recognition that young people's voices have not been adequately addressed and listened to in the literature concerning consent to undergoing functional assessments and interventions. New approaches are being developed which are characterised by a process of empowerment, inclusiveness and the encouragement of active participation. The identification of the most appropriate methods to gain consent by the young person should be sought, in an attempt to explain the process of functional assessment.

Functional assessment involves repeated observations and it is fundamental that informed consent should be sought at all levels from the young person being observed and parent or guardian. Consent to participate would be essential and ethical as being constantly watched and observed can be a stressful event. It therefore is important that sharing what functional analysis involves with the young person be pitched at the right level, such as by using signing, using symbol appropriate packages or the picture exchange system (PECS). In the process of gaining the young person's consent, those professionals directly involved with their care should be consulted and assist in interpreting how the young person feels about being observed in an often long drawn out functional assessment. In many ways functional analysis can be considered intrusive and there is a danger that those involved in the care of the young person will try and over- persuade the young person to consent to being observed across various settings. It is important to bear in mind that the process of functional assessment should involve getting to know the young person being observed and to be sensitive to the young person's views on being observed. Most people would not allow themselves to be observed as it can be certainly be an uncomfortable, embarrassing situation to be in, especially if a health care professional is looking at you and writing down things about you. It is equally important for the clinician to be able to interpret and ascertain if the young person is willing to be observed at school. Some young people do not wish the school to know that they are involved with a local child and adolescent mental health team, so why should it be different for those with developmental disabilities? Young people who are involved in the process of functional analysis may have no way of indicating that they actually do not like the process and they may change their mind. Some young people may become restless and disturbed as they sense they are being watched all the time. The young person who is being watched may feel a sense of intrusiveness in their life.

3 Informed Consent

When carrying out a functional assessment, it is important to identify the most appropriate method of informing the young person of the process of functional analysis. Most people would be reluctant to agree to be watched for hours on end by a professional they do not even know and therefore the issue of informed consent is often overlooked. The reasons for this oversight could be the automatic assumption that a functional analysis is a positive intervention and consent is not necessarily that important. The young person has a right to know what is involved in the process of functional analysis, regardless of their level of disabilities. The process could be explained in a way that is communicated either by word, signing or the implementation of the picture exchange communication system. One way to help in gaining informed consent is to ask those involved with the young person's care how best they communicate. Assistance in understanding how the young person feels about undergoing a functional assessment would be crucial in this process.

3.1 Confidentiality

Data protection issues apply equally to young people with all levels of developmental disabilities. The young person undergoing a functional analysis should be guaranteed that the process will remain confidential to the clinic and associated professionals involved with their care. Professionals deciding on treatment are guided by both the requirements of the law and professional practice guidelines. Effective work must focus on the young person's needs and individual circumstances. Bartlett and Bunning (1997) highlight the importance of communication as a partnership process between clinician and client. It is imperative for professionals working with young people who are often not socially valued to be aware of the importance of working in a confidential way.

3.2 Empowerment

In carrying out a functional assessment intervention, the professional should take into consideration the inequalities that are evident in the process. Bearing in mind that lots of young people with developmental disabilities often feel that they are being 'controlled' by others, every effort should be made to make this process as helpful as possible. An encouraging and supportive style could be adopted, as it is certainly disempowering for anyone to have someone observe you for long periods of time. A positive strategy to help in empowering young people during a functional assessment is to provide feedback on the observations made to both carers and child. Invariably assumptions are made that the child is not able to understand and therefore not provided with direct feedback. One way of involving young people in this process is to creatively involve them in the process in ways that are empowering and that convey a sense of positive ownership.

3.3 Resources to assist functional assessment

The consultation process can be a difficult and often complex task. Detheridge (2000) found that small scale interpretative approaches when consulting young people with disabilities appears to be of particular significance. A range of methods will be discussed in the next section that may contribute to equipping clinicians with the skills required in the process of consultation. According to Stalker (1998) it is imperative for the clinician to spend time with the young person and learn about their individual methods of communication. Brewster (2004) highlights the importance of spending time with the person, getting to know them and their individual and unique communication patterns. During the consultation process, it may be important to involve other professionals as well as parents to aid in interpreting the young person's responses.

Various problems can occur if assessments and consultations are carried out in front of the parents or professional staff. Some have vested interests in offering certain information in the

assessment process; therefore some young people may be inhibited in the presence of a professional. They may also feel pressure to conform in the consultation process and provide answers that they know their parents or professional staff want to hear. Nevertheless it is important that clinicians take note of the situation and be able to offer a consultation that considers these factors. Computer generated assisted interviews have been developed to facilitate communication for young people with developmental disabilities. Talking mats have been developed to help young people with overall communication difficulties. Young people are asked to place graphic symbols around a board. This process can include the young person's photograph to help make the communication as realistic as possible. The overall goal of talking mats is to smooth the progress of conversation as participants can read aloud the speed of exchanges (Germain, 2004). Other methods could include discussion and play or art-based activities. This could offer different approaches to listening to the views and experiences of young people with developmental disabilities. These approaches may also offer the young person the opportunity of taking part in the initial consultation process and have a say about how they feel about being observed.

3.4 Summary

Although the functional assessment process has proved remarkably successful, the clinician should be cognisant of the inequalities and power relations between the young person with disabilities and the process of functional analysis. This review section has outlined strategies for gathering views from young people with developmental disabilities. This process highlights the ethical concerns that essentially need to underpin a functional analysis assessment. Although there are many difficulties associated with research in this field, constructive and inclusive strides have been made. Providing a non-judgemental and inclusive fair assessment should be part and parcel of the process. Although research argues that young people with developmental disabilities are often socially dependent on people

around them, this could lead to situations where unwarranted levels of control are used without hearing the voice, or views for that matter, of the young person. A strong desire to protect the young person from stress is often used as the main reason for not allowing them to be involved in the decision-making process, for example offering functional analysis assessment with no consultation. Unfortunately another reason can be the underlying belief that the young person lacks the inherent capacity to understand and respond appropriately as to whether they wish to be observed and indeed undergo a functional analysis. However, this approach has been heavily criticised and regarded as disrespectful to the young person's independence.

In fact with the appropriate support and strategies suggested in this review the young person could make a meaningful contribution if asked in the right way as to whether they wish to participate in a treatment approach such as functional analysis. This process of inclusive participation would in fact empower young people and help others to move away from a mentality that is oppressive and controlling. Consulting young people with developmental disabilities should be based on effective evidenced-based communication strategies that serve to enhance the process of communication. Planning a functional analysis assessment should aim at minimising the possibility of embarrassing the young person being observed. Planning a functional assessment should aim at making this a helpful experience for the young person, therefore should include a well thought out consultation plan to gain the young person's consent. A significant number of young people with developmental disabilities are not accustomed to people asking them how they feel about issues and may ultimately accept as true that their views are not important. Some young people with severe developmental delays are familiar with other people taking over most of the control in their environment that they do not feel able to contribute to this process. The functional analysis literature does not appear to take into consideration ways to help young people with

disabilities feel more empowered and valued in the observation process, such as sharing some of the findings and including ideas mentioned in the previous section. This would ensure that the young person's views are listened to and enable a positive shift away from a passive to an active role within the process.

Young people presenting with challenging and complex behaviour often require a detailed speech and language assessment. It is essential to know what the young person understands from verbal communication. In most cases behaviour breaks down when the young person struggles to recognise the verbal messages others are trying to put across to them. Bearing this in mind, in order to enhance the functional assessment process it would seem sensible practice to include an assessment of the young person's comprehension and expressive abilities. Young people regarded as profoundly disabled are able to recognise what is being said to them. Trying to identify what the young person uses to initiate communication such as words, signs or behaviours may help in providing a comprehensive functional assessment.

Professionals starting the functional assessment process may have their own agenda in mind, holding preconceived ideas about what works for the young person being assessed. The young person may have a completely different agenda to the clinician assessing the problems. So it becomes increasingly more difficult to accurately reflect both agendas in the process. Functional investigations often fail to consider the young person's agenda for behaving in certain ways. From time to time the assessing clinician's agenda of what will work for the young person takes priority over the young person's agenda. Automatic assumptions about agendas should be thought about throughout the assessment process. Equally, tensions can develop between professionals and care givers over how a young person should be helped with complex and challenging behaviour. Professionals often have their own agenda and may also forget just how difficult it can be parenting a child with developmental disabilities.

Research could also explore the positive ways that families cope and include these positive aspects in the functional assessment intervention.

Finally the purpose of this review on functional assessment leads to two main implications. Firstly, given the traditional framework of functional assessment the process, in my view, requires more extensive exploration. There is a paucity of research into exploring positive ways of empowering young people in the process of functional assessment. It is important to understand the conditions that promote empowerment within the framework of functional analysis. It is imperative to re-evaluate the tools used in functional assessment and to question whether or not the child has agreed to be watched for hours on end by people they do not know. Research in this area is limited; there is a possibility to develop practical ways of helping gain consent from young people at any level of disability. Investigators could explore positive ways of encouraging young people to play an active role in the functional analysis process, instead of being told what to do. Though it cannot be disputed that having someone observe your every move is invasive especially without your consent, positive ways to improve functional analysis techniques could be explored in greater depth. This review highlights and explores some of the ways that functional assessment could be improved. I think it imperative to continually develop and maintain professional standards that improve clinical best practice. This will ensure that the application of psychological principals promote the development, well-being and effectiveness of young people with all levels of developmental disabilities. The latter part of this review attempts to generate positive perceptions and new ways of working with those young people with additional challenges.

References

Ager, A., & O'May, F. (2001). Issues in the definition and implementation of best practice for staff delivery of interventions for challenging behaviour. *Journal of Intellectual and Developmental Disability, 26,* 240-250.

Asmus, J. M., Ringdahl, J. E., Sellers, J. A., Call, N. A., Andelman, M. S., & Wacker, D. P. (2004). Use of a short term impatient model to evaluate aberrant behaviour: *Journal of Applied Behavioural Analysis*, *37*, 280-290.

Bartlett, C., & Bunning, K. (1997). The importance of communication partnerships: A study to investigate the communicative exchanges between staff and adults with learning disabilities. *British Journal of Disability Research, 25,* 180-149.

Brewster, S. (2004). Putting words into their mouths? Interviewing people with learning disabilities and little or no speech. *British Journal of Learning Disabilities, 32*, 4, 160-165.

Carr, E. G., & Durand, V. M. (1985). Reducing Behaviour Problems Through Functional Communication Training: *Journal of Applied Behavioural Analysis*, *18*, 90-120.

Carr, J. E., Coriaty, S., & Dozier, C. L. (2000). Current issues in the function based treatment of aberrant behaviour in individuals with developmental disabilities. In J. Austin & J. E. Carr (Eds.). Handbook of applied behavioural analysis, *10,* 90- 112.

Clements, J. (1997). Challenging needs and problematic behaviour. In J. O' Hara. &A. Sperlinger (eds.) Adults with learning disabilities: A practical approach for health professionals Chichester: John Wiley.

Derby, K. M., Wacker, D.P., Sasso, G., Steege, M., Northup, J., Cigrand, K., et al. (2003).

Brief functional assessment techniques to evaluate aberrant behaviour in an outpatient setting: A summary of 79 cases. *Journal of Applied Behaviour Analysis*, *25*, 713-715.

Didden, R. (2007). Functional analysis methodology in developmental disabilities. In P. Sturmey (Ed.), *Functional analysis in clinical treatment*. San Diego, CA: Elsevier Academic Press.

Didden, R., Duker, P.C., & Korzillius, H. (1997). Meta-analytical study on treatment effectiveness for problem behaviours with individuals who have mental retardation, *American Journal of Mental Retardation, 101*, 300-380.

Detheridge, T. (2000) Research involving children with severe learning difficulties. In Lewis, & Lindsey, G. (Eds) *Researching Children's Perspectives*. Buckingham: Open University Press.

Elsek, P.E., Greenhalgh, T. (2001). The challenge of complexity in health care. *British Medical Journal, 323*, 600-620.

Emerson, E., Cummings, R., Barrett, S., Hughes, H., McCool, C. & Toogood, A. (1998). Challenging behaviour and community services: Who are the people who challenge services? Mental Handicap, 16, 12-18.

Gardner, W. I., & Sovner, R. (1994). Self injurious behaviour: Diagnosis and treatment. Willow Stress, PA: Vida Publishing.

Germain, R. (2004). An exploratory study using cameras and talking mats to access the views of young people with learning disabilities on their out of school activities. *British Journal of Learning Disabilities*, *32*, 170-172.

Gresham, F., McIntyre, L.L., Olson-Tinker, H., Dolstra, L., McLaughlin, V., & Van, M. (2004).

Hanley, G. P., Iwata, B. A., & McChord, B. E. (2003). Functional analysis of problem behaviour: A Review. *Journal of Applied Behaviour Analysis*, *36*, 140 – 170.

Harding, J., Wacker, D.P., Berg, W. K., Barretto, A., & Ringdahl, J. (2005). Evaluation of relations between specific antecedent stimuli and self injury during functional analysis conditions. *American Journal of Mental Retardation*, *110*, 200-207.

Herzinger, C. V., & Cambell, J. M. (2007). Comparing functional assessment methodologies: A quantitative synthesis. *Journal of Autism and Developmental Disorder*, *37*, 1400-1440.

Holden, B., & Gitlesen, J. P. (2006). A total population study of challenging behaviour in the country of Hedmark, Norway: Prevalence, and risk markers. *Researchers in Developmental Disabilities*, *27*, 400-450.

Iwata, B. A., Pace, G. M., Dorsey, M. F., Zarcone, J. R., Vollmer, T. R., Smith, R. G., et al. (1994). The functions of self-injurious behaviour: An experimental epidemiological analysis. *Journal of Applied Behavioural Analysis*, *27*, 200-230.

Kern, L., Hilt, A. M., & Gresham, F. (2004). An evaluation of the functional behavioural assessment process used with students with or at risk for emotional and behavioural disorders. *Education and Treatment of Children*, *27*, 400-420.

Lang, R., O'Reilly., M., Machalicek, W., Lancioni, G., Rispoli, M., & Chan, J. M. (2008). A preliminary comparison of functional analysis results when conducted in contrived versus natural settings. *Journal of Applied Behaviour Analysis, 41,* 399-420.

Lewis, A. (2002). Accessing through research interviews, the views of children with difficulties of learning. *Support for learning*, *17*, 100-108.

Lindsay, G. (2000) Researching children's perspectives: ethical issues. In Lewis, A. & Lindsay, G. (Eds). Researching children's perspectives. Buckingham: Open University Press.

McChord, B. E., Iwata, B. A.,Galensky, T. L., Ellingson S. A., Thompson, R. J. Functional analysis and treatment of problem behaviour evoked by noise. *Journal of Applied Behaviour Analysis 2001, 34,* 400-450.

Newcomer, L. L., & Lewis, T. J. (2004). Functional behavioural assessment: An investigation of assessment and reliability and effectiveness of function based interventions. *Journal of Emotional and Behavioural Disorders*, *12*, 163-179.

O' Neill, R.E.,Horner, R.H., Albin, R. W., R. W., Sprague, J. R., Storey, K., & Newton, J. S. (1997). Functional assessment and program development for problem behaviour: A practical handbook. Pacific Grove, CA: Brooks/Cole Publishing Company.

Reese, R. M., Richman, D. M., Zarcone, J., & Zarcome, T. (2003). Individualizing functional assessment for children with autism: The contribution of preservative behaviour and sensory disturbances. *Focus on Autism and Other Developmental Disabilities*, *18*, 80-88.

Scotti, J. R., Evans, I. M., Meyer, L. H., (1991). A meta-analysis of intervention research with problem behaviour: Treatment validity and standards of practice. *American Journal of Mental Retardation, 96*, 00-260.

Sigafoos, J., Arthur, M., & O'Reilly, M. (2003). Challenging behaviour and developmental disability. London: Whurr.

Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry, 71*, 200- 240.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society*, *13*, 1, 4-10.

Sturmey, P. (1994). Assessing the functions of aberrant behaviours: A review of psychometric instruments. *Journal of Autism and Developmental Disorders*, *18*, 80 – 90.

Wilder, D. A., Harris, C., Reagan, R., & Rasey, A. (2007). Functional analysis and treatment of noncompliance by preschool children. *Journal of Applied Behavioural Analysis*, *40*, 170-173.

Winborn, L., Wacker, D. P., Richman, D. M., Asmus, J., & Geier, D. (2002). Assessment of mand selection for functional communicational training packages. *Journal of Applied Behaviour Analysis*, *35*, 290 - 299.