

**Bangor University**

## **DOCTOR OF PHILOSOPHY**

### **Parenting a child with intellectual and developmental disabilities : Psychological variabilities and their relationship to well-being**

Lloyd, Tracey Jane

*Award date:*  
2008

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Prifysgol Bangor  
Bangor University

**Parenting a child with intellectual and developmental disabilities:  
Psychological variables and their relationship to well-being.**

Tracey Jane Lloyd

Thesis submitted to the School of Psychology, Bangor University, in partial  
fulfilment for the degree of Doctor of Philosophy

November, 2008



## Acknowledgements

**This thesis is dedicated to the memory of my father, Harold Booth (1922 – 2002)  
and to Matthew Lloyd, my son.**

There are many people who deserve to be thanked for their input in this work. Space prevents me from naming them all. I would, however, like to thank Professor Richard Hastings, my friend and mentor for putting his faith in me and always knowing what I was capable of, especially when I didn't. Thanks also go to the entire team at the Intellectual and Developmental Disabilities Research Group past and present for their constant support and encouragement. The Acceptance and Commitment Therapy group in Bangor have provided me with invaluable emotional support and for this I am grateful. I would also like to acknowledge the staff and students at Bangor University for their support; in particular my thanks go to Sue Peet, Barbara Edwards and Michelle Martin for providing tea, cake and sympathy.

I would also like to thank the many other people in the field of ID who have given their time to talk through ideas with me and provide reassurance when it was needed.

Thanks also go to all the families who took part in the studies, to the mothers and fathers who talked with me and shared their lives with me.

Most of all I would like to thank Matthew Lloyd, my son. Everyday he inspires me a little more. Without him, this thesis would not have come to fruition.

Thank you.

Diolch.

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Preface

The Serenity Prayer

God grant me the serenity  
to accept the things I cannot change;  
courage to change the things I can;  
and wisdom to know the difference.

Living one day at a time;  
enjoying one moment at a time;  
accepting hardships as the pathway to peace;  
taking, as He did, this sinful world  
as it is, not as I would have it;  
trusting that He will make all things right  
if I surrender to His Will;  
that I may be reasonably happy in this life  
and supremely happy with Him  
forever in the next.  
Amen.

--*Reinhold Niebuhr*



## Summary

Recent research has begun to acknowledge that parents of school-aged children with intellectual and developmental disabilities experience both positive and negative impacts when raising their children. Since some parents report feelings of a positive and a negative nature concurrently, within families research must attempt to discover the psychological variables that foster adaptation. This thesis aimed to extend current research in three ways. First parental cognitive variables and their incorporation into existing models of adaptation were critically discussed (Chapter 2). Second, relatively unstudied psychological variables were investigated with respect to both positive and negative parental adjustment. Third, longitudinal methodologies were used to draw conclusions as to the causal directions of the relationships and to ascertain whether the psychological variables acted as moderators or mediators i.e. were state- or trait-like.

In Study 1 (Chapter 3) acceptance was a psychological variable that was found to be associated with maternal well-being. Mothers who were generally more accepting reported fewer psychological adjustment problems. Acceptance entered into a bi-directional relationship with anxiety and depression. No significant associations were found for mindfulness and maternal well-being. Parental locus of control was examined in Study 2 (Chapter 4) and was significantly associated with measures of both maternal positive perceptions and with maternal distress. Furthermore, dimensions of parental locus of control were significant predictors of negative maternal adjustment. Parental internal-external locus of control was related bi-directionally to stress over 18 months. Hope was the focus of Study 3 (Chapter 4) and was analysed separately for fathers and mothers. For mothers, hope was predictive of depression and positive affect and child behaviour problems predicted maternal depression. For fathers, hope was predictive of anxiety, depression and positive affect. An interaction effect was found for hope agency and pathways in the prediction of maternal depression such that mothers reporting high levels of both hope dimensions reported the lowest levels of depressive symptoms.

Findings from the three empirical studies were discussed in relation to their theoretical value and their implication in intervention research. Recommendations for further study were made, which included a call for further stringently defined study into an area that has the potential to be a valuable assessment tool for intervention work.

Chapter 1. Raising a Child with Intellectual Disabilities: An Introduction to Current Family Research.

The purpose of this thesis is to investigate cognitions in parents of children with intellectual disabilities and/or autism. Research shows that parents adjust differently to raising a child with special needs and cognitive variables may go some way to explaining why this might be. It is important to fully explore this area; if research can account for why some parents enjoy their children and report positive experiences of parenting, these data could potentially be valuable in helping those parents who do not adjust so well.

*An introduction to intellectual disability and autism*

Intellectual disability (ID) or, as it is still sometimes known, mental retardation, is classified under the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (fourth edition, text revision; DSM-IV-TR, 2000) as a disorder usually first diagnosed in infancy, childhood, or adolescence and thus, is distinct from autistic disorder, which is classified as a pervasive developmental disorder. Both ID and autism are studied under the umbrella term of intellectual and developmental disability.

To set the context for the data put forward in this thesis, it is necessary to present a brief overview of recent families research within the field. Therefore, this introduction will describe both ID and autism, before going on to describe and discuss research in the field. In particular, the focus will be on family research in ID and autism, with an emphasis on the experiences of parenting a school-aged child with ID and/or autism.

*Intellectual disability*

Intellectual disability is characterised by “significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.” (American Association on Intellectual and Developmental Disabilities, p.1). This medical definition of ID focuses on the description of deficits that must be present for a diagnosis of ID to be made. These deficits must manifest across the dimensions of both intellectual functioning (assessed through IQ testing) and adaptive ability (the mastery of everyday living skills) and be of early onset.

To be diagnosed as having ID, a person’s IQ must fall approximately two standard deviations below the population mean. In real terms, people with an IQ of between 50-55 and 70 are said to have mild impaired intellectual functioning, people with an IQ of between 35-40 and 50-55 have moderate impairment, those with an IQ of between 20-25 and 35-40 have severe impairment and those with an IQ below 20-25 are said to have profound impairment in intellectual functioning. Impairments must also be present in adaptive skill areas, such as social skills, communication skills, and day to day living activities, including self-care, health and safety, and work and leisure related impairments (Baroff & Olley, 1999).

*Autistic disorder*

Autistic disorder and Asperger’s syndrome are classified as pervasive developmental disorders (DSM-IV-TR, 2000). These disorders are often detected in the first few years of life and may (though not necessarily) be associated with ID. Autism is most often described as a triad of impairments (Wing & Gould, 1978). Diagnosis of autism is based on behavioural criteria; for a person to be diagnosed

with autism, they must have impairments in reciprocal social interaction and both verbal and non-verbal communication and also display restricted, repetitive and stereotyped behaviour and interests (Happé, 1994). Asperger's Syndrome is distinct from autism in that there is a lack of early language delay or early deviant language use (DSM-IV-TR).

### *Family research within the field of intellectual disability and autism*

Currently in the UK, approximately 1.5 million people have an intellectual disability and more than 29,000 people with an intellectual disability live with family carers over the age of 70 (Mencap, Important facts about learning disability). The National Autistic Society (NAS) state that there are no published studies to date that include the prevalence of autism, Asperger's syndrome and pervasive developmental disorder, but estimate that nearly 1 in 100 children in the UK fall on the autistic spectrum. There are no figures available for the prevalence of autism in adults (NAS Statistics, how many people have autistic spectrum disorders?).

The high prevalence of autism and ID in children in the UK has led to a great deal of research into how families adapt to the special needs of a child. In general, this research suggests that families of children with ID feel greater stress and psychological ill-health as compared with families of typically developing children (e.g. Baker, Blacher, Crnic, & Edelbrock, 2002; Duarte, Bordin, Yazigi, & Mooney, 2005; Dumas, Wolf, Fisman, & Culligan, 1991; Hodapp, Fidler, & Smith, 1998; Konstantareas, 1991; Sivberg, 2002). This research extends not only to parents, but includes sibling adjustment and well-being (e.g. Hastings 2003a; Orsmond & Seltzer, 2007; Stoneman, 2005) and studies investigating the role of grandparents within the family system (Hastings, Thomas & Delwiche, 2002; Hillman, 2007).

*Parenting research within the field of intellectual disability and autism*

Research into parenting a child/children with ID typically focuses on the impact the child has on the parent. For example, comparative research studies show that parents of children with ID report more stress, have more depression and more anxiety than parents of typically developing children (Baker et al., 2002; Baker et al., 2003; Beresford, 1996; Cahill & Glidden, 1996; Hastings, 2002b; Herring et al., 2006; Krauss, 1993; Olsson & Hwang, 2001). Furthermore, parental stress and psychological ill-health have been shown to remain stable over time (Baker et al., 2003; Lecavalier, Leone, & Wiltz, 2006). This factor implies that familial stress may be chronic in nature, and therefore, that this is a problem that must be addressed through psychological intervention.

In a meta-analysis of 18 studies of maternal depression conducted in the USA between 1984 and 2003, Singer (2006) found a moderate effect to confirm that mothers of children with developmental delay are at elevated risk of depression compared with mothers of typically developing children. Approximately 29% of the mothers of children with developmental delay reported depression within the clinical range, as opposed to approximately 19% of the mothers of typically developing children. Whilst it is clear from this study that a large percentage of mothers report depression and this is obviously of huge concern, there remains the fact that over 71% of the mothers of developmentally delayed children did not report depression. Research must attempt to account for this variance.

Indeed, in a longitudinal investigation into adoptive and birth mothers of children with ID, Glidden and Schoolcraft (2003) looked to see whether depression was stable over time or whether it fluctuated during different phases of the child's life. The authors found that whilst depression remained low over an 11 year period

for adoptive mothers of children with ID, this was not the case for birth mothers. The time of initial diagnosis was, for birth mothers, a time when they reported significantly more depression than adoptive mothers. Thereafter, at two further time points, birth mothers were not statistically different from adoptive mothers on measures of depression. Additionally, only 6.7% of adoptive mothers and 9.3% of birth mothers were over the clinical cut off for depression, though in both groups, levels of reported depression had increased from time 2 to time 3, thus indicating a trend towards mothers experiencing more depression as time progresses and their child ages.

In a review of the literature on parental adaptation to caring for a child with ID, Hassall and Rose (2005) state that the evidence for why parents report high levels of stress is unclear, with some studies reporting significantly more stress in families of children with ID and others reporting no differences. Furthermore, Hassall and Rose also show that stress appears to be related to many different factors and that not all families find the same things stressful.

Research has, therefore, attempted to account for the factors that might contribute to distress (anxiety, stress, depression) in parents of children with ID. Various factors have been posited to explain the fact that, whilst many parents do experience distress, the vast majority of parents do not report psychological upset. Among the factors thus far investigated are child diagnosis, child behaviour problems, parental race and culture, social support and parental poverty. We will briefly describe and discuss this research before presenting the rationale for the investigation of the topic of parental cognitions.

*Child variables and parental well-being*

Research has shown that parents of children with ID are affected differently by their children, depending on their child's diagnosis. For instance, Dyson (1993) conducted a longitudinal comparison study with parents of children with various diagnoses including developmental delay and ID. Results showed that at time 1, 39% of parental stress was accounted for by the child's diagnosis and at time 2, this had increased to 43% of the variance. In addition, Duarte et al. (2005) compared 31 mothers of children with autism with 31 mothers of typically developing children and found that maternal stress was predicted most strongly by being the mother of a child with autism. This finding that parents of children with autism report more stress than parents of typically developing children is one that has been replicated many times (Abbeduto et al., 2004; Dumas et al., 1991; Eisenhower, Baker, & Blacher, 2005; Konstantareas, 1991).

Autism is not the only diagnosis that has been the subject of investigation in comparison studies. The effect of a Down syndrome diagnosis on parental well-being has also been investigated. Compared with parents of typically developing children, parents of children with Down syndrome report more distress (Rodrigue, Morgan, & Geffken, 1992), though, in comparison with families of children with other intellectual disabilities, parents of children with Down syndrome report less stress (Kasari & Sigman, 1997). The findings are less straightforward than those for an autism diagnosis, since researchers have asked the question of whether sufficient matching of groups has taken place to allow valid conclusions to be drawn (Cahill & Glidden, 1996).

Research has also investigated child behaviour in relation to parental outcome. Hastings (2002b) proposed a model in which parenting stress, parenting behaviour,



parental negative reactions and child behaviour problems were related, with parental psychological resources acting as a buffer between the relationships.

Empirical research supports the notion that parents of children with ID are affected by child behaviour problems more than they are by the child's cognitive delay. Baker et al. (2002) investigated behaviour problems in 225 three year old children with and without developmental delay and found that for the parents of the children with developmental delay, child behaviour problems predicted stress over and above the child's cognitive delay.

In a more recent study, Herring et al. (2006) reported on the parents of 123 children aged between 20 and 51 months. Of this sample, 84 children were diagnosed with pervasive developmental disorder. The results of this study were similar to those of Baker et al. (2002) in that mothers, at the time of diagnosis and one year later, were more affected, as shown by measures of stress, by their child's emotional and behavioural problems than by their child's diagnosis or delay.

However, there still remains the question of why some parents are affected differently by their child than others. Though adaptive behaviour and behaviour problems are clearly candidates for associations with parental distress, the presence of a child with ID or autism is not sufficient to explain either parental distress, or indeed parental well-being.

### *Environmental variables and parental well-being*

There are many studies that look at parenting a child with ID by asking what environmental factors could interact to influence parental well-being. Of these, race and culture have received recent research attention. In an early study Flynt and Wood (1989) interviewed 90 mothers of children with moderate developmental delay in the

USA and found that there was a significant difference in maternal stress depending on the ethnicity of the family. Black mothers reported less stress than white mothers and the authors question whether this was because black mothers reported more familial social support than white mothers.

More recent research has supported these findings. In a population study looking at the impact of developmental disability on 505 families in the USA, Neely-Barnes and Marcenko (2004) found that different variables predicted impact on the family for white, African-American and Hispanic families. For white families, medical needs and receipt of therapy predicted negative family impact, whilst for African American families, only medical needs was a significant predictor. For Hispanic families however, there were five separate predictors of family impact; the child's care needs, special education provision, receipt of therapies outside of the school, and having a person other than the parent to co-ordinate services were significant positive predictors while less frequent participation in organised activities by the child was negatively associated with family impact.

Whilst clearly showing that there are racial/cultural differences in parental adjustment, there are many other environmental factors that could also account for these findings. Social support and poverty would both be candidate variables to account for variance in parental distress and have both been extensively researched within the parenting field.

Social support can come in the form of support from family, friends and clubs, churches, etc. (informal social support) or from professional sources (formal social support). Studies have shown that familial support in the form of spousal support (Sloper, Knussen, Turner & Cunningham, 1991) and support from grandparents (Hastings et al., 2002) is associated with lower levels of distress in parents of children

with ID. Support from formal sources has also been found to be helpful to parents (King, King, Rosenbaum, & Goffin, 1999), but there are also many studies that show that formal social support has increased parental stress (Quine & Pahl, 1991).

Several studies have tried to explicate these contrasting findings. In a study that looked at the amount and types of social support in 68 mothers of children with autism, Bromley, Hare, Davison and Emerson (2004) found that single parent mothers received less support compared with two parent families. Additionally, mothers of girls reported less informal support than mothers of boys and mothers in poor housing reported low social support. Less family support was also reported in mothers of children with a high rating for disruptive behaviour.

Bromley et al. (2004) also investigated the use of formal support and found that those mothers with younger children and children with more severe developmental delays had accessed more formal support in the last six months. Greater developmental delay was also associated with a greater number of appropriate formal supports accessed by the family.

White and Hastings (2004) used a range of measures to assess the types of social support, the availability of social support and the helpfulness of social support used by 33 parents of adolescents with ID. The authors then used these measures to explore the associations between social support and parental well-being and found that perceived helpfulness of informal social support, rather than the number of supports available, was related to improved parental well-being. Practical support (as opposed to emotional support) was also positively associated with parental well-being. However, formal social support was not associated with parental well-being, though the evidence suggests that formal social support may be related to the child's needs.

However, though detailed measures of social support were used to gain information in both of these studies, questions still remain unanswered. The data collected were cross-sectional only and relatively small sample sizes from the UK were used, limiting the generalisability of the data to other families. In particular, across both studies, only 5 of the participants were parenting children at or below the age of 5 years of age, and few families were living in poverty.

Poverty is another environmental factor that may affect parental well-being. In general, studies show that poverty causes ID and that parents of children with ID are more likely to live in poverty (Emerson, 2007). Recent research with children and adolescents with ID living in the UK shows that they are at an increased risk for health and mental health problems compared with typically developing children and that socioeconomic factors account for a large portion of this increased risk (Emerson & Hatton, 2007a; 2007b). This is likely to have an impact on the psychological well-being of the parents of these children.

Indeed, in an earlier study, Emerson (2003) reported on a sample of 9,726 British mother/child dyads (243 of whom were identified as having a child with ID) and showed that mothers of a child with ID were significantly more disadvantaged than families where the child did not have ID. Furthermore, socio-economic disadvantage was associated with poorer psychological health for mothers in both groups, however, having a child with ID marginally reduced the odds of maternal mental health problems.

In a further study by Emerson, Hatton, Llewellyn, Blacker and Graham (2006), the authors developed a model to predict self-efficacy, self-esteem and happiness in 6,954 mothers living in the UK (514 of the mothers had children with ID). Mothers of children with ID reported significantly less happiness, efficacy and

self-esteem than the mothers in the typically developing group, however, when socio-economic position was controlled for, maternal characteristics (age, health and marital status) and household composition fully accounted for the group differences for the happiness variable and accounted for over 50% of the increase in risk for poorer self-esteem and self-efficacy.

It seems then, from the evidence described above, that there are a myriad of factors that could potentially affect psychological well-being in parents of school aged children with ID and/or autism. Research needs to try to account for these factors within models of stress and adaptation in order to inform both further theoretical research and intervention research.

#### *Positive aspects of parental adjustment*

However, parental well-being is not merely a lack of distress. There now exists a core of research that shows that not all parents experience these elevated levels of psychopathology. Indeed, evidence shows that families also report positive aspects of raising their child with ID (Blacher & Baker, 2007; Hastings, Allen, McDermott & Still, 2002; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000; Taunt & Hastings, 2002).

In a review of research on families' positive perceptions of their child with ID, Hastings and Taunt (2002) concluded that whilst families of children with ID tend to report more stress than families of typically developing children, there is no evidence to suggest that these families are any less positive than families of typically developing children. Indeed, families can report both stress and positive aspects of raising their child simultaneously, suggesting that positive and negative factors may

be predicted by different factors and thus are different dimensions within psychological theory.

Blacher and Baker (2007) conducted two studies that looked at the perceived positive impact of children with ID. In their first study, Blacher and Baker asked 282 mothers of young adults with ID about their child's impact on the family and about their challenging behaviour. They also asked about maternal health and well-being. Blacher and Baker found main effects of mothers' positive perceptions of their child with ID on maternal health. Positive perceptions also moderated the relationship between parenting stress and the adult child's mental health. In their second study, Blacher and Baker's participants were mothers and fathers of 214 pre-school children (92 children formed the delay group and 122 children the non-delayed group). The authors found no differences across groups in levels of positive impact, showing that parents of children with and without ID appreciated the positive effect that their child had had on their lives. Additionally, no gender differences were found between mothers' and fathers' perceptions of positive impact.

In fact, research has shown that, not only do parents acknowledge the positive aspects that their child with ID can bring to the family, but some families actually thrive on raising a child with a disability (Scorgie & Sobsey, 2000). Taken alongside the studies of parental distress, the literature on positivity in families of children with ID shows that there is obviously huge variability in parental well-being that must be accounted for by research.

In order to try and answer the question of why some parents in similar situations seem to cope well and others do not, researchers have turned to the investigation of internal variables that may have an effect on parental well-being. Parental thoughts and beliefs are known as cognitive variables and may go some way

to explaining the differences in parental adaptation. Parental cognitions are implicated in many models of adaptation (e.g. McCubbin & Patterson, 1983, Lazarus & Folkman, 1984) and, as such, may be vital elements of the factors needed to create a complete picture of life for parents raising a child with ID. These cognitive variables have yet to be investigated fully, and thus, form the basis of this thesis.

### *Structure of the thesis*

This thesis follows the format of an introduction to the reasons behind the studies contained in this thesis, four research chapters and a discussion chapter. Each of the empirical chapters has been, or will be, submitted for publication and thus is written as a stand-alone piece of work. Chapter 2 is a literature review that describes and critically discusses the existing literature on parental cognitions in families of children with ID. This chapter calls for the refinement of the definitions used within the parental cognitions literature and for the application of these variables into existing models of adaptation. It is also noted that, in many cases, parental cognitions are not the main focus of research and due to their importance within adaptation models, more rigorous research is suggested. More research is also required on how parental cognitions can change during interventions to ensure that parent intervention programmes are empirically driven.

Chapter 3 was therefore designed to address these issues with the investigation of a promising cognitive variable - acceptance. Acceptance is an area gaining credence within psychology, but has yet to be researched thoroughly within the ID field. It is a stringently defined construct that has been used in intervention studies in various fields (e.g. Bond & Bunce, 2000; Dahl, Wilson, & Nilsson, 2004; Gifford et al., 2004). In Chapter 3, longitudinal data are reported and the results of the study are

very promising showing that acceptance is a cognitive variable that is implicated in maternal adaptation and, therefore, may be a good candidate for use in empirically derived intervention work.

Chapter 4 addresses parental locus of control, a cognitive variable that has, to date, received little direct research attention within the field of ID research, despite showing promise as a factor in parental adaptation within research with families of children with ADHD, sickle cell disease and congenital heart disease (Barakat, Lutz, Nicolaou, & Lash, 2005; DeMaso, Campis, Wypij, Bertram, & et al., 1991; Ostrander & Herman, 2006; Treacy, Tripp, & Baird, 2005). A longitudinal design was employed and correlational and regression analyses are reported. Findings showed that parental locus of control was associated with both maternal positive perceptions and with maternal distress and that overall parental internal-external locus of control entered into a bidirectional relationship with stress over an 18 month period.

Chapter 5 focuses on parental hope. Specifically, we look at why some parents cope well with parenting a child with ID and posit that hope may be a resilience variable explaining parental stress outcomes. This study looks at the well-being of both fathers and mothers and explores the differences and similarities in parental adaptation. The results of this study show that hope functions in different ways for fathers and mothers. In general, though, hope acted as a resilience factor for both parents.

Chapter 6 forms a discussion chapter that brings together the findings from the empirical research and makes recommendations for further research within the domain of parental cognitions. Implications for applied uses for the research are also discussed. The thesis ends with a call for more work in this area to be carried out, not



only with parents, but also with siblings and extended family members in order to fully describe and understand the true functioning of families of children with ID.

Chapter 2: Experiences of Parenting a Child with Intellectual Disabilities: A Review  
of the Literature on Parental Cognitions

### Abstract

Research within the field of intellectual disabilities (ID) is moving toward the exploration of models that account for both positive and negative impacts of parenting children with special needs. In order to do this, parental cognitions, or psychological variables, are being explored. This paper describes and discusses current literature on parental cognitions. The implications of the findings are discussed and recommendations for future research are made. In particular, we call for the development of clear definitions of cognitive variables and discuss the theoretical similarities between constructs. We also discuss the importance of applying the research to existing models of family adjustment with ID research. Finally, we review three papers that comprise the literature on intervention and parental cognitive variables and call for further research within this area.

Research has approached the topic of parenting a child/children with intellectual disability (ID) from various perspectives and with varying results. However, studies have typically focused on models that concentrate on putative stressors, such as child characteristics, especially behaviour problems (Hastings, Daley, Burns & Beck, 2006) familial socio-economic status (Brinker, Seifer, & Sameroff, 1994), social support (Bromley, Hare, Davison, & Emerson, 2004), child's age (Dyson, 1993), gender (Krauss, 1993) and diagnosis (Dumas, Wolf, Fisman, & Culligan, 1991). Both between and within families studies have been conducted. These studies generally show that parents of children with ID tend to show more psychopathology than parents of typically developing children (e.g. Baker, Blacher, Crnic, & Edelbrock, 2002; Blacher, Shapiro, Lopez & Fusco, 1997; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999) and that mothers report more adjustment problems than fathers (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

However, findings also show that parenting a child with ID can be a positive, life changing experience (Scorgie & Sobsey, 2000; Scorgie, Wilgosh & McDonald, 1999). Parents report that their lives have been changed for the better by their child with special needs and that they can recognize the positive contributions that the child has made to their family (Hastings et al, 2002; Hastings & Taunt, 2002; Stainton & Besser, 1998). Since it is apparent from the literature that, whilst some families cope well with parenting a child with ID, many families also suffer from clinical levels of psychopathology, we must now account for this variability within families.

Researchers must try to establish whether there are variables that account for individual variability and thus for differential outcome.

The purpose of this review is to summarise evidence relating to parental cognitions that may explain some of the variability in parental outcomes. By parental

cognitions, we mean psychological constructs relating to beliefs/thoughts that parents might experience. These include optimism, hope, self-efficacy, locus of control, sense of coherence, hardiness, acceptance, and mindfulness. One cognitive variable that is not included in this review is that of coping. This is partly a pragmatic decision – there are many studies including coping as a construct – and partly one driven by theories applied to understanding the adjustment of parents of children with disabilities. These theories include Lazarus and Folkman's (1984) Process Model of Stress and Coping, McCubbin and Patterson's (1983) Double ABCX model and Patterson's (1988) Family Adjustment and Adaptation Response model. Common to these theories is a recognition that parents' coping strategies will play a role in determining adjustment outcomes. Other parental cognitions feature less clearly in these models and there is a proliferation of them explored in the ID research field apparently with little reference to relevant theory or conceptual analysis.

Also not included in this review is the impact of social support on parental adjustment. We recognize that it is more typically *perceived* rather than objectively measured support that is associated with parental adjustment (Factor et al., 1990; Quittner, Glueckauf, & Jackson, 1990; White & Hastings, 2004). However, social support per se is not a parental cognition variable in the sense of representing thought processes or parental beliefs.

We carried out searches of databases using the terms locus of control, sense of coherence, competence, parenting efficacy, hardiness, hope, optimism, acceptance, mindfulness, mothers, fathers, parents, intellectual disability, developmental disability, mental retardation, and autism. We restricted our searches to studies published from 1990 onwards to ensure that recent research was the focus. Twenty one empirical (using quantitative or qualitative methods) studies were identified all of

which were focused on mothers, fathers, or either parent or children with ID. Only studies that reported relationships between parental cognitions and some measure of parental adjustment were included. Parental adjustment was defined very broadly (stress, mental health, life satisfaction etc.). First, we present a summary of the research findings as described in research studies on various parental cognitions. Second, we consider conceptual/theoretical issues and questions for future research. Third, we briefly discuss the practical implications of research findings on parental cognitions currently available.

### Parental cognitions of mothers and fathers of children with intellectual disabilities

#### *Sense of coherence*

Sense of coherence is a parental cognitive variable that is associated with the appraisal of stress and has only recently become the subject of investigation within the field of ID research. Sense of coherence was defined by Antonovsky (1987) as a mechanism comprising three components; comprehensibility, manageability, and meaningfulness. People are rated as being high or low on sense of coherence depending on the way they cope with stressors. Those with a high sense of coherence will classify a possible stressor as one that they can make sense of (comprehensibility), will view the circumstance as one with which they possess the resources to cope (manageability), and will appraise the situation as a challenge that they find worthy of investment of their resources (meaningfulness). Therefore, those with a high sense of coherence will feel less stressful effects from their environment than someone who has a low sense of coherence.

Of the five examples of research into sense of coherence that we could find, three were conducted in Sweden. Hedov and colleagues (2002; 2006) published two studies looking at the health of parents of children with Down syndrome in Sweden and sense of coherence was among the variables studied. Hedov, Annerén and Wikblad (2002) reported on 86 families of children with Down syndrome and 87 families of typically developing children and concluded that there were no significant differences in levels of sense of coherence in parents of children with Down syndrome when compared with parents of typically developing children. However, in both groups, parents with a high sense of coherence reported less stress than parents with a low sense of coherence. Hedov and colleagues also investigated possible gender differences in sense of coherence, but found no significant differences between levels of sense of coherence in mothers and fathers.

In another study with the same sample of parents, Hedov, Wikblad and Annerén (2006) again looked at sense of coherence, this time in relation to the number of days taken from employment due to parental sickness or sickness of a child. Hedov et al. concluded that parents of children with Down syndrome who took no sick days from their job between 1997 and 2001 reported a *higher* sense of coherence than parents who took sick leave. Conversely, they also report that parents from the control group (where the children were typically developing) who took no sick leave during the same time span reported their sense of coherence to be *lower* than those who had taken time off. This is an interesting finding since the implication is that sense of coherence as a cognitive variable works differently for parents of children with Down syndrome than for parents of typically developing children. However, the authors did not discuss the findings from the sense of coherence scale, nor did they make any suggestions as to why these results may have occurred. It is

also interesting to note that the authors excluded data from six families from the Down syndrome group. These six families accounted for over fifty percent of the sickness days taken from employment for this group and their inclusion in the study may have led to different findings.

Two main factors must be considered when interpreting the data from the two studies. First, the children of the families sampled were all aged below eight years and, second, the samples used were skewed, with the majority of the parents having a high level of education and being married. These factors make the generalisability of the studies questionable.

The third Swedish study into sense of coherence in parents of children with ID was conducted by Olsson and Hwang (2002). In a large-scale study of parents of children aged from newborn to 16 years, parents were grouped according to whether their child had an intellectual disability without autism (n=151), intellectual disability with autism (n=65) or were typically developing children (n=213). Mothers of children with ID and autism were found to have the lowest sense of coherence scores of the three groups, whilst mothers of typically developing children had the highest scores. There were no significant differences between the groups for fathers' sense of coherence scores. Mothers of children with ID had significantly lower sense of coherence scores than did fathers of children with ID. Sense of coherence was also related to depression such that mothers of children with ID who had low sense of coherence scores reported significantly higher levels of depression than mothers of typically developing children with low sense of coherence scores. In fact, no parent with depression scored within the high sense of coherence range and the authors pose the question of whether sense of coherence and depression are actually separable constructs.



Oelofsen and Richardson (2006) reported similar results in a between groups analysis of parents of pre-school children with ID (n=59 families) and parents of pre-school typically developing children (n=45). Significant group differences were found for mothers on health status, stress and sense of coherence measures (mothers in the ID group reported more stress and poorer health and weaker sense of coherence) and findings were similar for fathers (significant group differences for stress and sense of coherence). However, the authors also looked at within group differences and found that mothers of children with ID reported higher stress, poorer health and a weaker sense of coherence than their partners. This difference was not significant for the families of typically developing children.

In the most recent study of sense of coherence we could find, Mak, Ho and Law (2007) looked at whether sense of coherence would act as a moderator between autistic symptomatology and stress in 157 mothers of autistic children living in Hong Kong. The authors also investigated whether parental cognitions (child acceptance and parenting confidence) would mediate the putative effects of sense of coherence. Results showed that sense of coherence did moderate the effect of autism on maternal stress and post hoc analysis revealed that stress was higher when levels of autistic symptom severity were high and sense of coherence was low. A mediational effect of confidence in parenting ability and acceptance of the child was also found for the relationship between sense of coherence and stress, whereby mothers with a high sense of coherence showed more confidence in their parenting and more acceptance of their child, which, in turn, was related to a lower level of stress.

There are several caveats that should be borne in mind when considering these results. First the children in the sample ranged from infants to adults (age range 1.8 yrs to 28 yrs) and over 37% of them had normal intelligence i.e. formed a sample of

children with Asperger's syndrome. Over two thirds of the children were not receiving treatment for their autism. It would be interesting to see whether the results would be the same if the sample had been partialled into ID verses non-ID groups.

The studies discussed above all emphasize the fact that sense of coherence is related to parental well-being in families where a child has ID. Specifically, low sense of coherence has been shown to be related to increased stress and depression and this is in keeping with Antonovsky's salutogenic theory of health in which sense of coherence is viewed as a resilience resource when a person encounters a stressor (Eriksson & Lindstrom, 2006). People with higher sense of coherence are more resilient to the negative effects of stress and depression.

Further investigation into sense of coherence now needs to look more closely at within families designs to elucidate the construct of sense of coherence further in relation to ID. Longitudinal studies are also now required to show whether these relationships are uni- or bi-directional and to attempt to address the question of causality. Similarly, further work needs to be undertaken to discover the effects of gender on sense of coherence, as the results reported are somewhat conflicting and suggest that sense of coherence may be a construct that is different for mothers and fathers, depending on their child's diagnosis. Although sense of coherence is a unitary construct, it may be beneficial to analyse the data according to the three components that constitute sense of coherence in order to uncover why there may be gender differences and how these differences could affect parental mental health.

### *Parenting efficacy and parenting competence*

Parenting efficacy is a construct that lacks a clear definition. Current definitions of what comprises parenting efficacy include locus of control, parenting

competence, illusion of control and balance of control between the parent and their child (Lovejoy, Verda, & Hays, 1997). Therefore, for the purpose of this review, we have discussed relevant research on these topics as a group.

Self-efficacy refers to a person's perceptions of their ability to carry out a specific task (Bandura, 1977). Self-efficacy, therefore, varies across people and situations is thus domain-specific (Hastings & Brown, 2002a) and may go some way to explain why families cope well with stressors at one time point, while at others they do not cope as well. Parental efficacy refers to self-efficacy that is specific to the parenting role and thus is a parent's perception of how capable they feel themselves to be in their parenting role (Coleman & Karraker, 1998).

In a study looking at both parenting self-efficacy and parenting satisfaction (the two factors comprising parenting sense of competence), Wannamaker and Glenwick (1998) asked mothers and fathers of pre-school children with cerebral palsy how they felt about their parenting role and about their mental health. Parents were also asked how they felt about their child's problematic behaviours. For mothers, both depression and stress were negatively related to parenting satisfaction and stress was significantly associated with feelings of efficacy. Efficacy was also found to be the only significant predictor in a model predicting mothers' feelings about their child's behaviour, indicating that mothers who perceive their child to be maladjusted behaviourally feel less efficacious in their parenting role. For fathers the story was somewhat different, with the only associations being between high stress and low levels of parenting satisfaction and high levels of perceived child maladjustment. However, the sample size of fathers was small (N=22) thus no firm conclusions could be drawn due to lack of statistical power.

In a later study, Hastings and Brown (2002a) investigated parenting self-efficacy in parents of school aged children with autism. Both fathers and mothers completed self report measures of anxiety, depression and self efficacy, whilst the problem behaviours of the child with autism were rated by the child's teacher. Using hierarchical regression, Hastings and Brown tested for the putative moderator and mediator effects of self-efficacy on parental distress and found that for mothers, self-efficacy acted as a *mediator* of the relationship between child behaviour problems and anxiety and depression. Self-efficacy, however, did not act as a moderator between the variables for the mothers. For fathers, the reverse was true; self-efficacy had no mediational effect for child behaviour and paternal anxiety and depression, but a *moderation* effect was found where self-efficacy moderated the effect of child behaviour on anxiety.

The findings of both of these studies are important for two reasons; first, they highlight the fact that self-efficacy varies in its effects on parental distress and second, this research highlights the need to investigate mothers and fathers separately when considering the issue of psychological factors. However, replication of this research is needed as Hastings and Brown used an unstandardised scale of only five items to measure parent self-efficacy. A more robust measure is necessary to clarify the role of efficacy in relation to parental adjustment. Additionally, both Hastings and Brown (2002) and Wannamaker and Glenwick (1998) only investigated parental self-efficacy with respect to negative adjustment. More research is needed to discover what effects parental self-efficacy may have on parental positive perceptions.

Parenting competence is the extent to which a parent feels that they are proficient in raising their child and is closely related to parenting efficacy; so much so that Kuhn and Carter (2006) define parenting self-efficacy as feelings of parenting

competence. Kuhn and Carter asked what factors can promote parenting self-efficacy in mothers of children with an autistic spectrum diagnosis. Specifically, they hypothesised that relationships would exist between maternal self-efficacy and maternal guilt, agency (the extent to which a parent actively engages in her child's development), and knowledge of autism, since feelings of efficacy are reinforced by experiencing success in raising a child. They also explored the relationships between these processes and maternal mental health and found that maternal self-efficacy was negatively related to feelings of stress, depression and guilt and positively related to feelings of agency. Furthermore, regression analyses revealed that self-efficacy was predicted by maternal stress, agency and guilt as well as the presence of another child with a disability. Autism knowledge was not related to self-efficacy, but the authors posit that this was due to a ceiling effect caused by the relatively affluent socio-economic status of the sample.

This study, whilst interesting in that it sheds light upon the factors that may encourage self-efficacy in mothers of school aged children with autism, has methodological issues. The sample was affluent and, since most of the mothers filled in the questionnaires online, may be unrepresentative of many families. This is of particular concern since self-efficacy was predicted by maternal agency; the very fact that a mother takes part in a research study suggests agency. The measures of agency, guilt and autism knowledge were untested in previous studies and therefore require further use before firm claims as to their utility can be made. Replication of this study should be conducted using a much broader demographic sample, one that includes fathers and parents of children with other diagnoses. Reports of parental agency should also be gained from people other than close family members, for example, teachers and health care professionals to ensure that an accurate assessment is made.

Taken together these three studies highlight the need for further research within the area of parenting efficacy in ID research. Clear links have been found between parental maladjustment and lack of parenting efficacy but important questions remain unaddressed. Research must begin to consider whether there exists a role for parenting efficacy in the development of interventions for parents and to do this we need to ask whether those parents who adjust well to their child's disabilities are also those parents who are high in efficacy. Research needs to assess feelings of efficacy as potential resilience factors and to evaluate the positive as well as the more negative aspects of the process.

Feelings of parental competence have also been found to be related to parental stress. Using the sense of competence scale of the Parenting Stress Index (PSI: Abidin, 1986), Fisman and Wolf, (1991) showed that maternal dysphoria, feelings of poor health and lack of perceived competence in the parenting role were related to stress in mothers of children with autism, Down syndrome and typically developing children. Further, Hanson and Hanline (1990), also using the PSI, found that mothers of children with Down syndrome did not differ significantly on the measure of competence from mothers of children with neurological problems or from mothers of children with hearing problems over a three year period. Maternal stress, satisfaction with parenting and availability of social support were all negatively correlated with sense of competence at years one, two and three during the study and the trend was for the strength of these correlations to increase with time.

Also using the PSI measure of parenting competence, Roach, Orsmond and Barratt (1999) compared families of children under the age of five with Down syndrome with families of typically developing children under five, on measures of child- and parent-related stress and caregiving difficulties. Roach et al. found that

parents of children with Down syndrome reported more stress associated with perceived parenting competence than the parents of typically developing children. Furthermore, for both samples, maternal lack of parenting competence was predicted by more reported caregiving distress and more paternal stress. For fathers, lack of parenting competence was predicted by having a child with Down syndrome, by reports of less childcare given and by more maternal stress.

Rodrigue, Morgan and Geffken (1992) looked at fathers' parenting competence as part of a comprehensive questionnaire battery that was used to assess whether fathers and mothers adapt to their children with ID in the same way. Fathers were compared across 3 groups; fathers of children with Down syndrome, fathers of children with autism and fathers of typically developing children. There were no significant differences across the groups in fathers' perceived sense of competence, though there were group differences in perceived caretaker burden, with fathers of children with Down syndrome reporting more burden than fathers of typically developing children.

These studies describe the differences in parenting competence in groups of parents of children with different diagnoses. Whilst these findings are interesting in themselves, there is a need to look within groups to discover whether parenting competence is different for parents of children with the same diagnoses. In each of these studies, competence was investigated as part of a larger research aim and thus, merits further research as a variable in its own right. This research could include the study of mediating effects to reveal how competence has its effect on parental well-being and to further reveal any protective relationships there may be.



*Parental locus of control*

Locus of control is the term used to describe a person's view that events are controlled by either internal or external factors (Rotter, 1966). A person is said to have an internal locus of control if they believe that the cause of events lies within themselves and that outcomes are contingent on their behaviour. A person is said to have an external locus of control when they believe that events are caused by external forces, such as, other people's behaviours, luck, fate and chance. As locus of control is a product of expectancies based on past behaviours (Rotter, 1975), it is situation specific. With this in mind, a parenting-specific measure was designed by Campis, Lyman and Prentice-Dunn (1986). The Parental Locus of Control Scale (PLOC) assesses whether a parent feels that they have control over their child and his/her behaviour (internal parental locus of control) or whether the parent believes that their child's behaviour is due to factors outside their control and that are unrelated to the parenting the child receives.

Henderson and Vandenberg (1992) looked at locus of control in 49 mothers of children with autism. Using a measure of general locus of control, they found that family adjustment (defined as cohesion, familial expressiveness and lack of conflict) was predicted by the agency from which the families were recruited, the severity of the child's symptoms, the social support received and the mothers' locus of control. The authors assumed that this was because mothers with an internal locus of control would be likely to attempt to deal with the stressor and were less likely to feel helpless when parenting their child than would parents with an external locus of control. No initial correlations were provided between the variables, nor were the subscales of the family adjustment measure explored in relation to locus of control. These data could have been of interest since locus of control could be either directly



related to family adjustment or to social support and thus could act as a moderating variable within the relationship.

Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) explored the relationships between locus of control, coping styles and social support to see if they were related to parental outcomes in parents of school aged children with autism. Using correlational analyses, Dunn et al. found that locus of control (measured with a general scale) was significantly negatively related to parental depression. Parents who had a high level of external locus of control reported increased depression. However, locus of control was not a significant predictor of parental outcome in step-wise regressions, where coping styles accounted for the variation. Locus of control was also negatively related to social isolation, where an external locus of control was associated with increased social isolation. However, again, locus of control did not predict social isolation in regression analyses. Dunn et al. also conducted moderation analyses with the variables (they tested direct effects and an interaction term for the potential predictors). However, once again, locus of control was not found to moderate the relationships between social support and parental outcomes.

Dunn and colleagues' findings suggest that the relationships between locus of control and parental outcomes are linear only in nature. This in itself is an interesting fact, since the implication here is that by encouraging parents to adopt a more internal locus of control, depression could be alleviated. However, Dunn et al., only tested relationships between locus of control and negative outcomes. It is possible that had more positive outcomes been investigated that locus of control may have been predictive with regression analyses.

Taken together these two studies show that locus of control is related to familial adjustment. However, these data are all cross-sectional and are based on

analyses from relatively few participants. Large-scale longitudinal studies that look at data from both fathers and mothers are now needed before firm conclusions can be drawn as to the nature of the relationships between locus of control and parental well-being.

More recent work has highlighted the need to explore parental locus of control and its relationships within models of family adjustment and coping. Jones and Passey (2005) looked at the role of parental locus of control within the context of the Double ABCX model of stress and coping (McCubbin & Patterson, 1983) and found that parents (n=48) who felt that their child's needs and demands dominated their lives felt more stress. In particular, child control was related to stress associated with dependency and management issues, limits on family opportunities, life span care issues, and terminal illness stress. In multiple regression analysis, total parental stress was predicted by feelings of control by the child and family coping style (maintaining family integration, co-operation and optimism).

Hassall, Rose and McDonald (2005) explored cognitive variables to test Mash and Johnston's (1990) model of parenting stress. This model focuses on the interaction of child, parent and environmental characteristics and their contributions to parent/child stress. Hassall and colleagues specifically looked at the relationships between parenting locus of control, parenting competence, familial support and stress in a sample of 46 mothers of school aged children with ID.

Since initial correlations showed an association between locus of control and stress, Hassall et al. explored this area further and found that two elements of parenting locus of control in particular were associated with stress; the extent to which a parent believed that their child controlled their life and the extent to which the parent felt that their child's behaviour was a product of their parenting. Parental

sense of competence was also related to stress such that mothers who had a higher sense of parenting self-esteem reported lower levels of parenting stress. Regression analyses including these variables revealed that parental locus of control accounted for 44% of the variance in maternal stress. A further 10% was accounted for when child parenting satisfaction was added and the total variance was 59% when child behaviour problems were added to the model. Putative mediational effects of parenting locus of control were also examined and parenting locus of control was found to mediate the relationship between social support and maternal stress.

Both Jones and Passey (2005) and Hassall et al. (2005) showed clearly that locus of control variables are related to stress in parents of children with ID. In particular, parents who feel that their lives are dominated by their child report more stress. However, the sample sizes of both studies limit the generalisability of the findings. Furthermore, no longitudinal data were collected; it may be that parenting locus of control is state- rather than trait-like and should therefore be explored across time, a factor which would also allow for causal interpretation of the data.

In summary, the research into locus of control and the well-being of parents of children with ID and/or autism, is still in its infancy. However, a promising start has been made with research that includes both measures of fathers' and mothers' general locus of control and parental locus of control, as well as a study looking at locus of control as a measure of the efficacy of an intervention. Further study now needs to focus on parental locus of control using longitudinal methodologies to establish possible moderating and/or mediating effects and causal pathways.

*Parental hardiness*

Hardiness is a construct that contains an element of control within its definition. However, hardiness differs from locus of control in that it refers to a combination of sense of purpose (commitment), rising to challenges as opposed to viewing them as insurmountable, and a feeling of control over life events (Ganellen & Blaney, 1984).

Gill and Harris (1991) looked at hardiness and social support in 60 mothers of children with autism and found that hardiness was positively related to social support; mothers who reported feeling more hardiness also reported higher levels of social support. Gill and Harris also looked at hardiness as a putative predictor of maternal depression and health related complaints. The commitment variable of hardiness was a significant predictor of depression (lower levels of hardiness predicted more depression) and a total hardiness score predicted somatic health complaints (a lower hardiness score predicted more reported somatic complaints).

Weiss (2002) conducted a similar study, again investigating hardiness and social support within mothers. This time a between groups methodology was used to look at group differences between mothers of children with autism, mothers of children with ID, and mothers of typically developing children. Mothers of typically developing children reported more hardiness, followed by mothers of children with ID only and mothers of children with autism reported least hardiness, these differences were statistically significant. Hardiness was also positively related to high levels of social support reported by the mothers. Weiss also analysed the three components of hardiness as a predictor variable and found that maternal depression was predicted by perceived control (mothers who reported more control reported less

depression). Anxiety was predicted by the challenge variable of hardiness; mothers who viewed challenges as opportunities reported less anxiety, and maternal burnout was predicted by a total hardiness score.

Whilst Weiss (2002) conducted her study with a large sample of mothers (40 mothers in each condition) thus indicating a high power analysis, the sample were somewhat skewed in that only 3 of the 120 mothers in the sample were not married and all of the families were middle class. Therefore, Weiss suggests that the study is not representative of single parent families and those of a lower economic status. This is an important factor, since social support and hardiness were positively related. It could be that hardiness moderates the effect of social support on the maternal outcome variables studied. However, despite these methodological considerations, Weiss did partially support the findings of Gill and Harris (1991) in that social support and hardiness were related. Interestingly, while both studies showed that hardiness was a predictor for depression, the two studies showed that different components of hardiness were related to maternal depression, thus suggesting that further research is needed to clarify the relationships.

#### *Acceptance and mindfulness.*

An area rapidly gaining credence within the general literature is that of acceptance and mindfulness. Research has begun to look at parenting from the perspective that parents who are accepting of their child, not only in terms of their disability, but also as a person in their own right, adapt well to the challenges of raising their child.

From the limited literature on parental acceptance of the child and their disability, qualitative data analyses show cultural differences. Scorgie, Wilgosh,

Sobsey and McDonald (2001) looked at the experiences of life management of 54 Canadian parents of children with Down syndrome and found that accepting the child for who they are was thought to be vital to life management and a positive outlook. Parents also felt that valuing their child and considering his/her goals and dreams was essential. Parents felt that their parenting experiences had enriched their lives and that they had to learn to accept the things in life that they could not control in order to avoid frustration. Parenting was thought to be a positive experience.

Lloyd and Hastings (2008) investigated acceptance from a more precise theoretical perspective. They took as their definition of acceptance one that is becoming more established within research. Acceptance (literally defined) is the ability to take what is offered (Hayes, Strosahl, & Wilson, 1999). In this context, acceptance is the polar opposite of experiential avoidance. Therefore, acceptance does not refer to a process of giving up control of one's life, rather it is acknowledging that thoughts and feelings (whether unpleasant or pleasant) are only thoughts and feelings and not personal truths. Acceptance also involves being in touch with, and moving toward, personal values and goals. Mindfulness is a facet of acceptance and is the calm and non-judgmental focus on the present (Singh et al., 2006). This awareness of the present moment is often practiced through meditation (Baer, 2003).

Lloyd and Hastings (2008) (reported as Chapter 3 in this thesis) used a longitudinal methodology to explore acceptance, mindfulness and active avoidance coping in mothers of school aged children with ID. Specifically, they looked to see if there were associations between mothers' cognitions and maternal distress and positive perceptions of their child, both cross-sectionally and longitudinally. 91 mothers responded to questionnaires at Time 1 and 57 mothers participated at Time 2.

Lloyd and Hastings found that maternal general acceptance (i.e. acceptance not specific to the child) was negatively correlated with maternal distress and that acceptance entered into a bi-directional relationship with anxiety and depression across time. Active avoidance coping significantly predicted depression at Time 1 such that mothers who used more avoidance coping reported more stress.

Mindfulness was not related to maternal adjustment.

Lloyd and Hastings' research is the only paper we have found that looks directly at the effects of acceptance and mindfulness on maternal mental health across time and considers these variables as the main focus of investigation. This type of research allows for the development of an evidence base in the design of parenting interventions for mothers of children with ID. However, no fathers were included in the sample and Lloyd and Hastings claim to have had "an inherent measurement problem" (p. 46) when assessing acceptance. Therefore, although this research addresses the issues of parental cognitions directly, more work is yet required in this field in order for more conclusive results to be obtained.

The studies discussed provide an interesting beginning to research into a developing area. Although mindfulness as a construct dates back to Buddhist teachings, it has only recently been explored with families of children with ID. The work thus far conducted has focused on long accepted definitions of mindfulness and in this respect has some validity. Acceptance as a cognitive variable, however, is more ambiguous. The earlier, qualitative studies, lack a theoretical definition of acceptance and indeed may not be measuring the same precisely defined construct. However, since Acceptance and Commitment Therapy (ACT) has come to be recognized as an empirically developed intervention, the definition of acceptance has become more rigorous, as reflected in the work of Lloyd and Hastings (2008).



*Optimism and hope*

Hope and optimism are parental cognitions that, although closely related, are in fact separable constructs. Optimism refers to the generalized expectancy that good things (rather than bad) will happen and thus is a dispositional trait whereby optimists expect favourable outcomes to occur (Scheier & Carver, 1985). Hope theory (Snyder, et al., 1991; 1996) is a cognitive theory based on goal driven behaviour. Hope is defined as the expectation that one can reach one's goals and is comprised of two components, agency and pathways. Agency thinking refers to the perception that one can achieve one's goals and pathways thinking refers to the perception that one can find alternative routes to reach these goals should the need arise.

Though researchers have looked at the issue of optimism with regards to specific events or situations within families ID research, (e.g. Hyman & Oliver, 2001) we could find only one study that looked explicitly at optimism in parents. Baker, Blacher and Olsson (2005) studied optimism in parents of pre-school children with ID. They found that parental optimism was negatively associated with child behaviour problems in both mothers and fathers. Furthermore, for mothers, optimism moderated the relationships between child behaviour problems and depression, negative impact of the child on the family and marital adjustment and for fathers, optimism was a buffer between child behaviour problems and depression and negative impact. Thus, there is evidence that parents who are more optimistic are able to manage better with child behaviour problems.

The construct of hope is one that has received much research attention within education and health psychology, but little consideration has been given to this variable within ID families literature. We could find only one study that looked at hope in relation to parental well-being. Using Snyder's Trait Hope Scale (Snyder et



al., 1991) Horton and Wallander (2001) investigated the role of hope in maternal distress in mothers of children with chronic physical conditions (including 32 mothers of children with cerebral palsy) as well as mothers of children with diabetes and spina bifida. Results of regression analyses showed that hope, as well as marital status and disability-related stress was significant in the prediction of maternal distress.

Furthermore, hope was also found to act as a moderator in the relationship between disability-related stress and maternal distress. Specifically, when mothers reported high levels of disability-related stress, those with high levels of hope reported less distress than those with low hope. This effect did not occur when stress was low.

Though these results are interesting and suggest that hope may play a role in maternal adjustment in families of children with ID, the three groups were combined, thus this is a study, not of mothers of children with ID per se, but of a wider group of mothers.

Whilst hope and optimism appear to be variables that are salient in the lives of parents of children with ID, they are also variables that require further, more thorough, exploration. There is a dearth of literature that relates hope to parental well-being. Hope theory (Snyder et al., 1991; 1996) is clearly defined and thus suitable for empirical testing within the ID field, yet despite the growing use of positive psychology within ID, it is an area under-studied. Research into hope and parental optimism now needs to focus on the prediction of parental well-being, both cross-sectionally and over time.

#### Conceptual/theoretical issues

One of the aims of this review of the literature was to examine the issues surrounding the definitions used in research on parental cognitions. From the evidence presented, it is clear that though some variables are tightly defined (for

example, hope theory), other variables are not only vague in their definitions, but appear to be measures of overlapping constructs. Table 1. (below) highlights the definitional similarities within many of the constructs thus far discussed.

*Table 2.1. The definitional similarities between parental cognitive variables.*

Central theme	Variables		
Control	Hardiness – control	SOC – manageability	Locus of control
Making meaning	Hardiness – challenge	SOC – comprehensibility	
Worthiness	Hardiness – commitment	SOC – meaningfulness	Acceptance – values
Efficacy	Parenting efficacy	Parenting Competence	Hope Theory – agency

In particular, the constructs of hardiness and sense of coherence show common characteristics. Though worded differently, the definitions of the constructs highlighted above cover the central themes of control, making meaning, worthiness and efficacy. Rotter (1990) contends that the usefulness of a construct depends upon the exactness of its definition. Without stringent definition, it becomes difficult to operationalise variables and thus to measure them accurately. From the evidence presented, it is clear that several of these constructs are somewhat abstract, a factor that will undoubtedly affect the way a parent responds to an item in a questionnaire. It has also been noted within research that at least one of the cognitive variables may, in fact, be a measure of depression (Olsson & Hwang, 2001). More research into the validity and reliability of existing measures is therefore vital to ensure that they are measuring the correct construct and only that construct. It may be beneficial to

conduct exploratory factor analysis studies with samples of parents of children with ID to discover whether these items do indeed measure similar concepts, followed by confirmatory factor analysis studies to further refine the items.

Whilst it is possible to test the validity of existing measures, it may also be useful to develop new measures, specifically designed for use within research with families of children with ID. By encouraging parents to think about their day to day lives and interactions with their child, it may be possible to encourage parents to think and respond more specifically about their cognitions. The development of situation specific measures is one that is also supported by theory. Taylor (1983) in her theory of cognitive adaptation states that cognitions are treated as if they are fixed variables, whereas they can change with a given situation and so may have multiple meanings. To develop definitions and measures that are theoretically sound, it will be necessary to return to the original theories. In the following section, therefore, we return to the theoretical context under which the cognitions have been studied.

### *The relationships between parental cognitions and parental well-being*

Having reviewed the extant literature, we must now turn to the question of how parental cognitions relate to parental psychological adjustment. We will consider this in the context of relevant theories below. However, it is important first to establish some definitions relating to how parental cognition variables might function conceptually. There are three main ways that cognitions could affect well-being: 1) there may be main effect relationships in which cognitive variables act as risk or resilience (compensatory) factors, 2) they may be mediators (intervening variables) in the relationships between a stressor and well-being and 3) they may act as moderators by interacting with other risk variables to increase or decrease

psychopathology or by interacting with resilience/compensatory variables to increase well-being.

Before we begin a discussion of these possibilities, it is useful to clarify what exactly the terminology used above means. For a variable to function as a mediator, it must be able to act as an intervening variable within a given relationship and be able to account (either partially or fully) for the relationship between an independent and a dependent variable. Moderators are conceptually and statistically different to mediators in that they are based on an interaction between variables and imply a buffering relationship (Baron & Kenny, 1986). Moderators are typically fixed variables that are trait-like and involve the interaction of variables to predict a dependent variable. Therefore, a moderator is a characteristic that is already present and is activated by a stressor and a mediator becomes a characteristic as a response to a stressor (Grant et al., 2003).

Another distinction that is made within the literature is that of risk as opposed to resilience. A risk factor is a main effect variable that increases the chance of an adverse reaction to a stressor, whereas a resilience factor is a main effect variable that increases the chance of adaptive reactions to stressors, either by having a positive association with positive outcomes or a negative association with negative outcomes (Luthar & Zigler, 1991). In more simple terms, resilience is thriving when faced with adversity (Patterson, 2002) and thus is also referred to as a compensatory factor. A final distinction that can be made is one of protection versus vulnerability. A protective factor is one that acts as a buffer against distress. Theoretically, protective processes have an impact on adjustment by interacting with the risk factors, rather than by having a direct effect. A protective factor is said to be working when a person who is high in a particular trait is unaffected by a stressor. The reverse is true of a

vulnerability factor, a person who is high in a particular trait is susceptible to the negative impact of a stressor. Again, vulnerability can be identified by the presence of an interaction effect.

Given the possibilities outlined above, we will now take each cognitive variable in turn and discuss its possible function in the relationship with well-being. Antonovsky's (1987) theory of sense of coherence is one that potentially could act as either a moderator or a mediator as well as having main effect relationships. Longitudinal studies of sense of coherence have found that sense of coherence is a trait variable, implying a buffering effect, but it can also be a response to a stressor, therefore implying mediation (Schnyder, Buchi, Sensky & Klagofer, 2000). This empirical evidence is also corroborated by evidence from a recent systematic review (Eriksson & Lindstrom, 2006) that shows that sense of coherence can have a main effect relationship, a mediating relationship and a moderating relationship with health in general, and mental health in particular. Theoretically, sense of coherence is made up of a behavioural element (manageability), a cognitive component (comprehensibility) and a motivational element (meaningfulness); this goes some way to explaining why sense of coherence can be studied from all three of the possible perspectives.

Of the five studies of sense of coherence reviewed, four have looked at main effect relationships only. The conclusion that can be drawn from the results of these studies is that sense of coherence acts as a resilience factor for parents of children with ID. Data from the remaining study (Mak et al., 2007) support this suggestion and also show both moderational and mediational effects of sense of coherence. Research into sense of coherence now needs to move in the direction of testing these relationships longitudinally in order to clarify the relationships found thus far and to

add a dimension of causality, a factor that would add strength to tests of mediation and moderation.

Since parenting efficacy is a domain specific variable, theoretically it should function as a mediator as well as potentially having main effect relationships. The main effect relationships of parenting efficacy and maternal distress (parenting efficacy acts as a protective factor) were confirmed by the three studies reviewed. Furthermore, Hastings and Brown (2002) found that self-efficacy mediated the effect of child behaviour problems on maternal distress and moderated the effect for paternal anxiety, however, this is the only study within the parenting literature that shows this finding and so we must be very cautious in interpreting the evidence. Furthermore, a very small sample size of 26 mothers and 20 fathers was used, thus reducing the robustness of the analyses employed. Until further study is undertaken, it may be safest to assume that since efficacy theoretically should act as a mediator, it should be explored in this way. However, these findings do highlight the fact that whether a variable acts as a moderator or a mediator is dependent upon context. Thus researchers need to establish firm theoretical bases for making predictions before beginning a research programme.

Significant main effects of parenting competence were found in each of the four studies reviewed where higher competence was consistently related to lower reports of distress, thus acting as a resilience factor. The findings applied to both fathers and mothers. As competence is closely related definitionally to efficacy, we would expect it to function in much the same way i.e. competence should act as a mediating variable. Longitudinal research is now needed to examine whether competence does act as a mediator for fathers and mothers and whether any relationships found would be the same for both parents.

According to Rotter's (1966) theory, locus of control should act as a moderator as well as having main effects. As locus of control is situation specific and based upon past expectancies, it is likely that this construct would act as a moderating variable. Taken together, the studies in this review have shown that parental locus of control is a resilience factor for parental distress. This is no evidence to show that locus of control moderates relationships with parental well-being (in fact, Dunn et al., 2001, report that no moderation was found between social support and parental distress). However, a mediational relationship was found by Hassall et al. (2005) whereby locus of control acted as a mediator in the relationship between social support and maternal distress. Theory suggests that locus of control should moderate the relationship, but statistical testing reveals a mediational relationship. Theoretically this mediational relationship makes little sense since control in the parenting role should have little bearing on social support. A more theoretically based model could include locus of control intervening in the relationships between parental well-being and child behaviour, since there is a clear relationship between issues of control and child behaviour. Further research is needed to attempt to replicate Hassall et al.'s findings. Longitudinal research could also clarify the findings by establishing causal pathways between the variables.

In the three studies reviewed, hardiness has only been tested for main effects on psychological well-being. However, theory suggests that, as hardiness is a trait variable, it should also perform as a moderating variable. Hardiness is thought to affect how people appraise their current situation, those who are high in hardiness perceive fewer situations as stressful, and when stress is perceived, they tend to use more active coping methods and have a better outcome than those low on hardiness (Sansom, Wiebe & Morgan, 1999). Thus hardiness could have a moderating effect



on well-being by affecting stress at the appraisal and coping stages. For example, it could be that parents high in hardiness experience less stress due to child behaviour problems, as they do not perceive the problems to be beyond their control. Research is now needed to establish hardiness as a potential resilience factor.

Optimism and hope are both resilience factors for parents of children with ID. Theoretically, these constructs are dispositional variables and should show moderation effects as well as main effects on parental well-being. Indeed, Baker et al. (2005) showed that optimism acted as a moderator in the relationship between child behaviour problems and distress and Horton and Wallander (2001) showed that hope moderated the relationship between disability-related stress and distress. This is in keeping with theories that suggest that optimism and hope are dispositional variables and therefore are not responses to stressors. However, these data are cross-sectional only and though they go some way to explain the relationships between the cognitive variables and parental well-being, longitudinal data are needed to clarify the direction of the relationships. In chapter 5 of this thesis, hope is investigated as a potential resilience factor and thus hope theory is discussed in more detail at this point.

Finally, acceptance and mindfulness is an area that is still in its infancy within ID families research. Lloyd and Hastings (2008) found a main effect for acceptance and maternal distress, suggesting that acceptance acts as a resilience factor. Future research needs to investigate acceptance and mindfulness, specifically with respect to conducting mediation and moderation analyses. As both acceptance and mindfulness are global variables, they have potential to act as buffers for stressors and parental well-being. However, acceptance can also be changed during intervention (Blackledge & Hayes, 2006) and as such, has the potential to act as an intervening



variable. Both avenues of research need to be explored fully before firm conclusions can be drawn.

To conclude, research into parental cognitions needs to be conducted from a sound theoretical base. In general, the existing research has not looked at parental cognitions as variables worthy of research in their own right, rather, cognitive variables have tended to be measured as an adjunct to other research questions. This is something that needs to be addressed for two reasons. First, cognitions form the basis of several stress models (a selection of which are discussed below). Second, some parental cognitions are amenable to change and therefore, could form the basis of potential interventions for parents who are not adjusting to parenting their child with ID as well as they would like. We finish this review with a brief discussion of intervention literature.

### *Parental cognitions and the stress modelling literature*

Of the studies reviewed here 7 researchers (Baker et al., 2005; Gill & Harris, 1991; Hassall et al, 2005; Hastings & Brown, 2002; Jones & Passey, 2005; Oelofsen & Richardson, 2006; Weiss, 2002) have applied their findings to existing models of stress. Therefore, from a stress modelling perspective, relatively little work has been carried out to investigate how parental cognitions may contribute to stress and well-being in families of children with ID. With this in mind, we briefly present three stress models and illustrate within each where parental cognitive variables fit before highlighting how they may be useful in interpreting parental stress.

The Double ABCX Model (McCubbin & Patterson, 1983) is one model that incorporates within its structure the opportunity for the consideration of parental cognitions. According to this model, family outcome is a combination of the

perception of the characteristics of a stressor (e.g. severity), the family's resources (e.g. social support), the cognitive processes involved in defining the stressor (e.g. locus of control) and coping strategies (e.g. problem focused coping). This model takes into account that things can change as people adapt over time to stressors. It is therefore possible that the moderating effects of trait variables such as hope or optimism may affect the parents' perception of the crisis. Post crisis, the mediating effects of state variables such as self-efficacy, may increase the chances of the parent readjusting to the stressor and adapting successfully.

Whilst there is much literature concerning coping strategies and familial resources, the literature available for the cognitive processes involved is sparse. Any of the variables reviewed here would be candidates for inclusion within the Double ABCX model and indeed Jones and Passey (2005) investigated parenting locus of control from the framework of the Double ABCX model. However, though they clearly state that this is the purpose of their study, when drawing conclusions, Jones and Passey fail to refer to the model. Future research needs to be clear in testing this model, both from the perspective of a test of theory and also in drawing firm conclusions about the utility of the constructs within the model.

Lazarus and Folkman (1984) developed a transactional model of coping. Also known as the Process Model of Stress and Coping, this model assumes that stress is a product of the interaction between the stressor, the person's appraisal of the situation and their resources and the person's coping response. The model consists of two stages of appraisal followed by reappraisal and lends itself well to the application of cognitive variables. Primary appraisal occurs when the stressor is detected and consists of the person deciding that a threat exists, secondary appraisal is the person asking themselves what they can do to deal with the stressor. It is at this point that the

feeling of stress is mediated by cognitive processes. For example, a person with a high level of parenting competence may realise that they have the personal resources to deal with the situation and cope easily. This would lead them to the reappraisal stage where a person would evaluate the efficacy of their coping. Within this model, parental cognitions would play a mediating role between the stressor and parental well-being. Those cognitions that theoretically could play a mediatory role need to be investigated more fully with respect to this model. However, those cognitions that have a primarily moderating function could also be tested within this model to confirm their roles as moderators or to discover mediatory relationships and thus refine the theory on which their functions are based.

Although many recent studies make mention of the transactional model, none of the studies we have looked at investigate parental cognitions from the perspective of Lazarus and Folkman's (1984) model. However, in a recent study that was not included in this review as it did not measure parental adjustment, Lam and Mackenzie (2002) investigated maternal experiences of raising a child with Down syndrome in Hong Kong. They used qualitative data collection techniques to attempt to gain a better understanding of which variables made up the stressors, the resources and the coping strategies of the mothers. Though the data presented clearly elucidate both the stressors and the coping strategies, little mention was made of the resources for coping. Therefore, much further investigation is required to discover the role of parental cognitions within the transactional framework. In particular, investigations need to centre on the putative mediating effects of cognitive variables.

The Family Adjustment and Adaptation Response model (Patterson, 1998) is a model whereby families, when faced with a stressor, attempt to balance problems with resources in order to preserve a typical level of familial functioning. To do this,

parents must balance family demands with family capabilities. These two factors interact with family meaning to create a level of family adjustment. Family demands are defined as stressors, strains, and hassles and family capabilities refer to physical and psychosocial resources and coping behaviours; these can include money and time (physical resources) and educational level and parental beliefs and cognitions (psychosocial resources). Family meaning refers to a family's appraisal of the situation, their world view (i.e. values and beliefs) and a sense of family identity. When demands outweigh capabilities, a crisis is reached. The family then aims to restore the balance by changing coping behaviours and/or gathering new resources. This then leads to adaptation to the situation.

Within this model there is clearly scope for the application of parental cognitive variables, yet no research that we could find has investigated parental cognitions in families of children with ID and applied this to the FAAR model. Theoretically, parental cognitions could be seen as psychological resources within the model. When parents are trying to achieve a balance between demands and capabilities, their cognitions could play a vital role in whether the demands of the situation are perceived as a problem or as a challenge. For instance, a parent who is high in optimism (a psychological resource) may be able to balance the demands of the daily hassles associated with raising their child more easily than a parent who has less optimism. Parental cognitions are also implicated in the family's making meaning of the situation. For example, parents who are high in acceptance may be able to make more meaning of a given problem and thus, adjust better to the situation.

Models of stress and adaptation are vital ways to predict and test theories. They provide frameworks that can be refined and re-evaluated as theory develops and results are collated. It is therefore somewhat surprising, that parental

cognitions have been investigated so little in relation to the prominent models described above. In fact, the newer concepts that have only recently come to the fore in ID research, for example, acceptance and hope, have not been applied to, or tested within any models of adjustment. Researchers now need to recognise the need for empirically derived and tested theory that may form the bases of new paradigms. Parental cognitions need to be explored more fully so that their roles as protective, resilience, or as risk factors, can be established. These data could then be used in the development of interventions.

#### *Practical applications of parental cognitions research*

According to Didden, Duker, and Korzilius (1997) over 60 different techniques were used in behavioural interventions with children with ID between 1968 and 1994. Horner, Carr, Strain, Todd and Reed (2002) suggest that parents may be able to facilitate children's behaviour change by changing their parenting behaviours. However, relatively few studies evaluate the efficacy of methods used as interventions for the psychological distress of parents of children with ID (Singer, Ethridge & Aldana, 2007). Since evidence-based interventions are the gold standard for intervention research (Gardner, Burton, & Klimes, 2006) the assumption would be that parental cognitions would be evaluated as a matter of course during interventions that attempt to change parental cognitions. However, in a recent review of stress interventions for parents of children with ID, Hastings and Beck (2004) concluded that data pertaining to parental cognitions are rarely gathered. We could find only three studies that measured change in the parental cognitions we have reviewed and therefore represent research on the efficacy of interventions.

Margalit and Kleitman (2006) examined factors that predicted maternal stress at the beginning of, and one year after, an early childhood intervention package that included speech and occupational therapy, an educational component and a component focusing on mother/child interactions. 70 mothers took part in the study that investigated stress as an outcome measure and sense of coherence as a cognitive variable. Regression analyses showed that sense of coherence negatively predicted maternal stress at the beginning of the intervention and one year post intervention. However, analysis of the group means for stress and sense of coherence showed that there were no significant differences in the variables across the one year period. Therefore, we can conclude that both maternal stress and maternal sense of coherence remained stable over time and continued to be associated such that mothers with a higher sense of coherence reported less stress.

Though these findings indicate that the intervention in question did little to reduce maternal stress, it is the only one that we could find in which the intention was to measure and change parental cognitions as part of an intervention. This is therefore an important study as it highlights the role cognitions could play in intervention research.

Blackledge and Hayes (2006) developed an Acceptance and Commitment Therapy (ACT) based intervention for parents of children with autism. 15 mothers and 5 fathers of children with autism participated in this within subjects study (though no data are given on the children themselves, e.g. age, severity of autism etc.) and it is reported that five married couples were among the participants, thus 15 families took part.

The acceptance-based intervention was delivered as a two day intensive course, covering 14 hours of instruction and participation in experiential exercises and

it was presented in a group-based workshop format. Parents took part in various experiential exercises designed to highlight their personal goals and values, to allow them to get in touch with their individual unworkable control strategies and to defuse themselves from their thoughts. Mindfulness exercises were also used to help parents to focus on the present moment.

Outcome and process measures were collected at four time points and results showed that the parents' mean scores for depression and distress decreased from pre- to post-treatment, but had begun to increase again by the three month follow up (though this increase was not to levels reported at pre-treatment). No significant changes in parental psychiatric health were found. Most treatment gains were made by parents who were in the clinical cut off range for depression prior to intervention. General acceptance and automatic negative thoughts about the self were found to be significantly different from post-intervention to follow up. This is an interesting finding; as acceptance did not significantly change from pre- to post intervention, all gains must have been made retrospectively of the intervention.

Although this paper forms an interesting foundation for acceptance research within families of children with ID, the authors did not use a control group and therefore, were unable to predict with certainty whether acceptance acted as a mediator for the change in parental outcomes across time. Post-treatment follow up data were only collected at one time point. Bearing in mind the slight increase reported in the means of the parental outcome measures, it would have been interesting to follow up these data further to see if the gains were, in fact, maintained longitudinally. This study included only 15 families and only 5 parents met the clinical cut off for depression (though no data are provided that can confirm whether these parents were in the same or in different family units). Therefore, the moderate



gains made may translate to larger gains if this intervention were to be used with parents with greater psychological distress.

In a recent multiple baseline study on mindfulness as a parenting intervention, Singh et al. (2006) used mindfulness training with 3 mother-child dyads. All the children were diagnosed with autism and were aged between 4 and 6 years. The study comprised a baseline phase in which data pertaining to typical child management techniques were gathered, a mindfulness training phase in which mothers were taught focused attention techniques, nonjudgmental acceptance of their child and meditation techniques and, finally, a mindfulness practice phase that lasted a full year post-intervention was also assessed. Results showed that, when compared with baseline, children's levels of aggression, self-injury and non-compliance significantly decreased during and after mindfulness training for their parents. In self-report measures mothers also reported increased satisfaction in their parenting skills and in their interactions with their child.

Both observational and self-report data were used within this study and the mothers were followed up for a considerable period. However, only three mothers were included in this study and all of these parents had requested mindfulness training following contact with a service provider who had previously received mindfulness training. Therefore, further empirical evidence is required before firm conclusions as to the utility of this method of parent-training can be made. Singh et al., also posit that the mechanisms through which this intervention had its effect may be due to unconditional acceptance of the child and a reduced tendency of the mothers to respond to their child's behaviour in previously learned and unsuccessful ways. These factors are consistent with the general tenets of mindfulness and acceptance. However, since these factors were not assessed directly, these conclusions must



remain tentative. In fact, no processes were reported to have been measured during this intervention study, thus we cannot be sure what it was that changed for parents, whether it was purely a change in mindfulness levels that was associated with increased parent satisfaction, or whether other processes, such as change in parental cognitions, mediated this relationships.

The studies discussed above suggest that Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 1999) or mindfulness based-programmes, such as Mindfulness-Based Cognitive Therapy have the potential to become useful evidence-based interventions for parents of children with ID. However, whilst these results are encouraging, since no data are available on the parental cognitions that may have mediated the change in parental well-being, or whether the changes were actually due to the intervention or not, we can only speculate about the possibility of the future utility of these interventions.

Whilst there is some research on cognitive based therapies for people with intellectual disability (see Sturmey, 2004 for a review), little research has been conducted into cognitive therapy for parents of children with ID. The few studies that do attempt to investigate the efficacy of cognitive based therapy (Gammon & Rose, 1991; Nixon & Singer, 2002) have focused on group-based interventions as the mechanism for bringing about behavioural change. The study by Margalit and Kleitman (2006) is the only research we could find that measured the change in parental cognitions as a way of assessing the efficacy of the intervention.

In summary, parental cognitions are potentially interesting as variables that can be changed through intervention and thus measured and evaluated for their contributions in bringing about behaviour change in parents and possibly alleviating parental distress. However, the dearth of evidence evaluating the change in parental

cognitions when parents receive a therapeutic intervention suggests that this is an area that requires a great deal more research.

Having reviewed the literature, we believe that there are two main types of research that now need to proceed. First, due to the lack of evidence on whether cognitions are resilience or protective variables, more research is needed to clarify the role of cognitions in parents of children with ID. Second, more research needs to be conducted into the efficacy of cognitions in changing behaviour. Future intervention studies that aim to change the way parents think about their family situation should measure variables such as parental acceptance, hope, locus of control, self-efficacy, etc., in order to better inform therapists of the mechanisms of change that parents may undergo during the intervention itself. Evidence must be gathered to indicate whether well-being can be improved as a result of a particular intervention and whether the improvement was achieved by changes in parental cognitions. In gathering such data, it would be possible to develop more evidence-based interventions and provide an empirically driven framework from which clinicians could proceed.

### *Conclusions*

Having described and discussed the literature, we now turn to the main focus that motivated this review. First, we asked the question of whether the study of parental cognitions within ID research requires more stringent definitions of the variables. We anticipated that the definitions of the constructs measured would require some clarification. Whilst this was the case, we also found that the study of parental cognitions, in general, is beginning to be conducted from a more theoretically driven perspective. Lloyd and Hastings (2008) and Baker et al. (2005) have both

produced studies with a sound research question that asks about parental cognitions as its main focus.

Hope theory and locus of control are also both well-researched theories that have begun to be investigated within ID families research. In particular, Hassall et al. (2005) and Jones and Passey's work (2005) have attempted to investigate parental locus of control from a theoretical perspective. These types of study that focus exclusively on parental cognitions and parental outcomes are necessary to show how parental cognitions might be related to outcome. However, these two studies were not longitudinal in nature. Cognitive variables now need to be studied from a longitudinal perspective to establish if, in fact, they are functioning as process variables. If this were found to be the case then we could say with more certainty that these variables would be amenable to change by intervention.

Finally, we asked how the findings of the studies under review were applied. Two particularly promising pieces of research were reviewed. Blackledge and Hayes' (2007) work and Singh et al's. (2006) study of a mindfulness based intervention are studies that clearly attempt to change parental cognitions to relieve parental distress. Both of these studies take a methodological approach by considering both the theoretical underpinnings of the variables and their potential utility within intervention research. Future research should aim to assess the role of cognitive variables in intervention studies, using control groups where possible to show the changes taking place in parental cognitions through the course of the intervention.

In conclusion, the area of parental cognitions is one of great promise for research. It has the potential to inform both theory and practice if studied from a theoretically driven perspective. Several of the more recent studies reviewed have adopted this approach and others are encouraged to do the same.

Chapter 3. Psychological Variables as Correlates of Adjustment in Mothers of  
Children with Intellectual Disabilities: Cross-sectional and Longitudinal  
Relationships\*

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\* A version of this chapter has been published as Lloyd, T., & Hastings, R. P. (2008). Psychological Variables as Correlates of Adjustment in Mothers of Children with Intellectual Disabilities: Cross-Sectional and Longitudinal Relationships. *Journal of Intellectual Disability Research*, 52(1), 37-28.

### Abstract

**Background** – Existing research studies suggest that parenting a child with intellectual disabilities can be a stressful experience. However, there are few data addressing the question of how or why parents might experience considerable distress. In the present study, psychological variables (acceptance, mindfulness, avoidant coping) are explored that may explain some variance in maternal distress.

**Method** – Questionnaire data were gathered from mothers of children attending special schools at two time points, 18 months apart (n=91 at Time 1; n=57 at Time 2). In addition to measures of the child's functioning, the questionnaire pack included: a measure of acceptance of unwanted thoughts/feelings, a measure of attention to the present (mindfulness), a measure of active avoidance coping, measures of maternal anxiety, depression and stress, and a measure of mothers' positive perceptions of their child.

**Results** – In cross-sectional analysis, acceptance was negatively associated with maternal anxiety, depression, and stress, such that mothers who were generally more accepting reported fewer psychological adjustment problems. Longitudinal analysis showed that acceptance is bi-directionally related to anxiety and depression.

Mindfulness was not significantly related to maternal distress, and avoidance coping was positively cross-sectionally associated with depression only. There were no associations between psychological variables and maternal positive perceptions.

**Conclusions** – These data suggest that acceptance, in particular, may be a construct that explains some variance in maternal distress. Further research could focus on the utility of acceptance-based interventions (e.g., Acceptance and Commitment Therapy) in the support of families with a child with intellectual disabilities.

Parents of children who have an intellectual disability often report more distress (including stress, anxiety, and depression) than parents of typically developing children (Dyson, 1993; Olsson & Hwang, 2002; Piven, Chase, Landa, Wzorek, & et al., 1991). However, it is not all parents of children with intellectual disabilities who report significant distress. For many parents, having a child with ID can also make positive contributions to family life (Hastings & Taunt, 2002; Helff & Glidden, 1998; Turnbull et al., 1993) and perceptions of positive contributions appear to be relatively independent of more negative adjustment outcomes (Hastings, Beck, & Hill, 2005). Therefore, there is a need to account for the fact that some families report positive perceptions whilst some families report considerable negative impact, and also that parents can report both positive and more negative experiences concurrently.

The relevant question is, therefore, how or why parents may be affected by their child with ID. By focusing on this question, we are not referring to variables that have typically been found to be directly associated with distress in parents of children with ID (e.g., behaviour problems). Rather, we are referring to the psychological processes through which these variables might have their effects. For example, Hastings and Brown (2002) found that maternal self-efficacy mediated the relationship between the behaviour problems of their child with autism and maternal depression. That is, having a child with high levels of behaviour problems reduced mothers' feelings of efficacy, which, in turn, predicted increased depression. The psychological variable of maternal self-efficacy explained how child behaviour problems come to have an impact on maternal depression. Although it is clearly possible to intervene to improve children's behaviour problems and reduce parental distress at the same time (e.g., Baker, Landen & Kashima, 1991), many variables

associated with parental distress in research carried out to date (e.g., child gender, age, and diagnosis) are not amenable to change. The advantage of working with psychological process variables is that they may be directly targeted for change using various psychological therapies (Hastings & Beck, 2004).

Psychological variables have been explored only rarely in research with families of children with ID. Hastings and Brown (2002) studied parental self-efficacy as outlined above and Kuhn and Carter (2006), in an internet-based cross-sectional survey of 170 mothers of children with autism, found that parenting self-efficacy was negatively predicted by maternal stress, depression and guilt. Hassall, Rose, and McDonald (2005) focused on parenting self-esteem and locus of control in a questionnaire study of 46 mothers of children with ID and found that high levels of parenting self esteem were associated with lower levels of stress. Furthermore, mothers who had an internal locus of control also reported lower stress levels.

Other researchers have explored parents' sense of coherence. This is a psychological mechanism implicated in the appraisal of stress and consists of three components; comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). Thus, a person with a high sense of coherence will define a possible stressor as one that they can make sense of (comprehensibility), will perceive the situation as one with which they have the resources to cope (manageability), and will appraise the situation as a challenge that they find worthy of investment of their resources (meaningfulness). Parents of pre-school children with ID have been found to have lower sense of coherence scores than parents of typically developing pre-schoolers (Oelofsen & Richardson, 2006). Olsson and Hwang (2002) showed that mothers of children with autism had a lower sense of coherence than mothers of children with ID and mothers of typically developing children. These authors also reported that

parents of children with ID who have a low sense of coherence have higher levels of depression than parents of typically developing children.

The purpose of the present study was to broaden the investigation of psychological variables to some processes that have been the subject of recent research attention outside of the ID field and that are also related to therapeutic interventions with a strong evidence base. These psychological process variables are: acceptance, mindfulness, and avoidant coping. We consider each of these in turn below and how they might dovetail with the research literature on parents of children with ID.

Acceptance (literally defined) is the ability to take what is offered without trying to avoid experiences (Hayes, Strosahl, & Wilson, 1999). In the ID context, acceptance might seem to have a good degree of face validity, as it is unlikely that a child's ID can be completely ameliorated. Thus, to adjust positively, parents might benefit from moving towards a state where they can accept their child as they are and the associated difficulties that will come along with parenting a child who presents challenges. Although acceptance-based therapies have been used successfully with many psychological problems including stress in the workplace (Bond & Bunce, 2000), trichotillomania (Twohig & Woods, 2004), smoking cessation (Gifford et al., 2004), and stress and pain symptoms (Dahl, Wilson, & Nilsson, 2004), we could find only one study where acceptance has been used as a part of an intervention to support parents of children with disabilities (Blackledge & Hayes, 2006).

Blackledge and Hayes (2006) used Acceptance and Commitment Therapy (ACT, Hayes et al., 1999) as a group intervention for reducing depression and stress felt by parents of children with autism. Experiential acceptance training, including cognitive diffusion strategies, mindfulness exercises, and exploration of values that



might motivate parents, were used during 14 hours of workshop-based intervention. Three treatment groups were assessed pre-, during, and post-intervention, but there was no control group comparison. Both depression and stress were significantly reduced post treatment and at 3 month follow up and mothers also showed significantly increased levels of acceptance across these time periods. The data were suggestive of a mediational relationship between acceptance and psychological distress (i.e., the intervention may have had its main effect by increasing acceptance), though these findings are not conclusive, since no control group was used.

The second process variable, mindfulness, refers to a non-judgmental observation and awareness of the present moment that is often practiced through meditation (Baer, 2003). Mindfulness-based therapies have been used successfully with substance abusers (Leigh, Bowen, & Marlatt, 2005), hospice workers (Bruce & Davies, 2005), and cancer patients (Smith, Richardson, Hoffman, & Pilkington, 2005). Furthermore, Dumas (2005) has developed a mindfulness-based parent training model to encourage everyday mindfulness in parents of disruptive children.

Singh and colleagues (2004) have shown the benefits of mindfulness-based interventions for support staff who work in services with adults with ID. Using a multiple baseline design, Singh et al. showed that adults with profound disabilities were significantly happier when cared for by a caregiver who had received mindfulness training than when interacting with a caregiver from a control group, who had not received the training. Similar results have been found when mindfulness practice is applied to families. Singh et al. (2006) developed a mindfulness-based parenting program for mothers of children with autism and found that, over a twelve week period, mothers' mindful parenting was associated with a decrease in their child's behaviour problems. However, we could find no research studies addressing

putative relationships between mindfulness and adjustment in parents of children with ID or other developmental disabilities.

The third construct to be explored in the present study was that of avoidant coping. Experiential avoidance is a core concept in both acceptance and mindfulness-based therapies. Within both approaches, avoidance is a process that leads to psychopathology and acceptance and mindfulness techniques are designed at least partly to reduce avoidance. Coping behaviour of parents of children with ID is an area that has received considerable attention from researchers (e.g., Abbeduto et al., 2004; Judge, 1998; Smith, Oliver, & Innocenti, 2001). Some existing data suggest that avoidance coping is associated with higher stress and more mental health problems in parents of children with autism (Hastings, Kovshoff et al., 2005). However, these findings require further investigation.

Given their already demonstrated potential in therapeutic interventions for parents of children with ID, we explored acceptance, mindfulness, and avoidant coping as predictors of adjustment in mothers of children with ID. Based on the general research literature (e.g., Hayes et al., 2006), we expected mothers who showed higher levels of acceptance and mindfulness to report less stress, anxiety, and depression. We also expected that mothers who use more avoidant coping strategies would report more stress, anxiety, and depression (cf. Hastings, Kovshoff et al., 2005). In recognition of the fact that parents report both negative and positive adjustment often concurrently, we explored whether acceptance, mindfulness, and avoidant coping would explain some variance in mothers' positive perceptions of their child. Given the lack of data on positive perceptions, we did not make any particular predictions about relationships in this domain and these analyses are exploratory. Finally, we included a longitudinal element to the research to begin to

explore causality questions. We could find no research studies in the ID field that explored acceptance, mindfulness, or avoidant coping over time in parents.

## Method

### *Participants*

All families that took part in the study lived in the South East of England and were recruited through special schools and all mothers were primary carers for their children who lived at home full time. Ninety one mothers of children with intellectual disabilities took part in the study at Time 1. Their ages ranged from 28 years to 58 years ( $M = 41.57$  years;  $SD = 6.32$  years). The majority of mothers ( $n = 75$ ) were married or currently living with a partner, although 16 were divorced or otherwise single and not currently living with a partner. Fifty three of the mothers worked full or part time, with the remaining 38 not working outside the home. Sixty six of the mothers had a partner who engaged in paid work outside of the home. Average annual family income was in the region of £30,000 (roughly equivalent to \$45-55,000 US dollars during the time of the research). The mothers in the sample were well educated, with 41 having a college or university education, 43 graduating from high school, and only 7 with no formal educational qualifications.

The children with ID were 64 boys and 27 girls between 3 and 19 years of age with a mean age of 10.75 years ( $SD = 50.62$  months). Thirty nine children were reported as having a diagnosis of autism in addition to their ID, 15 had Down syndrome, 12 children had cerebral palsy, and the remainder were a mixed aetiology ID group. According to the Vineland Adaptive Behavior Scales (VABS, Sparrow, Balla & Cicchetti, 1984,) completed with the mothers, 37 children had profound/severe developmental delay, whilst the remaining 54 had moderate/mild developmental delay.

Longitudinal data were collected from 57 mothers approximately eighteen months later. At this time, mean maternal age was 43.96 years (SD = 5.54 years). Mothers of 41 boys and 16 girls participated at Time 2 and they had a mean age of 12.40 years (SD = 49.26 months). Twenty two children had autism and ID, seven had Down syndrome, and six had cerebral palsy, with the remaining children of mixed aetiology. Mothers and children who participated at both time points were compared with those families who participated at Time 1 only. No significant differences were found on any of the child, family, or mother demographic variables described above. Thus the sample for whom longitudinal data were collected appeared to be reasonably representative of the initial sample.

### *Measures*

Nine measures were included in the study, one of which was a demographic questionnaire that assessed characteristics reported in the Participants section (see Appendix A).

*Child Measures.* Children's problem behavior was measured using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997, see Appendix B). This is a brief 25 item behavioural screening questionnaire that can be completed in about five minutes by parents. The SDQ has four problem behaviour sub-scales assessing Conduct disorder (e.g., "often has temper tantrums"), Emotional symptoms (e.g., "many worries, often seems worried", "often unhappy, downhearted or tearful", "nervous or clingy in new situations"), Hyperactivity (e.g., "easily distracted"), and Peer relationships (e.g., "has at least one good friend"). The SDQ Total Difficulties score was used as the measure of problem behaviour in the analyses reported below. Research with children with ID suggests that good levels of reliability are maintained when the scale is used in this population (Beck, Daley, Hastings & Stephenson, 2004;

Emerson, 2003; 2005). In the present sample, a Cronbach's alpha of .88 was obtained for the total difficulties score.

The Vineland Adaptive Behavior Scale (VABS) – Survey Form (Sparrow et al., 1984) was used as a measure of adaptive behaviour. This semi-structured interview measure contains a range of 297 items that provide an assessment of adaptive behaviour across four domains: Socialization, Communication, Daily Living Skills, and Motor Skills. These adaptive skills items are arranged in developmental sequence and not all 297 questions are asked in an interview. Rather, the standard administration procedure is that the interviewer estimates an adaptive level and asks in detail about skill items in this range to arrive at an accurate estimate of a child's abilities. An overall composite score can be derived with reference to age during typical development at which children can perform the task items. This VABS composite score was used in the present analysis as an overall index of the child's adaptive skills.

*Family Deprivation.* Given the associations in previous research between socio-economic variables and parental well-being, (Emerson, Graham, & Hatton, 2006) we constructed a measure of family deprivation as a risk index from several variables available in this study. Three variables that were all significantly correlated with each other were converted to z scores and then summed together to give an overall index of family deprivation. These variables were maternal education, annual family income, and the neighbourhood deprivation index score derived from the mothers' postal (zip) code. A low score on the family deprivation index indicated families in more deprived circumstances. Neighbourhood deprivation was assessed using the Index of Multiple Deprivation (Noble et al., 2004). This index combines national data on 37 separate indicators in seven domains: income; employment; health

and disability; education, skills, and training; barriers to housing and services; living environment; and crime. Data are available for the whole of England using neighbourhood areas that contain an average population of 1,500 people and are based on the 2001 national census.

*Psychological Variables.* Psychological acceptance was measured using the Acceptance and Action Questionnaire (AAQ, Bond & Bunce, 2000, see Appendix C). The AAQ is a broad measure that focuses on the various aspects of acceptance and contains 16 items focused on action and willingness sub-scales. Items are measured along a seven point Likert scale, where 1 = never true, and 7 = always true. The internal consistency of this scale was explored for a total score and for the action and willingness sub-scales separately, but Cronbach's alpha coefficients were found to be unacceptably low. We explored whether a reduced set of items could be identified as a reasonably robust measure in the present research. We focused on a total acceptance score and systematically removed items with the lowest corrected item-total correlations until these values all exceeded .30 and an alpha value in excess of .70 was obtained. Eight items remained in the scale to give a total acceptance score (Cronbach's alpha = .72). The remaining items were (items preceded by R were reverse scored):

- I am able to take action on a problem even if I am uncertain what is the right thing to do.
- R - When I feel depressed or anxious, I am unable to take care of my responsibilities.
- I'm not afraid of my feelings.
- Despite doubts, I feel as though I can set a course in my life and then stick to it.

- I am in control of my life.
- If I get bored of a task, I can still complete it.
- R - Worries can get in the way of my success.
- If I promised to do something, I'll do it, even if I later don't feel like it.

The Mindful Attention Awareness Scale (Brown & Ryan, 2003, see Appendix D) was used as a dispositional measure of mindfulness. The MAAS contains 15 items, for example: "I find myself doing things without paying attention"; "I could be experiencing an emotion and not be aware of it until sometime later"; "It seems I am 'running on automatic' without much awareness of what I am doing". Items are loaded onto a single factor and are rated on a six point Likert scale, ranging from "almost always" to "almost never". A high score indicates more mindfulness.

Psychometric properties in community samples are excellent (Brown & Ryan, 2003), and in the present sample internal consistency was very high (Cronbach's alpha = .92).

Avoidant coping was measured using items from the Brief Coping (Carver, 1997, see Appendix E) that were factor analysed by Hastings, Kovshoff et al. (2005) into four coping factors that described coping strategies in parents of children with developmental disabilities: active avoidance coping, problem focused coping, positive coping, and religious/denial coping. The items from the Active Avoidance Coping scale were used in the present research. This is an eight item measure, rated on a 4 point Likert-type scale, where participants select the response that best seems to describe their method of coping with their child with special needs. Items include "I give up trying to deal with it"; "I say things to let my unpleasant feelings escape"; "I blame myself for things that happen". Hastings, Kovshoff et al. found an alpha level

of .78 for the Active Avoidance Coping scale, and internal consistency was also found to be acceptable for the present sample (Cronbach's alpha = .69).

*Maternal Well-Being Measures.* Mothers' positive perceptions of their child with ID were measured using the Positive Contributions Scale of the Kansas Inventory of Parental Perceptions (Behr, Murphy & Summers, 1992, see Appendix F). The Positive Contributions Scale (PCS) comprises 50 items derived from a large-scale research study of parents of children with disabilities. Items in the scale measure the belief that the child with disability has had a positive impact on the parent (e.g., the child is responsible for the parent learning patience, the parent has an improved social network, the parent has a different perspective on life) and the wider family (e.g., bringing the family closer together, helping other family members to become more understanding of other people), and that the child has a number of positive characteristics (e.g., kind and loving, fun to be around). A PCS total score was used in the present analyses. Internal consistency for the PCS is good, with a level of .92 reported for the total score in a study of mothers of children with ID (Hastings, Beck, & Hill, 2005). A comparable Cronbach's alpha of .93 was found for the present sample.

Maternal mental health was measured using the Hospital Anxiety and Depression scale (HADS: Zigmond & Snaith, 1983, see Appendix G). Although originally developed for residential populations, this measure has been used extensively in community research. Research with various populations has also suggested that the HADS has good agreement with other mental health measures such as the Center for Epidemiological Studies Depression scale (e.g., Katz, Kopek, Waldron, Devins, & Tomlinson, 2004). The HADS contains 14 four point items, with seven assessing depression (e.g., "I feel as if I am slowed down") and seven assessing



anxiety (e.g., “I get sudden feelings of panic”). A dimensional approach was taken for the analyses in the present study with total scores on the two sub-scales being used. Previous research with mothers of children with developmental disability has shown that the HADS maintains good reliability (Cronbach’s alpha coefficients in excess of .80) within these populations (Hastings, 2003; Hastings et al., 2005; Hastings & Brown, 2002). For the current sample, Cronbach’s alpha levels of .82 for the anxiety subscale and .77 for the depression subscale were found.

As a general measure of maternal stress, the Parent and Family Problems subscale of the Questionnaire on Resources and Stress Friedrich short form (QRS-F: Friedrich, Greenberg, & Crnic, 1983, see Appendix H) was chosen. This scale contains 20 items assessing impact on the parent and family (e.g., “Other members of the family have to do without things because of N”, and “N is able to fit into the family social group”). Parents are asked to indicate whether the items are true or false as far as they and their family are concerned. A total stress score is derived by summing the number of negatively endorsed items (i.e., positively worded items are reverse scored). Five items that have been shown to constitute a robust measure of depression in parents of children with disabilities (Glidden & Floyd, 1997) were removed from the scale. This ensured that there was no overlap between the measures of stress and of mental health used in the present research. In the present sample, a Kuder-Richardson co-efficient of .86 was obtained for a total score derived from the remaining 15 items.

### *Procedure*

Before data were collected, ethical approval to conduct the research was granted by Bangor University (see Appendix I). At Time 1, letters of introduction to the research (see Appendix J) were sent to 17 special schools and nine chose to

participate by distributing information to the families of children in their schools. One hundred and thirty mothers responded to the advertisements and of these 91 returned a completed questionnaire pack (see Appendix K for consent form) and completed an interview (a response rate from initial expressions of interest of 70%). Once they had completed and returned the questionnaires, mothers were sent a thank you letter (see Appendix L) stating that a researcher would telephone them later during the week to talk with them about their child. If the questionnaires were not returned within a two-week time period, a personally addressed reminder letter (see Appendix M) was mailed to the home. The VABS was conducted by telephone, usually within a week of receipt of the completed questionnaire. The procedure for administering the VABS as a telephone interview is no different from that used in a face-to-face interview. The VABS has been used previously as a telephone interview with parents of children with intellectual disabilities, and strong agreement has been found between data gathered by telephone and face-to-face (Beck, Daley et al., 2004). Eighteen months later, mothers were invited to participate in a follow-up study and those who expressed a wish to do so were posted a questionnaire that was identical in content to the first.

### Results

Kolmogorov-Smirnov tests were used to explore the distributions of the study variables. All of these tests were non-significant, suggesting that variables were reasonably normally distributed and thus suitable for parametric statistical analysis. The data were analysed using three steps. First, Pearson's correlations were used to explore univariate associations between all demographic, child, and process variables with maternal adjustment measures. For dichotomous variables (e.g., presence or not

of a diagnosis of autism), point-biserial correlations are reported in Table 1. Second, linear regressions were conducted with maternal adjustment variables as dependent variables and all significant univariate correlates as predictors. Thus, we could explore the independent contribution of the predictor variables. Finally, we explored the longitudinal relationships between the psychological variables and maternal adjustment measures.

#### *Cross-Sectional Analysis at Time 1.*

Univariate associations between study variables are shown in Table 3.1. Although all adjustment measures, psychological variables, and child behaviour scores are included in the table, demographic and background variables are only represented if they were associated significantly with at least one maternal adjustment measure. The data in Table 3.1 show that acceptance is strongly negatively associated with anxiety and depression and moderately negatively correlated with maternal stress. Active avoidance coping is positively associated with the adjustment variables, showing a moderate association with anxiety and depression and a smaller association with stress. Mindfulness was not significantly correlated with any of the variables and scores on the PCS were not associated with any child or process variables, but were negatively correlated with stress.

Table 3.1. Correlation Matrix for Study Variables at Time 1.

Measure	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Anxiety		.57***	.38**	-.04	-.53***	-.13	.33***	.12	.16	-.04	-.14	.03	.10
2. Depression			.49***	-.19	-.53***	-.13	.36***	.19	.60	.00	-.21*	-.03	-.00
3. Stress				-.29**	-.32**	.02	.22*	.45***	-.08	.28**	.02	-.08	.25**
4. Positive contributions					.19	-.07	-.01	.01	.19	-.03	.17	-.24*	-.17
5. Acceptance						.18	-.35***	-.22*	-.17	-.06	.30**	-.09	-.09
6. Mindfulness							-.15	.02	.05	.13	-.03	-.13	-.09
7. Active avoidance coping								.14	.21	.02	-.02	.05	.04
8. Child behaviour problems									-.10	.39***	.09	-.10	.05
9. Adaptive behaviour										-.01	.04	.04	-.09
10. Diagnosis of autism											.03	-.08	-.07
11. Marital status												-.01	-.11
12. Primary carer job													-.00
13. Family Deprivation													

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

All variables that showed significant correlations with maternal adjustment variables at the  $p < .05$  level were entered into multiple regression analyses for maternal depression, anxiety, and stress. Positive contributions scores were not analysed further as only one initial correlation (with maternal stress) was found. The results of these regression analyses are summarized in Table 3.2.

Table 3.2. Regression Analysis of Maternal Distress at Time 1.

Dependent Variable	Predictor Variable	$\beta$	$p$
Anxiety <sup>1</sup>	Acceptance	-.534	.001
	Active Avoidance Coping	.172	.076
Depression <sup>2</sup>	Acceptance	-.462	.001
	Active Avoidance Coping	.196	.001
Stress <sup>3</sup>	Autism diagnosis	.125	.226
	Family deprivation	.212	.028
	Child behaviour problems	.327	.002
	Acceptance	-.199	.056
	Active Avoidance Coping	.106	.297

<sup>1</sup>( $R^2 = .30$ ,  $F(2, 89) = 18.40$ ,  $p < .001$ ), <sup>2</sup>( $R^2 = .32$ ,  $F(2, 89) = 19.96$ ,  $p < .001$ ), <sup>3</sup>( $R^2 = .32$ ,  $F(5, 82) = 7.09$ ,  $p < .001$ )

For maternal anxiety, active avoidance coping and acceptance were entered into the regression model. Overall, a significant percentage of the variance in anxiety scores was explained by the regression model. Although active avoidance coping was a marginally significant predictor, this prediction was primarily accounted for by

acceptance. For maternal depression, active avoidance coping and acceptance were again entered into the regression model and a significant percentage of the variance in depression scores was explained. Both active avoidance coping and acceptance were found to be significant independent predictors of depression scores. Finally, for stress, the child's behaviour problems, family deprivation, the child's autism diagnosis, acceptance, and active avoidance coping were entered into the regression and accounted for a significant proportion of the variance in stress scores. After accounting for the impact of other variables, active avoidance coping was not a significant predictor of stress although acceptance was a marginally significant negative predictor. It is worth noting that both family deprivation and child behaviour problems were significant independent predictors of maternal stress.

### *Longitudinal Analysis*

Regression analyses using longitudinal data focused on the psychological variables that were significant predictors of maternal distress at Time 1. Although acceptance was only a marginally significant predictor of maternal stress, we also explored this relationship longitudinally. We followed procedures used in several other recent longitudinal studies in ID family research (Baker et al., 2003; Hastings et al., 2006; Lecavalier et al., 2006). Therefore, when predicting maternal adjustment, we entered Time 2 anxiety, depression and stress as dependent variables in the models and as predictor variables we included those psychological variables that were significant predictors at Time 1. We also entered the Time 1 scores for the dependent variables, and for the psychological variables we entered both the Time 1 scores and the change scores across time. Change scores were produced by subtracting Time 1

scores from Time 2 scores on the psychological variables. The results of these regression analyses are summarized in Tables 3.3-3.5.

Table 3.3. Longitudinal Analysis of Maternal Anxiety.

Predictor	Beta	<i>P</i>
Anxiety Time 1	.675	<.000
Acceptance Time 1	-.173	.133
Change in Acceptance T1 to T2	-.460	<.000

R = .77, R<sup>2</sup> = .59, F(3, 52) = 24.84, p < .001

Table 3.4. Longitudinal Analysis of Maternal Depression.

Predictor	Beta	<i>p</i>
Depression Time 1	.648	<.000
Acceptance Time 1	-.052	.672
Change in Acceptance T1 to T2	-.448	<.000
Active avoidance coping Time 1	.069	.526
Change in Active avoidance coping T1 to T2	.192	.073

R = .79, R<sup>2</sup> = .62, F(5, 49) = 16.36, p < .001

Table 3.5. Longitudinal Analysis of Maternal Stress.

Predictor	Beta	<i>p</i>
Stress Time 1	.709	<.000
Acceptance Time 1	-.103	.368
Change in Acceptance T1 to T2	-.296	.009

R = .75, R<sup>2</sup> = .56, F(3, 50) = 21.35, p < .001

After controlling for anxiety at Time 1, the change in acceptance over 18 months, but not initial acceptance scores at Time 1 predicted anxiety at Time 2. Those mothers whose acceptance scores increased over time reported less anxiety at Time 2. The same pattern of results was found for the analysis of Time 2 stress. Mothers whose acceptance scores increased over time also reported less stress at Time 2. Finally, acceptance and not active avoidance coping was related to depression scores over time. Again, mothers whose acceptance scores increased over time reported fewer symptoms of depression at Time 2.

Given that acceptance and all three distress measures were related over time, we also carried out regression analyses predicting Time 2 acceptance scores from the initial level (Time 1) and change over time in each distress variable whilst controlling for Time 1 acceptance. These analyses are not presented in detail here. However, the findings showed that increasing anxiety symptoms and increasing stress were related to lower acceptance at Time 2. Furthermore, both the initial level of depression symptoms and increasing depression over time were negatively related to acceptance at Time 2 (i.e., higher depression symptom scores at Time 1, and increasing depression symptoms over the 18 months independently predicted lower acceptance at Time 2).

### Discussion

As expected from the broader psychopathology literature, general maternal acceptance (i.e., not specific to the child with ID) was found to be reliably negatively associated with maternal distress but not with maternal positive perceptions. Specifically, acceptance was found to enter into a bidirectional relationship with symptoms of anxiety and depression over time. Acceptance was found to be a



marginally significant predictor of maternal stress at Time 1, and this association was also found to be bi-directional. Active avoidance coping was a significant predictor of symptoms of depression at Time 1, though no longitudinal relationship was found. Dispositional mindfulness was not found to be a predictor of maternal adjustment in the present study.

In common with several previous research studies (e.g., Baker et al., 2003; Hastings et al., 2006; Lecavalier et al., 2006), the child's behaviour problems were a predictor of maternal stress. Family deprivation also independently explained variance in stress scores (cf. Emerson, 2003). Furthermore, there was a lack of association between the study variables and maternal perceptions of positive contributions. Although there was a significant correlation with maternal stress scores, this association was small and supports the argument that negative and positive adjustment in families of individuals with ID are relatively independent constructs (Hastings & Taunt, 2002).

The practical implications of these results are perhaps the most important to consider. First, we have presented evidence that maternal acceptance may be bidirectionally related to a range of negative adjustment variables and that these relationships are stable over time. By improving acceptance, one would predict positive effects on the adjustment of parents of children with ID. This suggests that interventions based on acceptance developed outside of ID might be usefully applied in the field. The present data lend direct support to the rationale behind Blackledge and Hayes' (2006) intervention for parents of children with autism based on the principles of Acceptance and Commitment Therapy (ACT). Also within the present results, there was some evidence that active avoidance coping explained variance in maternal negative adjustment. Given that ACT explicitly targets avoidance and

instead encourages acceptance (Hayes et al., 1999), these results are further support for exploring ACT interventions for parents in more detail.

The second set of practical implications relate to the measurement of the processes by which support interventions for parents have their effects. As yet, there are few links between family research and intervention design within the field of ID (Hastings & Beck, 2004; Hastings et al., 2006). Therefore, there is a need to build a research-based model of parental adjustment to enable the development of empirically driven parent support interventions. By looking directly at psychological mechanisms, the present results go some way towards this aim, in suggesting that therapeutic interventions that function to increase acceptance and/or reduce avoidant coping may be those that will be most successful in positively affecting the adjustment of mothers of children with ID. Therefore, measures of these two constructs could be included in studies evaluating support interventions for parents, as a method for testing these predictions. Both the shortened acceptance measure used in this study, and the active avoidance coping measure derived from Hastings, Kovshoff et al.'s (2005) research, may be candidate measures for this endeavour.

The acceptance measure used in the present research does have an inherent measurement problem. Active avoidance coping is assessed with respect to the strategies mothers use to cope with the difficulties of raising a child with ID. The acceptance measure is a general dispositional scale and not one that is specific to the process of mothers accepting their child with ID. Acceptance measured at the level of the child should be explored in future research, alongside the need for replication of the results presented here. This does identify further questions that might be asked about mindfulness. Although mindfulness was not associated with maternal adjustment in the present study, it was measured at a dispositional (or "trait") level

and this may explain why no associations with maternal well-being were found. It may be that to generate a more valid measure of mindfulness in mother-child relationships, a child-focused (or “situational”) measure is required. Thus, the parent would be asked explicitly about their mindful responses to their child’s demands and more generally in their day-to-day interactions with their child. In future research, it would be interesting to explore whether the ability to be “in the present moment” with one’s child with ID is predictive of adjustment and especially perhaps of child-related stress.

In addition to the conceptual and methodological issues already addressed, there are a number of points that need to be borne in mind when interpreting the results of this research. First, the study is focused only on mothers of children with ID. Hastings and Brown (2002) showed how self-efficacy might function differently for mothers and fathers, so it is important not to assume that the psychological processes implicated in maternal adjustment will also hold true for fathers. Research on paternal psychological process is needed, in addition to similar research on perhaps sibling adjustment and extended family members including grandparents. A second issue is that of sample size. With so many variables under consideration, a larger sample size would add to the validity of the findings. However, the children with ID within this sample represent a large age range (3-19 years) and have differing levels of disability and this adds support to the idea that acceptance as a mechanism may be applicable to many parents.

A third consideration is the suitability of the acceptance measure used in the present study. Quite apart from the level of measurement (see above), we had to discard 50% of the items to arrive at a coherent (internally consistent) measure of

acceptance. Thus, more work is needed on this measure and other potential ways of assessing acceptance in parents of children with ID.

Although the data presented are longitudinal and go some way to showing temporal relationships, further evidence of causal links need to be established. Such evidence might be gained through the use of interventions targeted at specific psychological processes. Mediation analyses (Baron & Kenny, 1986) can then be used to explore whether positive outcomes in an intervention group are accounted for, as an example, by changes in acceptance from pre- to post-intervention.

Chapter 4. Parental Locus of Control and Psychological Well-Being in of Mothers of  
Children with Intellectual Disabilities

### Abstract

**Background** – Psychological mechanisms may help to explain the considerable variance observed in parental psychological adjustment in parents of children with intellectual disabilities. In this study, parental locus of control and its role in relation to maternal psychological well-being was explored.

**Method** – Questionnaires were sent to 91 mothers of children with ID at two time points, 18 months apart.

**Results** – Parental locus of control was associated with both maternal positive perceptions and with maternal distress. Regression analyses showed that dimensions of parental locus of control were significant predictors of negative maternal adjustment. Maternal positive perceptions were predicted by perceived control of the child and belief in fate or chance. Overall parental internal-external locus of control entered into a bidirectional relationship with stress over 18 months.

**Conclusions** – Parental locus of control is a construct that may explain some of the variance in maternal well-being and thus is a construct that merits further research.

Parental adaptation to raising a child with intellectual disabilities (ID) is a complex process that has been studied from many perspectives. A wide range of variables, including child (e.g., behaviour problems, severity of disability), family (e.g., parental age, income, marital status), and environmental factors (e.g., social support, respite) have been investigated to explain variation in parental psychological well-being. However, an area less fully explored within the ID literature is that of parental cognitions and it is only since the 1990s that ID family researchers have begun to actively study putative psychological processes to attempt to explain the variance in familial well-being. Foci for recent interest have included parental self-efficacy (Hastings & Brown, 2002a; Kuhn & Carter, 2006), parental sense of coherence (Oelofsen & Richardson, 2006; Olsson & Hwang, 2002), and parental acceptance (Lloyd & Hastings, 2008). In general, findings show that parental cognitions are associated with well-being, both cross-sectionally and longitudinally.

One construct that has received little research attention is that of parental locus of control. Locus of control was first defined by Rotter (1966) as a person's tendency to view events as being controlled by either internal or external factors. According to Rotter, a person with an internal locus of control would believe that an outcome is contingent on their own behaviour and a person with an external locus of control would believe that the outcome had occurred, not as a result of their own actions, but because of other people's actions, or due to fate, luck or chance. Locus of control has been investigated by psychologists in several domains, for example, in educational settings (see Findley & Cooper, 1983, for a review) and in the workplace (see Ng, Sorensen, & Eby, 2006, for a review). In these contexts, it has generally been shown that internal locus of control is associated with more positive outcomes, such as

greater academic achievement, more favourable work outcomes, and greater job motivation.

Locus of control has also been associated with psychological problems. Research has shown that people with an internal locus of control are less susceptible to the effects of stress than those with a more external locus. Anderson (1977) found that people with an external locus of control perceived more stress and responded with more defensiveness than those with an internal locus of control. Locus of control has also been associated with anxiety. Sandler and Lakey (1982) found that college students with a high external locus of control reported significantly more anxiety than students with an internal locus of control. Additionally, in a meta-analysis of studies investigating locus of control and depression, Benassi, Sweeney and Dufour (1988) found strong support for the association between higher levels of depression and greater levels of external locus of control.

Despite much early research, little current evidence is available on the general concept of locus of control. This is due to the fact that locus of control is situation specific (Rotter, 1975). A person's locus of control can vary across situations and behaviours depending on past history of reinforcement and behavioural expectancies. Therefore, situation specific measures of locus of control have been developed. The Parental Locus of Control Scale (PLOC; Campis, Lyman, & Prentice-Dunn, 1986) was developed specifically to measure the locus of control construct for parents. The measure consists of five subscales that form an assessment of a parent's locus of control orientation towards the parent/child relationship. A parent with an internal parental locus of control will perceive that they have control over their child and that the child's behaviour and development are products of the parenting they receive. A parent with an external locus of control will, conversely, believe that the child's



behaviour and development are due to factors that are unrelated to the parenting the child receives and that they have little control over their child. Since the development of the PLOC measure, there is a growing research literature on the relationships between parental locus of control and the behaviour of typically developing children, children with challenging behaviours, and children with various clinical diagnoses (e.g., Barakat, Lutz, Nicolaou, & Lash, 2005; Hagekull, Bohlin, & Hammarberg, 2001; Janssens, 1994).

Locus of control in parents has also been studied in families where a child has an intellectual or developmental disability. Early studies have shown relationships between general locus of control (locus of control at a global, or non-specific, level) and maternal adaptation. Locus of control has been shown to be related to maternal stress (Friedrich, Wilturner & Cohen, 1985) and pessimism (Rimmerman, 1991). Additionally, relationships between locus of control and adjustment in parents of children with autism have been found. Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) showed that an external parental locus of control was associated with increased reports of parental depression and Henderson and Vandenberg (1992) showed that high internal locus of control predicted improved family adaptation.

More recently, researchers in the ID field have used the PLOC measure as a specific assessment of parenting beliefs. Hassall, Rose, and McDonald (2005) explored parenting self-esteem and parental locus of control in mothers of children with ID. Forty six mothers of school aged children, with levels of stress that were significantly higher than normative samples, responded to a questionnaire asking about parental locus of control, self-esteem, and social support. Results showed that parental locus of control was highly correlated with maternal stress, in that a high score on external locus of control was positively associated with high maternal stress

levels. This correlation was primarily accounted for by the parental control and the child control subscales of the PLOC scale. Thus a parent who felt unable to control their child's behaviour (parental control) and who felt that their child's needs dominated their life (child control) reported a high level of stress. In regression analyses, Hassall et al found that a model containing parental locus of control, parenting satisfaction and child behaviour problems predicted maternal stress.

Jones and Passey (2005) studied parental stress and locus of control in 48 family caregivers of children with ID using the PLOC measure and found initial positive correlations between three of the PLOC subscales and stress. Parental feelings of ineffectiveness in the parenting role, lack of parental feelings of responsibility for the child's behaviour, and parental perceptions of the child's needs dominating their lives were all related to increased reports of stress. Further analyses revealed that 32% of the variance in parental stress was predicted by the child control subscale of the PLOC scale such that parents who believed that their child's needs dominated their lives reported more overall stress.

Results of locus of control research with parents of children with intellectual and developmental disabilities are generally consistent. Using global measures, an external locus of control has generally been found to be maladaptive. Similar results have been found using a situational measure of locus of control. Thus, based on previous research, we developed two predictions for the present research. First, we expected external parental locus of control to be positively associated with maternal distress (stress, anxiety, and depression) and internal locus of control to be positively associated with maternal positive perceptions of the child with ID. Second, we predicted that any relationships between maternal well-being and locus of control would be found longitudinally as well as cross-sectionally. In addition to these

predictions, we included an exploration of whether maternal locus of control would act as a moderator in the relationships between: a) child behaviour problems and maternal distress, and b) child adaptive behaviour and maternal distress. Moderated effects have not been tested in previous ID research but theoretical perspectives suggest that external locus of control might exacerbate the impact of demands on psychological well-being whereas an internal locus of control might be protective.

### Method

*Participants.* Ninety one mothers of school aged children with intellectual disabilities took part in the study at Time 1. All the mothers lived in the South East of England and were primary carers for their children who lived at home full time. Maternal ages ranged from 28 years to 58 years ( $M = 41.57$  years;  $SD = 6.32$  years). Most of the mothers ( $n = 75$ ) were married or currently living with a partner, with 16 who were divorced or otherwise single and not currently living with a partner. The mothers in the sample were well educated; 41 mothers had a college or university education, 43 mothers had graduated from high school, and only 7 mothers had no formal educational qualifications. Fifty three of the mothers had a full or part time job outside of the home, while the remaining 38 mothers were not in employment. Sixty six of the mothers had a partner who worked outside of the home. The average annual family income at the time of the research was approximately £30,000 (roughly equivalent to \$73,000 Australian dollars).

The children with ID comprised 64 boys and 27 girls between the ages of 3 and 19 years with a mean age of 10.75 years ( $SD = 4.22$  years) who attended schools for children with special educational needs. According to maternal report, 39 children had a diagnosis of autism in addition to their ID, 15 had Down syndrome, 12 children had cerebral palsy and 25 children had either no identified aetiology for their ID or an

aetiology shared by only one or two other children in the sample. Fifty four children had moderate/mild developmental delay and 37 children had profound/severe developmental delay, according to the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla & Cicchetti, 1984) completed with the mothers.

Approximately 18 months later, longitudinal data were collected from 57 of the mothers. At Time 2, mean maternal age was 43.96 years (SD = 5.54 years). Mean child age was 12.40 years (SD = 49.26 months). There were 41 boys and 16 girls at Time 2; 22 children had autism and ID, seven had Down syndrome, and six had cerebral palsy. We compared mothers and children who participated at both time points with those who participated at Time 1 only. No significant differences were found on any of the study variables, indicating that the sample for whom longitudinal data were collected were reasonably representative of the initial sample.

*Measures.* Seven measures were used in the study, including a demographic questionnaire that assessed characteristics reported in the Participants section (see Appendix A).

*Child Measures: The Vineland Adaptive Behavior Scale (VABS) – Survey Form (Sparrow, Balla & Cicchetti, 1984).*

Child adaptive behaviour was measured using the VABS, which takes the form of a semi-structured interview measure where the interviewer estimates an adaptive level (i.e., the stage at which the child functions in day to day activities) and asks in detail about skill items in this range to arrive at an accurate estimate of a child's abilities. The interview assesses four domains: Socialization, Communication, Daily Living Skills, and Motor Skills. These items are arranged in developmental sequence but not all 297 questions are asked in an interview as the interview focuses on the stage at which the child is performing. An overall composite score can be

derived from the data based on age-related norms. This VABS composite score was used in the present analysis as an overall index of the child's adaptive skills.

*The Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997).*

The SDQ (see Appendix B) was used as a measure of children's behaviour. The SDQ is a 25 item behavioural screening questionnaire that contains four problem behaviour subscales that can be summed to give a total difficulties score. These problem behaviour subscales assess hyperactivity (e.g., "easily distracted, concentration wanders"), emotional symptoms (e.g., "often unhappy, downhearted or tearful"), conduct problems (e.g., "often lies or cheats"), and peer problems (e.g., "rather solitary, tends to play alone"). A total difficulties score was used as the measure of problem behaviour in this study. In addition to the assessment of problem behaviour, the SDQ also contains a prosocial behaviour subscale (e.g., "considerate of other people's feelings") and this was used as the measure of prosocial child behaviour. Although originally developed for use with families of typically developing children, research with families of children with ID suggests that good levels of reliability are maintained when the scale is used with this population (Beck, Daley, Hastings, & Stevenson, 2004; Emerson, 2003, 2005). In the present sample, a Cronbach's alpha of .88 was obtained for both the total difficulties and the prosocial behaviour scales.

*Maternal Measures: Parental Locus of Control Scale (PLOC: Campis, Lyman, & Prentice-Dunn, 1986)*

Locus of control that is specific to the parent/child relationship was measured using a modified version of the Parental Locus of Control Scale (Campis et al., 1986 see Appendix N). In its original form, the PLOC consists of 47 items measured over 5 factors: parental efficacy (e.g., "What I do has little effect on my child's

behaviour”), parental responsibility (e.g., “My child’s behaviour problems are no one’s fault but my own”), child control of parent’s life (e.g., “I feel like what happens in my life is mostly determined by my child”), parental belief in fate/chance (e.g., “I’m just one of those lucky parents who happened to have a good child”), and parental control of child’s behaviour (e.g., “It is often easier to let my child have his/her own way than to put up with a tantrum”).

Although Campis and colleagues (1986) reported a Cronbach’s alpha of .92 for the total score for their scale, alphas for their individual subscales were less promising (range .65 - .77). Despite following scoring recommendations by Campis et al. that included the removal of one item and one subscale, the Cronbach’s alpha levels for the subscales for the current research were unacceptably low (range .59 - .65). Therefore, an item reduction procedure was used to develop a more robust measure for the present research. We focused on each of the subscales in turn and systematically removed the items with the lowest corrected item-total correlations until the most robust set of items for each subscale was achieved<sup>1</sup>. We removed two items from the parental efficacy subscale, two items from the child control subscale and one item from the fate/chance subscale. Forty two items remained, and the subscales for this revised scale then reached acceptable alpha levels (parental efficacy .69, 8 items; parental responsibility .81, 10 items; child control .70, 5 items; fate/chance .67, 9 items; parent control .82, 10 items). The Cronbach’s alpha for the total PLOC score (general internal-external orientation) based on these 42 items was also good at .81.

The scoring for the revised scale remains the same, with a high overall score on the PLOC indicating a parent who has an external locus of control specifically with

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<sup>1</sup> Details of the items deleted from the scoring of each subscale can be obtained from the corresponding author

regard to parenting their child. Items are scored on a five point Likert-type scale. A high score on the parental efficacy subscale denotes a parent who does not feel effective in their parenting role. High scores on the parental responsibility subscale show that the parent does not feel responsible for their child's behaviour. For the child control subscale a high score indicates that the parent feels that their child's needs and demands dominate their life. A high score on the fate/chance subscale reveals a parent who believes that both their behaviour and that of their child is influenced by outside factors. Higher scores on the parental control subscale indicate a parent who feels unable to control their child's behaviour.

*Positive Contributions Scale (PCS; Behr, Murphy & Summers, 1992)*

Mothers' perceptions about the positive contributions their child with ID makes to the parent and the family were measured using the Positive Contributions Scale (PCS) from the Kansas Inventory of Parental Perceptions (Behr et al., 1992, see Appendix F). The PCS is a 50 item measure containing items derived from a large-scale research study of parents of children with disabilities. The scale uses a four point Likert-type method to assess positive perceptions across nine domains that include learning through experience with special problems in life; happiness and fulfilment; family strength; understanding life's purpose; awareness about future issues; personal growth and maturity; expanded social network; career/job growth; and pride and co-operation. A PCS total score was used in the present research. Previous research shows that reliability for the PCS is good; a Cronbach's alpha of .92 was reported in a study of mothers of children with ID (Hastings, Beck & Hill, 2005). For the present sample, a comparable alpha of .93 was obtained.



*Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).*

Maternal mental health was measured using the Hospital Anxiety and Depression scale (see Appendix G). Although originally developed for use in hospital populations, this measure has been used extensively in research with the general population and has good agreement with other measures of mental health, for example, the Center for Epidemiological Studies Depression Scale (e.g., Katz, Kopek, Waldron, Devins, & Tomlinson, 2004). The HADS contains 14 items, measured on a four point Likert-type scale. Seven items assess anxiety (e.g., “I feel restless as if I have to be on the move”) and seven assess depression (e.g., “I still enjoy the things I used to enjoy”). In the present study a total score for depression and a total score for anxiety were used. Previous research with mothers of children with developmental disability has shown that the HADS is a reliable instrument, having a Cronbach’s alpha of .80 or above for both anxiety and depression within these populations (Hastings, 2003; Hastings, Beck, Daley & Hill, 2005; Hastings & Brown, 2002). For the current study, Cronbach’s alpha levels of .82 for the anxiety subscale and .77 for the depression subscale were found.

*Questionnaire on Resources and Stress Friedrich short form (QRS-F Freidrich, Greenberg & Crnic, 1983)*

The Parent and Family Problems subscale of the QRS-F short form (see Appendix H) was used as a general measure of stress. This 20 item scale assesses the effect that the child has on the parent and the family (e.g., “I have given up things I have really wanted to do in order to care for N”, and “There are many places where we can enjoy ourselves as a family when N comes along”). Parents are asked to indicate whether the items are true or false for themselves or their family. A total stress score is computed by summing the number of negatively endorsed items



(positively worded items are reverse scored). Five items were removed from the scale as they have been shown to constitute a robust measure of depression in parents of children with disabilities (Glidden & Floyd, 1997). Removing these items ensured that there was no overlap between the measures of stress and of mental health used in the present research. For the 15 items used in the present sample, a Kuder-Richardson co-efficient of .86 was found.

*Procedure.* Before participants were contacted, ethical approval was granted for the research by Bangor University (see Appendix I). Initial contact with participants at Time 1 was facilitated by letters of introduction that were sent to 17 special schools (see Appendix J). Nine schools chose to participate and distributed information packs to the families of children in their schools. One hundred and thirty mothers requested more information and, of these, 91 returned a completed questionnaire pack. This represents a response rate from initial expressions of interest of 70%, though it is unclear how many families initially received invitations to participate. All mothers gave informed consent for their data to be used in the research (see Appendix K). After the mothers had completed and returned the questionnaires, they were sent a thank you letter arranging an appointment time for a researcher to telephone them and talk with them about their child (see Appendix L). If the questionnaires were not returned within a two-week time period, a personally addressed reminder letter was mailed to the home (see Appendix M). The VABS was conducted by telephone, usually within a week of receipt of the completed questionnaire. Though often administered face-to-face, the VABS has been shown to be suitable for telephone administration with parents of children with ID (Beck et al., 2004). The same procedure is used for telephone interviews as for face-to-face interviews. At Time 2, 18 months later, mothers were invited by letter to participate in

a follow-up study. Mothers who expressed a wish to do so were mailed a questionnaire that was identical in content to the Time 1 questionnaire. Fifty seven mothers completed the questionnaire at Time 2 (a response rate at Time 2 of 63%). Participants were recruited on a voluntary basis and received no payment for taking part in this research.

### Results

The distributions of the study variables were explored using Kolmogorov-Smirnov tests, the results of which were non-significant, suggesting that the variables were reasonably normally distributed and thus suitable for parametric analyses. To analyse the data, we first used Pearson's correlations to determine the associations that exist between the demographic, child, and locus of control variables and the maternal well-being measures. For dichotomous variables (e.g., presence or not of a diagnosis of autism), point biserial correlations are reported. Having identified initial correlations, linear regressions were conducted with maternal well-being variables as dependent variables and all significant correlates as predictor variables. Thus, we investigated the independent contribution of dimensions of parental locus of control to the prediction of maternal well-being. We then explored the stability of the parental locus of control subscales before assessing their longitudinal relationships with maternal well-being measures. Finally, we performed exploratory moderated multiple regression analyses to assess whether locus of control interacts with child variables to affect maternal well-being.

*Cross-Sectional Analysis at Time 1.* Univariate associations between study variables are shown in Table 4.1. Demographic and background variables are only represented if they were associated significantly with at least one maternal well-being measure. The data in Table 4.1 show that maternal positive perceptions of the child

with ID were positively associated with maternal belief in fate/chance and negatively associated with maternal control. Thus mothers who perceive their child as a positive factor in their lives also believe strongly in fate and chance (external locus of control) and believe that they are more able to control their child's behaviour (internal locus of control). For maternal anxiety, parent control, child control and a total parental locus of control score were positively associated, indicating that mothers with a higher external locus of control are more anxious (mothers who are more anxious feel that their child's demands dominate their lives and that they are unable to control their child's behaviour). The same is true for both depression and stress; mothers who have a higher external locus of control (total PLOC score) and feel that they are unable to control their child's behaviour and that their child's demands dominate their lives, report more depression and stress. In addition, mothers reporting more stress and depression also feel less effective in their parenting role (external locus of control).

Table 4.1 Correlation Matrix for Study Variables at Time 1.

Measure	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Anxiety		.57***	.33**	-.04	.12	.02	.29**	.05	.37***	.27*	.14	.03	.10	-.04	.19	.14	.16
2. Depression			.49***	-.19	.25*	.03	.36***	-.02	.30**	.27*	.18	-.03	-.00	.00	.20	.06	.06
3. Stress				-.29**	.29**	.05	.55***	-.23	.49***	.43***	.16	-.08	.25*	.28**	.45***	-.30**	-.08
4. Positive contributions					-.16	-.15	-.02	.22*	-.23*	-.14	-.24*	-.24*	-.17	-.03	.01	.12	.19
5. Parental efficacy						.09	.11	.33**	.39***	.63***	.11	-.03	-.12	-.07	.33**	.10	-.12
6. Parental responsibility							.08	-.07	.07	.47***	-.04	.02	-.06	.12	.19	-.07	.04
7. Child control								-.03	.40***	.49***	-.07	-.10	.11	.26*	.15	-.23*	-.16
8. Belief in fate/chance									.20	.44***	-.07	-.07	-.11	-.03	.07	.17	.06
9. Parent control										.78***	.11	.12	.01	.12	.43***	-.08	-.81
10. Parental LOC total											.02	.04	-.07	.17	.47***	-.05	-.10
11. Number of children in family												-.22*	.16	-.03	.05	-.15	-.12
12. Primary carer job													-.00	-.08	-.10	.17	.04
13. Family deprivation														-.07	.04	-.07	-.09
14. Diagnosis of autism															.39***	-.46***	-.01
15. Child behaviour problems																-.37***	-.10
16. Child prosocial behaviour																	.23
17. Child adaptive behaviour																	

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

All variables that showed significant correlations with maternal well-being variables at the  $p < .05$  level were entered into linear multiple regression analyses for maternal positive perceptions, anxiety, depression, and stress. The analyses were divided into two distinct phases. First, we conducted regressions with the sub-scale scores from the PLOC as predictors. Second, we explored the PLOC total score as a predictor of maternal well-being. The PLOC total score was not explored alongside other dimensions of the PLOC because of the problem of multicollinearity. As there were no correlates of anxiety and depression other than PLOC scores, and PLOC total scores were not correlated with positive perceptions, we only conducted a regression analysis for stress using PLOC total as a predictor. The results of these regression analyses are summarized in Tables 4.2 and 4.3.

Table 4.2. Regression Analysis of Maternal Well-being at Time 1.

Dependent Variable	Predictor Variable	$\beta$	$p$
Positive perceptions <sup>1</sup>	Maternal employment	-.248	.023
	Number of children in the family	-.245	.024
	Belief in fate/chance	.236	.028
Anxiety <sup>2</sup>	Parent control	-.216	.047
	Child control	.142	.193
Depression <sup>3</sup>	Parent control	.314	.005
	Parent efficacy	.159	.142
	Child control	.278	.012
Stress <sup>4</sup>	Parent control	.128	.279
	Presence of autism	.002	.987
	Family deprivation	.120	.163
	Child prosocial behaviour	-.127	.201
	Child problem behaviour	.208	.055
	Parent efficacy	.130	.177
	Child control	.413	<.001
	Parent control	.202	.060

<sup>1</sup>( $R^2 = .47$ ,  $F(4, 75) = 5.17$ ,  $p < .001$ ), <sup>2</sup>( $R^2 = .15$ ,  $F(2, 86) = 7.89$ ,  $p < .001$ ), <sup>3</sup>( $R^2 = .17$ ,  $F(3, 85) = 5.89$ ,  $p < .001$ ), <sup>4</sup>( $R^2 = .49$ ,  $F(7, 76) = 10.55$ ,  $p < .001$ ).

Table 4.3. Regression Analysis of Maternal Well-being at Time 1, using Parental Locus of Control Total Score.

Dependent Variable	Predictor Variable	$\beta$	$p$
Stress	Presence of autism	.061	.561
	Family deprivation	.253	.008
	Child prosocial behaviour	-.153	.157
	Child problem behaviour	.197	.082
	Parental LOC	.376	.001

$R^2 = .39$ ,  $F(5, 75) = 9.59$ ,  $p < .001$ .

For maternal positive perceptions, the belief in fate/chance and parental control variables from the PLOC scale were entered into the regression model with maternal employment status and number of children in the family. Overall, a significant percentage of the variance in maternal positive perceptions (47%) was explained by the regression model. All of the variables entered were significant predictors. For maternal anxiety, parental control and child control were entered as predictor variables, and accounted for 15% of the variance. However only parental control was a significant independent predictor. For depression (17% of variance explained), parental efficacy, child control and parental control were entered and only maternal perceptions of their child's control over their behaviour was a significant predictor. Finally, for stress, in the PLOC sub-scales model, child control and parent control were significant predictors and child problem behaviour was a marginally significant predictor. The model accounted for 49% of the variance in stress scores. In the model that included the total PLOC score only, 39% of the variance was accounted for and both family deprivation and parental LOC were significant predictors of maternal stress.

*Stability of Locus of Control Across Time.* To test whether the parental locus of control scales remained stable over 18 months, we correlated the Time 1 data with the data gathered at Time 2. All but one of the subscales had stability coefficients indicating at least moderate stability over time (parental efficacy  $r = .54, p < .001$ ; parental responsibility  $r = .63, p < .001$ ; belief in fate/chance  $r = .63, p < .001$ ; parental control  $r = .54, p < .001$ ). The child control subscale, however, was not significantly correlated at Time 1 and Time 2, ( $r = .11, p = .415$ ) suggesting that maternal feelings that the child's needs and demands control their lives is a construct that is less stable. Finally, the PLOC total score also showed moderate stability over time ( $r = .61, p < .001$ ).

*Longitudinal Analysis.* Regression analyses using longitudinal data focused on those variables that were significant predictors of maternal well-being at Time 1. In conducting the longitudinal analyses, we adopted procedures used in other recent longitudinal studies within the field of ID family research (Baker et al., 2003; Hastings et al., 2006; Lecavlier et al., 2006). Therefore, when predicting maternal well-being, we entered Time 2 positive perceptions, anxiety, depression, and stress as dependent variables in the models and as predictor variables we included those parental locus of control variables and child variables that were significant predictors at Time 1. We also entered the Time 1 scores for the relevant dependent variable. For the locus of control variables and child variables we entered both the Time 1 scores and the change scores across time. Change scores were produced by subtracting Time 1 scores from Time 2 scores on the parenting locus of control and child behaviour variables.

After controlling for Time 1 maternal well-being and any relevant demographic and child variables, no parental locus of control sub-scales predicted



maternal well-being across time, although there was evidence that mothers whose children's behaviour problems increased over time reported increased stress over 18 months ( $\beta = .302, p = .005$ ). For the total parental locus of control score, however, the picture was somewhat different. After controlling for stress at Time 1, the change in parental locus of control across time was a significant predictor of stress at Time 2. Since parental locus of control and stress were related over time, we also tested to see if this was, in fact, a bi-directional relationship by conducting a regression analysis to predict Time 2 total parental locus of control from the change in stress over time, whilst controlling for Time 1 stress and Time 1 parental locus of control. The analysis showed that both change in stress over time and stress at Time 1 were significant predictors of parental locus of control at Time 2, indicating that a bi-directional relationship exists between maternal stress and parental locus of control. These results are shown in Tables 4.4 and 4.5.

Table 4.4. Longitudinal Analysis of Maternal Stress using Parental Locus of Control total score.

Predictor	$\beta$	$p$
Stress Time 1	.708	<.001
Deprivation Time 1	.061	.540
Parental LOC Time 1	.011	.927
Change in Parental LOC T1-T2	.242	.026

$R^2 = .60, F(4,45) = 16.98, p < .001$

Table 4.5. Longitudinal Analysis of the Parental Locus of Control total score.

Predictor	$\beta$	$p$
Parental LOC Time 1	.537	<.001
Deprivation Time 1	-.021	.856
Stress T1	.353	.015
Change in Stress T1-T2	.285	.026

$R^2 = .48, F(4,45) = 10.29, p < .001$

Finally, we tested the hypothesis that parenting locus of control would act as a moderator in the relationships between child behaviour problems and maternal distress and between child adaptive behaviour and maternal distress. We followed procedures suggested by Baron and Kenny (1986) and entered the main effect of the predictor variable into a regression analysis, followed by the main effect of the moderator variable, and then an interaction term derived from centred versions of these two variables. None of the interaction terms emerged as significant independent predictors of maternal well-being, suggesting no evidence of moderated effects.

#### Discussion

In the present study, we extended previous research on the construct of locus of control in mothers of children with ID in four ways. First, along with stress and depression, we included a measure of maternal anxiety; this has not been investigated previously. Second, we included a measure of maternal positive perceptions. It is important that we attempt to account for positive aspects of parenting a child with ID as well as investigating parental distress, since research has shown that many families adjust well to their child's ID and some families report both distress and positive aspects concurrently (Hastings & Taunt, 2002). This indicates that positive and

negative aspects may involve separate cognitive processes. Third, no other study of locus of control across time with an ID population exists. Therefore, we explored whether parental locus of control would have longitudinal relationships with maternal well-being. Finally, we investigated whether parental locus of control would moderate relationships between child variables and maternal well-being, again a factor thus far unstudied.

As predicted from the literature on parental locus of control and distress, parental locus of control in parents of children with ID was found to be significantly associated with stress and depression cross-sectionally. In addition, parental locus of control was correlated with maternal anxiety. Specifically, those mothers with more external parental locus of control were more likely to report more symptoms of distress. In contrast to Hassall, Rose and MacDonald's (2005) findings, our results revealed a positive correlation between feelings of parental efficacy and maternal stress, thus lending support to results on this dimension in the Jones and Passey (2005) study.

Parental locus of control was also associated with maternal positive perceptions of the child. These relationships were more complex. Mothers who believed more in fate/chance (external control) were more likely to appreciate the positive aspects of their child, whereas mothers who felt that they could not control their child's behaviour (external control) were less likely to appraise their child in a positive way. These findings may indicate that mothers who believe in fate/chance may not hold themselves responsible for their child's disability and may therefore be able to see their child for the person they are without feelings of guilt. This hypothesis needs further investigation. Elements of personal control also require further investigation since mothers hold positive perceptions of their child when they

feel in control of their child's behaviour. It would be interesting to see if positive perceptions are also related to control in other areas of the mothers' lives; this could be accomplished with the use of a more generic measure of locus of control.

It is interesting to note that the parental responsibility subscale was not related to any of the maternal well-being variables and that the parental control subscale was initially correlated with all the maternal well-being measures and made a significant independent contribution to the prediction of both positive perceptions and maternal anxiety at Time 1. Parental control was, therefore, the most robust predictor of maternal well-being from the PLOC measure, whilst parental responsibility was the least robust. Further research is needed to discover why this might be, but again, the issues of control in other areas of mothers' lives may shed some light on these findings. A possible theoretical explanation for these findings may be the theory of learned helplessness (Seligman, 1975), which posits that people in uncontrollable situations learn to be helpless. A mother who feels unable to control her child's behaviour may develop learned helplessness.

Consistent with existing research (Hagekull et al., 2001), the construct of parental locus of control was moderately stable across time, except in the case of the child control variable. The relative instability of the child control subscale may reflect the fact that parents may feel differently about how their lives are affected by their child's needs at different times and this is not surprising given that parents of children with ID have fluctuating demands and needs depending on their environment at any given time. For example, we might expect parental locus of control about the child's needs to change during periods of child illness or during school holidays as the environmental contingencies are somewhat different for parents at these times.

Reasons such as these may also account for the fact that locus of control did not act as

a moderator in the relationships between child adaptive behaviour and maternal well-being and between child behaviour and maternal well-being.

Longitudinal data analysis revealed no significant relationships between maternal well-being and parental locus of control sub-scales across time. However, a bi-directional relationship across time was found to exist between maternal stress and the change in the total parental locus of control score (i.e., general external-internal orientation in the parenting domain). This result indicates that as mothers' external parental locus of control increases across time, their reported stress levels also increase. It is therefore possible that by encouraging parents to develop more of an internal parental locus of control, stress may be reduced.

We must view this latter finding with caution. Because no other longitudinal relationships were found with PLOC sub-scales, we can only draw tentative conclusions about the relationship between parental locus of control and well-being in mothers of children with ID over time. This is not to say that research should not include longitudinal measurement of parental locus of control in future studies. Rotter (1966), in his original work on locus of control, highlighted the fact that behavioural expectancies are strengthened or weakened by the repetition of environmental events. Therefore, locus of control can be affected by the environment and can be said to have state-like properties. The moderate stability coefficients for the parental locus of control scores in the present study also tend to support a conclusion that parental locus of control is not a typical trait variable. It may be that other variables not measured in this study intervened to change the relationships established at Time 1. The effects of social support on parental locus of control may be a candidate for further investigation as cross-sectional relationships have been shown between levels

of social support and levels of parental locus of control (Dunn et al., 2001; Hassall et al., 2005)

Although our data show that parental locus of control is a construct that can explain variance in parental well-being in families of children with ID, these results must be interpreted with some caution. First, no fathers took part in this study. Since studies have shown that mothers and fathers differ in their experience of raising a child with ID (Hastings, Beck, & Hill, 2005) and that there is a difference in the way that mothers' and fathers' locus of control affects the child (Janssens, 1994), this study needs replicating with a sample of fathers.

Additionally, the sample of mothers we investigated was relatively affluent and well educated. This factor must be considered when interpreting the results, since locus of control may well be related to social status (e.g., Miech & Shanahan, 2000; Wang, Kick, Fraser, & Burns, 1999). Furthermore, due to the affluence of the sample, it is questionable whether these data can be generalized to a larger population of parents of children with ID. More research that incorporates a wider demographic is recommended.

Second, the PLOC measure requires further development. We know of at least three studies where the PLOC measure has been adapted (Barakat, Lutz, Nicolaou, & Lash, 2005; DeMaso, Campis, Wypij, Bertram, & et al., 1991; Hassall, Rose, & McDonald, 2005) from the original measure developed by Campis et al. and we have used another adapted version here. Therefore, it is difficult to assess the psychometric pedigree of the measure. In this study, we looked at the subscales of the PLOC scale and the reliability of measure was low, thus we used an item reduction technique to improve the Cronbach's alphas for the scale. The PLOC scale would benefit from more use with large populations (c.f. Hagekull, Bohlin, & Hammarberg,

2001) to ensure that it is a reliable measure of parental locus of control. It would also be worthwhile to carry out further item development studies to see if all the subscales are actually measuring parental locus of control and not any other parental cognitive variable. Indeed in an analysis of the discriminant validity of the PLOC scale, Lovejoy, Verda and Hays (1997) question whether the PLOC scores may also reflect parental distress and socially desirable response styles. Bugental, Johnston, New and Silvester (1998) voice concerns over possible impression management by parents completing self report questionnaires about their parental attributions. This must be considered for the PLOC measure in that parents may have defended socially less acceptable feelings of powerlessness by describing themselves as more dominant in their relationship with their child.

In conclusion, the concept of parental locus of control has been shown to be related to maternal well-being and thus merits further investigation within families of children with ID. It may be useful to extend the research to include other caregivers who look after the children on a daily basis, such as grandparents, teachers, or other paid carers in order to provide a bigger picture of the family system. Locus of control could also be a useful measure of parental attitude change during interventions. Roberts, Joe, and Rowe-Hallbert (1992), whilst developing parent training for children with oppositional behaviours found that parents who successfully completed the programme tended to develop an increasingly internal parental locus of control. However, before any further conclusions can be drawn, the construct of parental locus of control needs to be further refined and a more sensitive measure developed.

Chapter 5. Hope as a Psychological Resilience Factor in Mothers and Fathers of  
Children with Intellectual Disabilities



### Abstract

**Background** – Positive psychology is an area gaining credence within the field of intellectual disability (ID). Hope is one facet of positive psychology that is relatively unstudied in parents of children with ID. Hope is a theory of goal-driven action and is comprised of agency and pathways thinking (Snyder, Harris et al., 1991). In the present study, we explore hope and its relationships with parental well-being in parents of school-aged children with ID.

**Method** – 138 mothers and 58 fathers of children with ID took part in a questionnaire-based study. Parents reported on their feelings of hope and positive affect, other dimensions of psychological well-being (anxiety, depression and stress), and on their child's behaviour.

**Results** – For mothers, regression analyses revealed that hope (agency and pathways) and child behaviour problems predicted maternal depression. Positive affect was predicted by child behaviour problems and by hope agency. For fathers, anxiety, depression and positive affect were all predicted by hope agency. Hope pathways was not a significant predictor of paternal well-being. Hope agency and pathways interacted in the prediction of maternal depression such that mothers reporting high levels of both hope dimensions reported the lowest levels of depressive symptoms.

**Conclusions** – Hope is a construct that merits further investigation within families research, and is potentially a factor that could be utilised in intervention to help increase familial well-being.

Researchers have traditionally examined the experiences of raising a child with an intellectual disability (ID) from the perspective of the potential negative impact on parents' well-being (Helff & Glidden, 1998). However, recent data and conceptual reviews clarify that although parents may well be at increased risk for psychological distress, at the same time they report positive experiences (Hastings & Taunt, 2002). Research focused on positivity in parents of children with ID (e.g. Bayat, 2007; Blacher & Baker, 2007; Hastings, Beck, & Hill, 2005) is in line with a growing trend within psychology towards positive psychology, which is a focus on adaptive, rather than maladaptive functioning, and on strengths and abilities, rather than weaknesses (Seligman & Csikszentmihalyi, 2000). Thus, the orientation of positive psychology is towards identifying resilience as opposed to risk.

Several variables that fall under the umbrella of positive psychological constructs have been investigated as potential resilience factors for parents of children with ID. These include self-efficacy (e.g. Hastings & Brown, 2002b; Kuhn & Carter, 2006), optimism (e.g. Baker, Blacher, & Olsson, 2005), benefit finding (e.g. Pakenham, Sofronoff, & Samios, 2004; Rapanaro, Bartu, & Lee, 2008), acceptance (Lloyd & Hastings, 2008), and mindfulness (e.g. Lloyd & Hastings, 2008; Singh et al., 2006). For example, optimism was investigated in parents of 3 year old children, with and without developmental delays (Baker, et al., 2005). Focusing on optimism as a trait variable, Baker and colleagues found that, for both fathers and mothers, higher self-reported optimism was related to positive well-being.

At this point it is worth establishing more formally the nature of parental resilience factors. Resilience factors most consistently are perceived as variables that have main effect relationships with outcome variables of interest. Luthar and Zigler (1991) suggest that such variables should be called compensatory: having a positive

association with positive outcomes, or a negative (i.e., reducing) effect on negative outcome variables. In the Baker et al. (2005) research, optimism was a compensatory variable for both maternal and paternal adjustment.

Hope is one variable that has, as yet, received very little research attention within ID family research but has significant potential as a parental resilience factor. Hope is often thought of in lay terms as an emotion akin to optimism. However, the definition of hope as used in the present research is one that focuses on a person's goals and that person's perceived ability to reach those goals. This definition differs from that of optimism in that hope includes both the perception that goals can be met ("agency") and the ability to plan ways to meet these goals ("pathways") (Snyder, Rand & Sigmon, 2002). Hope theory (Snyder, Harris et al., 1991) focuses on the fact that human behaviour is primarily goal driven, and hope can, therefore, be defined as the perception that one can attain one's goals (Frankl, 1992). How a person thinks about goal attainment can have an effect on outcomes; those with high hope tend to experience positive emotions and view barriers to success as challenges, rather than as stressors (Oettingen & Gollwitzer, 2002).

To reach desired goals, Snyder and colleagues propose two inter-related components that comprise hope. Agency refers to a person's perception of how able they are to initiate and maintain the actions needed to meet their goals. This applies to past, present and future goals. The pathways component of hope refers to a person's perception that they have the ability to generate workable routes to reach these goals (Snyder et al., 1991; Snyder et al., 1996). These two components are both necessary in the formulation of a theoretical model of hope, whereby higher agency and higher pathways thinking are associated with higher hope. However, the components are not

necessarily dependent, thus it is possible for a person to be higher in agency or pathways, depending on their previous experience (Snyder, Rand & Sigmon, 2002).

Hope can be measured either at a dispositional (trait) level (Snyder et al., 1991), or at a situational (state) level (Snyder et al., 1996). When measuring hope as a trait, the assumption is that a person's agency and pathways thinking are relatively constant. However, when hope is measured at a state level, it is assumed that hope levels fluctuate with a given situation. We have chosen for this research to measure hope as a trait variable since the measure we have used has been shown to have temporal stability in test-retest reliability tests (Snyder et al., 1991) and also because the stresses associated with parenting a child with ID are chronic, as shown in recent longitudinal research (e.g. Hastings, Daley, Burns, & Beck, 2006; Lecavalier, Leone, & Wiltz, 2006; Lloyd & Hastings, 2008).

To date, hope has been explored as a construct in ID family research but not in the context of Snyder's theory of hope. In a qualitative analysis of parents' experiences of raising a child with a developmental disability, Kearney and Griffin (2001) found that hope was an issue of some importance for mothers and fathers. Parents commented that they felt that messages of no hope were imposed upon them by professionals, when they as parents felt optimistic and hopeful about the future. The parents also felt that when they expressed their feelings of hope, professionals interpreted this as behaviour that was maladaptive in their situation. Hope in this research was defined as belief in possibilities (cf. agency).

Somewhat differing results were obtained by Kauser, Jevne and Sobsey (2003), who asked 19 parents of children with ID to comment on their feelings of hope. Eight themes emerged from Kauser and colleagues' analyses, including positive attitudes and spirituality as sources of hope, hope as a consequence of the

realistic acceptance of the child and their disability, and hope as an outcome of parenting a child with ID. It is worth noting that Kausar et al. did not define hope rigorously, rather they provide a description of hope as a variable that is “intangible” and that is a “prerequisite for effective coping” (Kausar et al., 2003, p.35) and this is reflected in the subsequent qualitative analysis.

The relationship between challenging behaviour of children with ID and parental hope has also been investigated. Padencheri and Russell (2002) compared the levels of hope among 23 mothers and 23 fathers where the child with ID displayed no challenging behaviour, a single challenging behaviour, or multiple challenging behaviours. Results showed that parents of children with multiple challenging behaviours reported significantly less hope than parents in the other groups. However, whilst this showed that parental hope might vary as a function of child characteristics, no measures of parental psychological outcome were included.

We could find only one study where Snyder’s Hope Scale (Snyder et al., 1991) was used with families of children with ID. Horton and Wallander (2001) collected questionnaire data from 154 mothers of children with chronic health conditions and found that hope was negatively associated with maternal distress. In regression analysis, hope, marital status and disability-related stress predicted distress for mothers. Hope was also found to act as a buffer in the relationship between disability-related stress and maternal distress. However, these data were collected from mothers of children with spina bifida and diabetes, as well as from mothers of children with cerebral palsy and so these data do not exclusively represent the feelings of mothers of children with ID.

The present research had two main aims: a) to explore hope in parents of children with ID in a manner consistent with the main psychological theory of hope

(Snyder et al., 1991; Snyder et al., 1996) and b) to explore hope separately for both mothers and fathers given the lack of existing research on paternal hope. The exploration of hope focused on its potential as a resilience (compensatory) factor for parental psychological well-being. Thus, we explored main effect relationships between hope and parental psychological well-being. In addition, Snyder's hope theory suggests that those individuals with both high agency and high pathways hope will be those who experience the most positive outcomes. This suggests the potential for an interaction effect, and this was explored alongside main effect relationships in the present research.

### Method

*Participants.* One hundred and thirty eight mothers and 58 fathers (56 couples from the same families) from 139 different families of children with ID took part in this study. The mean age of the mothers was 39.56 years ( $SD=7.26$ , range 23-57 years) and the mean age of the fathers was 41.78 years ( $SD=6.91$ , range 23-54 years). Fifty nine percent of the mothers and fathers were married, 11% lived with a partner to whom they were not married, and the remaining 30% were single at the time of the research. In general, parents were well-educated, with 35% of mothers having a University education, 50% a high school education, and only 15% with no educational qualifications. Similarly, 48% of fathers graduated from University, 42% from high school, and 10% had no formal qualifications. Fourteen percent of the mothers worked full time, 35% were employed on a part time basis, and the remaining 51% were full time carers for their child(ren). For fathers, the picture was somewhat different, with 72% working full time, 7% part time, and 21% who were not employed outside the home.

There were 92 boys and 47 girls with ID for whom data were provided by one or more of their parents. The mean age of the children was 10.07 years ( $SD=4.09$ , range 3-18years). The children had diagnoses, based on parent report, of autism ( $N=56$ ), Down syndrome ( $N=26$ ), cerebral palsy ( $N=16$ ) and intellectual disability of unspecified/mixed aetiology ( $N=40$ ). In addition to their diagnoses, 12% of the children had epilepsy, and 28% of the children had mobility problems. All the children attended Special Educational Needs schools in North Wales or the North West of England.

*Measures.* Six measures were used in the study, including a demographic questionnaire that assessed characteristics reported in the Participants section (see Appendix A).

*Child Behaviour Problems.* Given the reliable relationship between child behaviour and mental health problems and parental well-being found in previous ID family research (Hastings, 2002), we included a measure of this dimension of the child's functioning as a control strategy. The Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994, see Appendix O) was completed by parents. This is a 60 item scale that asks about the behaviour of children in addition to an existing ID and comprises 10 factors: anger/self control, anxiety disorder, attention deficit, autism, conduct disorder, depression, poor self-esteem, psychosis, somatoform behaviours, and withdrawn/isolated behaviours. These scales can be used separately or summed to form a total behaviour problems score. A total score was used for this research. The Reiss Scales have been shown to have good psychometric properties (Reiss & Valenti-Hein, 1994) and in the present study Cronbach's alpha coefficients for the total score of .95 and .94 were found for mothers and fathers respectively.



*Parental Hope.* Dispositional hope was measured using the Trait Hope Scale (Snyder et al., 1991, see Appendix P). This is a 12 item scale, comprising four items that measure agency (e.g., “I meet the goals I set for myself”), four items that measure pathways (e.g., “There are lots of ways around any problem”), and four filler items that are disregarded during analyses. Items are coded according to a four point Likert-type scale ranging from definitely false to definitely true, with a high score indicating high hope. Internal consistency of the measure is generally good with Cronbach’s alphas of .71 to .76 for the agency subscale and .63 to .80 for the pathways scale (Snyder et al.). However, no reliability data have previously been reported for a population of parents of children with ID. For the present sample Cronbach’s alpha co-efficients of .78 and .73 were found for the sample of mothers for agency and pathways respectively. For paternal agency and pathways scores, Cronbach’s alphas of .69 and .80 were found.

*Parental Psychological Well-Being.* Parental well-being was measured across four domains: positive affect, stress, anxiety, and depression. Current positive affect was measured using the Positive Affect scale of the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988, see Appendix Q). This is a 10 item scale that asks the respondent to report the way they have been feeling over the past week. Items include, “interested”, “strong”, “inspired”, and “active” and respondents can rate these as very slightly/not at all, a little, moderately, quite a bit, or extremely. Scores are summed, with a high score indicating that the respondent is high in positive affect. For the present sample a Cronbach’s alpha co-efficient of .91 for mothers and of .87 for fathers was found.

The Parent and Family Problems scale of the Questionnaire on Resources and Stress Friedrich Short Form (QRSF; Friedrich, Greenberg, & Crnic, 1983, see



Appendix I) was used as a measure of stress. This subscale measures how the parent feels about the family situation as a whole, as well as problems for themselves and other family members and thus, can be seen as a general measure of family stress. Following recommendations from Glidden and Floyd (1997), five items were removed from the original 20 item subscale. These items were found to be a robust measure of depression in previous research and would therefore be likely to overlap with the measure of depression used in this research. The remaining 15 items have been used previously with families of children with ID and have shown good internal consistency (e.g., Lloyd & Hastings, 2008). A Kuder-Richardson co-efficient of .83 was gained for both fathers and mothers in the present sample.

Parents' mental health was measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983, see Appendix G). The HADS measures symptoms of anxiety and depression over the preceding week. Seven items assess anxiety, and seven assess depression. Although initially developed to monitor symptoms in hospital settings, the HADS has proved a useful tool for measuring anxiety and depression in community samples. The HADS has shown good levels of reliability when used with mothers of children with ID, with internal consistency co-efficients between .79 and .84 (Hastings et al., 2006). For the present sample, Cronbach's alphas of .82 and .79 were found for mothers' anxiety and depression and alphas of .79 and .71 were found for fathers' anxiety and depression.

*Procedure.* Ethical approval for the study to take place was gained from Bangor University (see Appendix R) before data collection began. Information about the research project was distributed through schools for children with ID in North Wales and the North West of England (see Appendix S). Included with the information was a response form and a business reply envelope addressed to the project team. Once

response forms had been returned, the primary parental caregiver was sent a questionnaire pack and a consent form for return to the University (see Appendices T and U). In families where a second parental caregiver also expressed interest in the research, a separate questionnaire and consent form was sent addressed to them. One hundred and eighty eight mothers, and 72 fathers were sent questionnaires. Thus, the final response rates (after up to two written reminders, see Appendix V) for mothers (76%) and fathers (83%) were good although the overall sample is clearly unlikely to be truly representative. Families were sent a thank you letter (see Appendix W) and were paid for returning the questionnaires to the research team in recognition of the time involved in participating in the research.

## Results

Mothers' and fathers' data were analysed separately. As the study variables were reasonably normally distributed, as assessed by Kolmogorov-Smirnov one-sample tests, Pearson's correlation co-efficients were used to explore the putative associations between demographic and background variables, child behaviour problems, and measures of maternal well-being. The same exploratory analyses were used for fathers, with the exception that paternal ratings of the child's behaviour problems were used. Point biserial correlations are reported for dichotomous variables (e.g., presence or not of epilepsy in the child with ID). Following the correlational analyses, linear regression was used to investigate the potential independent contributions made by hope in predicting well-being for mothers and fathers. Hope was analysed for main effect relationships (hope agency and hope pathways as separate predictors) and as an interaction between agency and pathways.

The interaction term was generated by transforming agency and pathways scores into z scores and calculating the product of these two new variables. The product term was entered as a separate predictor into the regression models.

Results of the correlational analyses are displayed in Tables 5.1 and 5.2. Only variables that were correlated with at least one parental well-being measure are represented in the Tables. Both hope agency and hope pathways were significantly associated with maternal well-being; moderate negative correlations were found for the measures of maternal negative adjustment (anxiety, stress and depression) and moderate to strong positive correlations were found for maternal positive affect. Additionally, for the three measures of maternal negative adjustment, child behaviour problems was a positive correlate. For maternal positive affect, child behaviour problems were moderately negatively associated.

Table 5.1. Correlations between demographic and hope variables and maternal well-being.

Variable	Anxiety	Depression	Stress	Positive Affect
Hope agency	-.37***	-.59***	-.32***	.68***
Hope pathways	-.33***	-.54***	-.29***	.55***
Child behaviour problems	.44***	.43***	.56***	-.32***
Number of adults in the home	-.26***	-.16	-.18*	.16
Gender of child	-.10	-.17*	-.09	.16
Autism diagnosis	-.03	.09	.30***	-.06
Down syndrome diagnosis	-.06	-.08	-.26**	.13
Epilepsy	-.24**	-.11	-.11	.14
Mobility problems	-.02	-.03	.02	.19*
Maternal age	-.20**	-.09	-.09	-.01
Maternal marital status	.21*	.05	.01	-.04
Maternal education	-.17*	-.07	.13	-.02

\* $p < .05$ \*\* $p < .01$ \*\*\* $p < .001$ 

For paternal measures of well-being, a somewhat different picture emerged. For fathers, hope agency and pathways were negatively associated with anxiety and depression, and positively correlated with positive affect. Hope was not significantly related to stress for fathers. Child behaviour problems were correlated only with stress. Fewer demographic variables were associated with paternal well-being than maternal well-being.

Table 5.2. Correlations between demographic and hope variables and paternal well-being.

Variable	Anxiety	Depression	Stress	Positive Affect
Hope agency	-.43**	-.55***	-.08	.60***
Hope pathways	-.29*	-.43***	.07	.43**
Child behaviour problems	.13	-.02	-.39**	-.12
Age of child	.08	.14	-.12	-.35**
Paternal age	.12	.31*	-.18	-.25
Paternal employment	.29*	.16	-.03	-.24

\* $p < .05$ \*\* $p < .01$ \*\*\* $p < .001$ 

All demographic and child behaviour variables that showed significant associations ( $p < .05$ ) with each of the parental well-being measures (anxiety, depression, stress, and positive affect) in the initial correlation analyses were entered into multiple linear regressions as independent predictors. Whether or not hope was correlated with parental well-being, both agency and pathways scores were entered as predictors following conventions for the assessment of interaction terms (Baron & Kenny, 1986), which stipulate evaluation of the interaction term after controlling for main effects. Thus, hope was evaluated for its independent contribution to the prediction of parental well-being after accounting for other potential predictor variables. The results of these analyses are displayed in Tables 5.3 and 5.4 separately for mothers and fathers. Given the potential problems of source variance, the regression analyses for maternal well-being were repeated on a reduced sample using paternal ratings of the child's behaviour problems. The pattern of results obtained was

the same and the size of regression coefficients for hope variables were very similar, offering some support that the findings are not simply due to source variance effects.

However, these additional exploratory analyses are not reported in detail here.

Table 5.3. Regression Analysis of Maternal Well-being.

Dependent Variable	Predictor Variable	$\beta$	$p$
Anxiety <sup>1</sup>	Presence of epilepsy in child	-.163	.034
	Maternal age	-.042	.601
	Maternal education	-.093	.221
	Number of adults in home	-.043	.693
	Child behaviour problems	.326	<.001
	Hope agency	-.159	.115
	Hope pathways	-.072	.463
	Hope interaction	-.132	.086
Depression <sup>2</sup>	Gender of child	-.033	.597
	Child behaviour problems	.272	<.001
	Hope agency	-.344	<.001
	Hope pathways	-.220	.008
	Hope interaction	.182	.004
Stress <sup>3</sup>	Number of adults in home	-.034	.636
	Presence of autism in child	.179	.026
	Presence of Down syndrome in child	-.107	.158
	Child behaviour problems	.384	<.001
	Hope agency	-.117	.221
	Hope pathways	-.072	.444
	Hope interaction	.106	.156
Positive affect <sup>4</sup>	Child mobility problems	.112	.065
	Child behaviour problems	-.148	.019
	Hope agency	.525	<.001
	Hope pathways	.146	.070
	Hope interaction	-.065	.290

<sup>1</sup>( $R=.60$ ,  $R^2=.35$ ,  $F(9, 125)=7.60$ ,  $p<.001$ ), <sup>2</sup>( $R=.71$ ,  $R^2=.50$ ,  $F(3, 133)=27.00$ ,  $p<.001$ ),

<sup>3</sup>( $R=.63$ ,  $R^2=.39$ ,  $F(7, 123)=11.39$ ,  $p<.001$ ), <sup>4</sup>( $R=.72$ ,  $R^2=.52$ ,  $F(5, 133)=28.72$ ,  $p<.001$ ).

Table 5.4. Regression Analysis of Paternal Well-being.

Dependent Variable	Predictor Variable	$\beta$	$p$
Anxiety <sup>1</sup>	Paternal job	.184	.152
	Hope agency	-.322	.037
	Hope pathways	-.071	.633
	Hope interaction	.110	.382
Depression <sup>2</sup>	Paternal age	.245	.037
	Hope agency	-.491	<.001
	Hope pathways	-.074	.594
	Hope interaction	.044	.693
Positive affect <sup>3</sup>	Age of child	-.235	.041
	Hope agency	.514	<.001
	Hope pathways	.079	.559
	Hope interaction	.056	.605

<sup>1</sup>( $R=.50$ ,  $R^2=.23$ ,  $F(4, 53)=3.95$ ,  $p<.01$ ), <sup>2</sup>( $R=.62$ ,  $R^2=.38$ ,  $F(4, 53)=8.27$ ,  $p<.001$ ),

<sup>3</sup>( $R=.65$ ,  $R^2=.42$ ,  $F(4, 53)=9.61$ ,  $p<.001$ ).

Hope agency was found to be a significant independent negative predictor of maternal depression and paternal anxiety and depression, and a positive predictor of both maternal and paternal positive affect. Hope pathways emerged as an independent negative predictor only for maternal depression. Also of interest is that child behaviour problems were a significant predictor for all four domains of maternal well-being. Finally, for maternal depression only there was a significant interaction term. Following Aiken and West (1991), this interaction was explored by plotting predicted maternal depression scores for high (one SD above the mean) and low (one SD below the mean) values for hope agency crossed by three levels of hope pathways (low, at the mean, and high). These data are displayed in Figure 5.1 and indicate that maternal depression was highest when both hope agency and hope pathways were low.



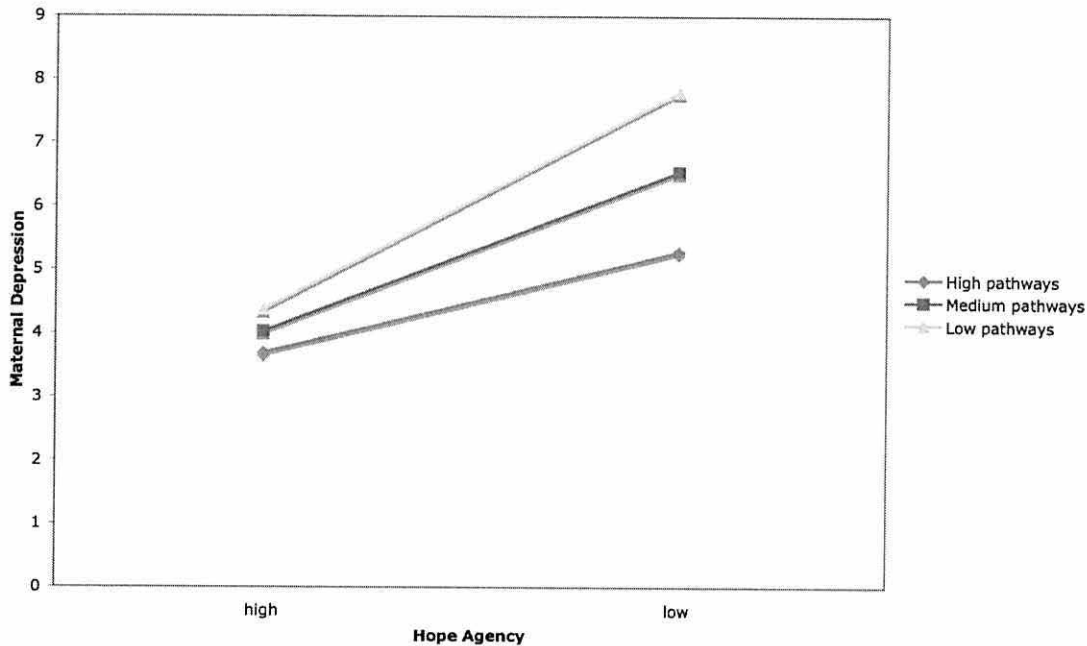


Figure 5.1. Interpretation of the interaction effect of hope agency and hope pathways on maternal depression.

### Discussion

As predicted from hope theory, hope agency was found to be a resilience factor for both maternal and paternal psychological well-being. Hope pathways was a resilience factor only for maternal depression. All of these analyses showed that hope functioned in a compensatory fashion - predicting increased positive well-being and decreased psychological distress. Also in keeping with hope theory, hope agency and pathways were found to interact in the prediction of maternal depression such that the highest levels of maternal depression were found when both hope agencies and pathways were at low levels.

Hope agency was more reliably related to parental well-being than hope pathways. This finding is in keeping with recent research by Arnau, Rosen, Finch, Rhudy and Fortunado (2007) who examined the effects of agency and pathways on anxiety and depression in a sample of 522 college students. Using cross-lagged panel analyses, Arnau et al. found that there was an effect of agency on both anxiety and

depression, but the pathways component of hope was not related to either outcome variable across time.

At a theoretical level, Snyder and colleagues (1991; 1996) clearly hypothesise that pathways and agency reflect different ways of thinking about goals. Agency forms the motivational component of hope and, as such, is the “can do” cognition, whereas pathways thinking, reflects a person’s thoughts about ways to reach goals, the “know how” cognition. Therefore, higher levels of motivational thinking may be the most relevant aspect of hope for psychological well-being being akin to positive thinking or the absence of learned helplessness or hopelessness. According to Snyder (2002), agency thinking is particularly pertinent when goals are blocked since it comes to the fore to enable people to channel motivation into “unblocked” pathways. Parents of children with ID typically face a number of barriers and ongoing stressors, thus agency thinking may well be more salient in the prediction of their well-being.

The significant interaction between hope agency and pathways in the prediction of maternal depression supports Snyder’s theory that both pathways and agency may contribute to hopeful thinking. However, only one significant interaction (from eight) was found, suggesting that the compensatory role of hope agency is the most salient for parents of children with ID. Several other researchers have also reported mixed findings in relation to the relationship between hope agency and hope pathways (e.g., Arnau, et al., 2007; Chang, 2003; Drach-Zahavy & Somech, 2002) and have suggested further research is needed to how these dimensions may or may not relate together.

There are some interesting theoretical and practical implications that can be drawn from our research findings. At the theoretical level, there may be an opportunity to incorporate the construct of hope within existing parental stress

theories that have been influential in the ID field. For example, hope could be conceptualised as a personal coping resource within the framework of a process model of stress and coping (Lazarus & Folkman, 1984), or as a familial internal resource in McCubbin and Patterson's (1983) Double ABCX model. Further theoretical research is needed to test hope as a variable within stress models such as these.

Second, hope is a cognitive variable and therefore may be amenable to change. Parents reporting higher hope at a trait level in this study also reported better psychological well-being. This may be because these parents view their lives more positively and adapt more positively to change by employing hopeful, goal-directed thinking. Therefore, if hope were targeted for change by intervention, an increase in hope could lead to parents perceiving set-backs as challenges and responding in a more positive way. Indeed, Snyder, Ilardi, Cheavens and Michael (2000) posit that cognitive-behavioural interventions that place an emphasis on goal-setting and generating workable strategies to reach goals may be particularly helpful in generating hopeful thinking. However, such strategies may be too closely related to pathways rather than agency thinking. Thus, motivational values-based interventions such as Acceptance and Commitment Therapy might prove to be more effective ways to improve hope (cf. Blackledge & Hayes, 2006; Lloyd & Hastings, 2008).

The results of the present study and the resulting potential practical implications need to be treated with caution for a number of methodological reasons. First, the present results clearly require replication in particular with a larger sample of fathers and also with other family members and/or others with roles as the primary caregiver. In terms of the last point, only four of the fathers in this study were reported to be the primary carers for their children. Therefore, caregiver status, rather

than gender, may account for the differences seen in the relationships between paternal and maternal hope and their well-being.

A second significant methodological issue is that in this study hope was measured at a trait level. However, research suggests that environmental factors may influence levels of hope (Snyder, et al., 1996), and hope can also be measured at a state level. In many ways, the state-trait distinction is related to questions about the validity of the findings in the present research. Specifically, we have not presented data about the implications of hope for the quality of relationships between parents and their children with ID nor for the nature of relationships with other family members. Thus, state (or trait) hope may well be significant in maintaining other dimensions of resilience such as optimism or self-efficacy. In this way, hope may have direct implications for parental involvement in children's therapeutic regimes and potentially for therapeutic outcomes. These possibilities, as well as the relationships between trait and state hope, should be explored in further ID family research.

Finally, since the data presented are correlational, no causality can be inferred from the present study. Thus, it is possible either that psychological well-being determines parental hope or that this relationship is bidirectional over time. However, given these initial promising results, longitudinal research is now needed to explore whether hope functions as a resilience variable over time for parents of children with ID.

Chapter 6. General Discussion.

Parenting a child with intellectual and developmental disabilities is a complicated experience. Like all other parents, mothers and fathers of children with ID feel joy and sadness and experience a gamut of emotions related to their role as parents. This thesis has attempted to expand upon our existing knowledge of parental cognitions by synthesising previous research and by investigating several cognitions thus far unexplored with families of children with ID. First, an in-depth review of extant literature was conducted (Chapter 2) then three empirical investigations were carried out (Chapters 3, 4, 5). This discussion will summarise the findings from the four chapters and then present the implications of thesis as a whole, before making recommendations for future research within the field.

*Research into cognitions in parents of children with intellectual disabilities*

Given the importance of parental cognitions in affecting the well-being of mothers and fathers of children with intellectual disabilities and/or autism, it is somewhat surprising how little systematic research attention has been given to this area. Chapter 2 reviews the extant literature on parental cognitions before recommending that research into both theory and the efficacy of interventions takes into account parental cognitions as a focus for study, rather than as an adjunct to on-going research.

Chapter 3 begins this work by investigating an area thus far unexplored within the literature, that of acceptance and mindfulness in parents of children with ID. Acceptance was found to be predictive of maternal distress both cross-sectionally and longitudinally and it was also found to enter into a bi-directional relationship with maternal depression across time.

Whilst previous studies have looked at maternal acceptance (Lam & Mackenzie, 2002; Scorgie, Wilgosh, Sobsey, & McDonald, 2001) this has been in relation to the acceptance of the child or of the child's disability. Our study has added to the literature in that we have looked at dispositional, or global, acceptance. Furthermore, we have employed a longitudinal methodology in order to try to unravel the issues of causality.

Chapter 4 of this thesis also investigates a construct thus far given little research attention, parental locus of control. Locus of control specific to the parenting experience was measured at two time points (18 months apart) and aspects of the control relationship between mother and child were predictive of both positive and negative maternal adjustment. A bi-directional relationship was found for parental locus of control and maternal stress.

This chapter adds to the literature as it is the first study that we know of to look at longitudinal relationships between locus of control and maternal well-being in mothers of children with ID. Furthermore, a measure of positive adjustment was included in this study. This factor is important since we make a move away from the assumption that parents of children with ID and/or autism show negative adjustment only. By measuring positive adjustment, not only are we acknowledging that this type of adjustment takes place, but we are also asking a question about parental resilience: What is it that stops some parents from adjusting negatively to their child with ID?

Our final empirical paper looks at the issue of hope in parents of children with ID. Contrary to other studies in the field (e.g. Kearney & Griffin, 2001; Kauser, Jevne, & Sobsey, 2003), we have used a tested questionnaire, developed from a widely researched theory to supply evidence to support the theory that hope affects

parental well-being. The use of a specific theory of hope on which to base our predictions is something thus far given little consideration in the literature on parental adaptation to a child with ID and thus is an important departure from earlier studies with less stringently defined variables. Our findings showed that hope was predictive of both positive and negative adjustment in mothers and fathers and the agency and pathways components of hope interacted to predict maternal depression.

### *Strengths and limitations of the current research*

Whilst this thesis makes a unique contribution to the ID families research field, it is not without its limitations. These limitations, along with the strengths of the research, are discussed below.

The largest methodological limitation we encountered during the research described in this thesis was that of the internal consistency (or the extent to which the items correlate, implying that the items are measuring the same construct) of the measures we used. In particular, there were two measures that we felt were poor (due to extremely low Cronbach's alpha levels) and thus we conducted item reduction techniques with each of them to improve the alpha levels.

First the Acceptance and Action Questionnaire (Bond & Bunce, 2003) was deemed to be internally inconsistent as a measure of dispositional acceptance. The AAQ was originally a measure containing two subscales, action (Cronbach's alpha .55) and willingness (Cronbach's alpha .46). However, as both subscales had unacceptably low alpha values, we conducted an item reduction procedure; by removing the eight items with the lowest corrected item-total correlations, we succeeded in obtaining an alpha value of .72 for a single subscale that measured overall acceptance.



The story was similar for the Parental Locus of Control measure (Campis et al., 1986). Prior to this research, several different versions of the PLOC measure have been used, apparently for different reasons and with little regard for the underlying theory. We systematically looked at the possible combinations of items that comprised each version, but were, in each case, left with unacceptably low alpha levels. Again, we decided that the item reduction method used with the AAQ measure should be employed. We reduced the PLOC scale from a 47 item questionnaire to a measure consisting of 42 items, over the five original subscales, all of which achieved Cronbach's alpha levels of above .67.

In general, an alpha level of above .70 is thought to be adequate for rating scales, whilst alphas of .80 and above are thought to show high reliability (Murphy & Davidshofer, 1994). An adequate level of consistency is necessary to ensure that measurement error is kept to a minimum. Low reliability will reduce the power of the measure to show effects. For the two measures mentioned above, we therefore used a statistical method to improve the reliability of the instrument. More research is needed, however, to further establish reliability and validity in these measures, both within a normative sample and within a population of parents of children with ID so that normative data for this population could also be attained eventually. To counter the fact that the measures of parental cognitions were largely untested within an ID population, we used measures of parental well-being that were well validated and had been shown to be reliable.

The first two empirical chapters of this thesis (Chapter 3 and Chapter 4) add significantly to the literature on cognitions in mothers of children with ID in that they both contain longitudinal data. It is important to include longitudinal methods in families research for two reasons. First, longitudinal analyses are necessary when

establishing whether there are causal pathways between the variables under investigation. As well as co-variation and non-spuriousness of the variables, temporal precedence must be established to demonstrate causality (Haynes, 1992). To establish temporal precedence one must show that changes in the causal variable precede changes in the outcome variable.

By investigating data longitudinally we have gone some way to showing causal pathways in that we have established temporal precedence. Furthermore, we have controlled for many factors within the regression analyses to attempt to eliminate spuriousness of the variables and by conducting initial correlations we have clarified which variables are associated, thus achieving the third criterion.

Longitudinal data are also necessary to discover whether the cognitive variables under investigation are dispositional (trait) variables or situational (state) variables. This is an important fact to discover as it may have a bearing on interventions carried out with parents. It is possible to change situational variables, whereas trait variables are less amenable to change by intervention. However, this does not mean that trait variables cannot change at all, rather that variables that come about as a response to the environment are more easily changed by intervention than are trait variables. The use of longitudinal data collection is vital in establishing whether a variable is a psychological mechanism and thus could mediate change.

Our longitudinal data collection covered a period of 18 months and may be considered to be a short period over which to claim the data had been analysed longitudinally. However, Lecavalier et al. (2006) and Baker et al. (2003) have both used periods of one year to assess familial well-being within ID families research. The research we have presented, therefore, is in keeping with previous studies in using a relatively short period of time between data collection phases.

A final comment on longitudinal data collection addresses the issue of stability of measures over time. Though all our measures proved to be stable across the 18 month time period, we have no way of knowing why this may be. Though previous research has shown parental distress to be relatively stable across time (Hastings et al., 2006; Lecavalier et al., 2006) there are no data concerning the stability of cognitions in parents across time. Changes in parental cognitions and well-being could be related to life events across the 18 month period, for example, the birth of another baby or enrolment in an intervention programme may change parents' cognitions.

In our study into hope in families of children with ID (chapter 5), we sampled parents at one time point only due to practical issues. Whilst this study lacks longitudinal data, it does investigate both fathers and mothers of children with ID. This is an important factor because we were unable to get a sample of fathers sufficiently large to take part in the two earlier empirical studies (chapters 3 and 4) and thus, they are limited in this respect. Previous research has shown that fathers and mothers respond differently to raising their child with ID (Moes, Koegel, Schreibman, & Loos, 1992; Roach, Orsmond, & Barratt, 1999; Sloper & Turner, 1993) and thus it is vital that we investigate the parental cognitive variables from the perspective of both parents.

We also included in our research two measures of positive adaptation. Research is fortunately moving away from the perspective that having a child with a disability is a cause for sorrow and disappointment (c.f. Olshanky, 1962). However, in order to maintain a more realistic viewpoint of parenting, research needs to include measures of both positive and negative adjustment as recommended by Hastings et al. (2003). By including measures of positive adjustment in our research, as well as

measures of negative adjustment, we have ensured that we have a more complete view of parental well-being.

Taken together then, the three empirical chapters form a comprehensive account of how four cognitive variables (acceptance, mindfulness, locus of control and hope) affect parental well-being, both over time (acceptance, mindfulness and locus of control) and for both fathers and mothers (hope). More research is needed to support these initial findings and to establish the reliability of the measures used.

One issue that none of the empirical chapters can contend with however, is that of the reliability of self-report measures. The issue of multiple informants represents a theoretical limitation of the research presented in this thesis. Parental cognitions are exclusive to the parent in question; they are subjective, retrospective reports of thoughts and feelings and, as such, it is difficult to say how valid the responses of the parents actually are. Parents may have responded to the measures in ways that reflect social desirability, particularly when an item has a moralistic element or an element whereby aspersions may be cast on the parent's ability to raise their child. For example, one item in the Active Avoidance Subscale of the Brief Cope measure (Hastings, Kovshoff et al., 1995) "I use alcohol or drugs to make myself feel better" was often left blank or parents chose to write a "disclaimer" about the amount of alcohol they consume in the margin next to the item.

Retrospective self-report research is not always an ideal way to gather data. Stone et al. (1998) compared retrospective reports on coping with momentary reports collected by palm top computer and found that cognitive coping was under-represented retrospectively, whilst behavioural coping methods were over-represented. These findings can probably be extrapolated to include retrospective self-report about parental well-being.

One way to increase the likelihood of gaining an accurate view of family life with a child with ID would be to use multiple informants from outside of the family. There are some elements of the research that would have benefited from the use of multiple informants. For example, child behaviour problems could have been rated, not only by the parents, but also by the child's teachers in order to get a more valid picture. The same could possibly be said of the measure of the impact of the index child on the family (the Questionnaire on Resources and Stress Short Form – Parent and Family Problems subscale), where another member of the immediate family could have been asked to fill in the same measure.

However, we did go some way to addressing this problem within our study of hope (chapter 5). We asked both fathers and mothers to report on their child's behaviour and conducted regression analyses for maternal well-being using paternal ratings of child behaviour. As the pattern of results obtained was the same, we concluded that there was little source variance and thus that we had a relatively reliable view of the child's behaviour problems.

We used within families samples to try to unpick the relationships between cognitions and outcome that are exclusive to parents of children with ID and/or autism. However, whilst it is necessary to look within families to answer questions aimed specifically at parents raising a child with ID, it is also necessary to maintain a degree of variability within samples to account for extraneous factors that may affect the results.

Hatton and Emerson (2003) note that families research has tended to overlook contextual variables. Whilst we have a variety of diagnostic groups from several parts of the UK represented in our samples, we have investigated fairly affluent families within our research. It is difficult to say why this might be the case; we

advertised our studies through several special educational needs schools in the South of England (chapters 3 and 4) and in North Wales and North West England (chapter 5) to try to ensure a variety of respondents, but nonetheless, the majority of families were relatively affluent, with at least one parent in employment and primarily well-educated.

Emerson (2003) highlights the need to control for poverty as a predictor of familial well-being due to the fact that poverty is associated with parental mental ill-health, general ill-health and distress. Though we did control for the effects of deprivation in our empirical studies, more research is now required to investigate whether deprivation is implicated in the relationships between parental cognitions and parental well-being.

#### *Theoretical implications*

In the literature review chapter (chapter 2) we discussed the use of parental cognitions within several theoretical models of stress. One such model that we have yet to describe and discuss is that of Mash and Johnston (1990) who developed a model of stress in parent/child interactions that includes environmental characteristics, child characteristics and parent characteristics. According to Mash and Johnston's model parent/child conflict is a product of stress that is as much a function of parent characteristics as child characteristics, with environmental variables also playing an equal role (see Figure 6.1).

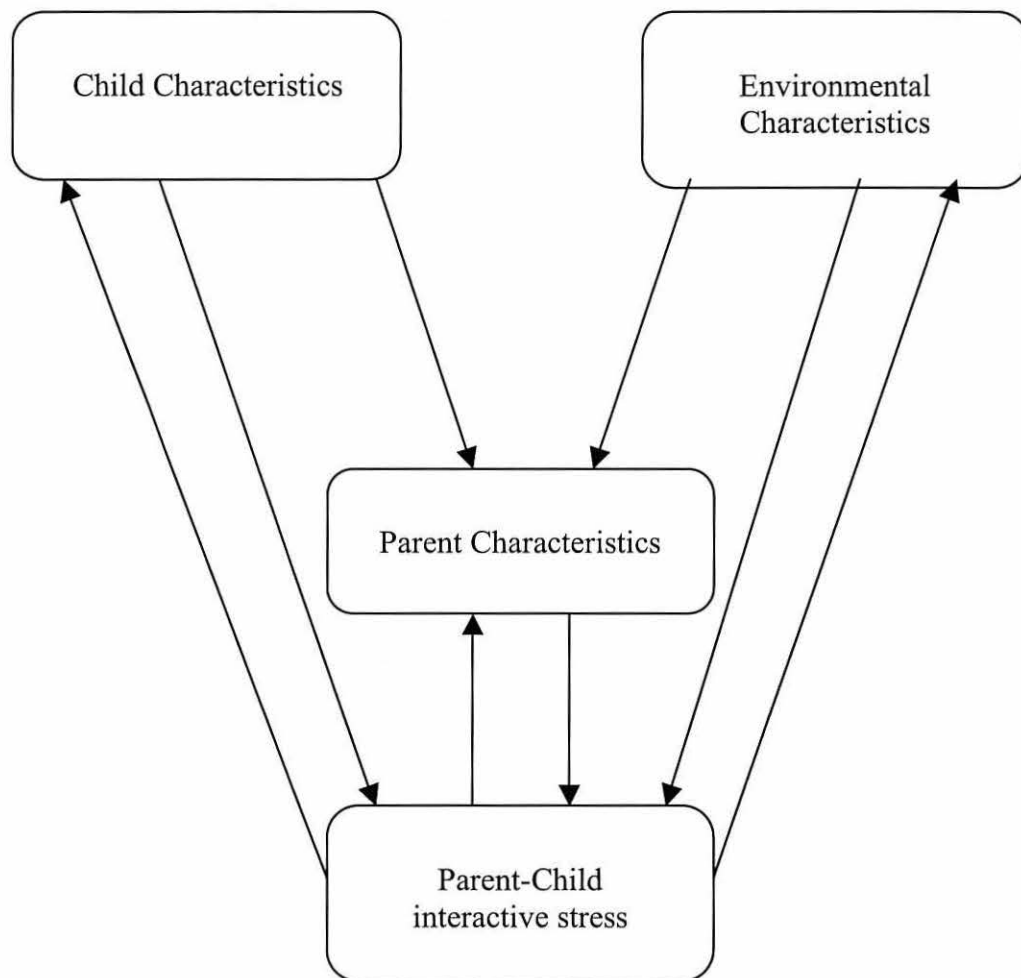


Figure 6.1. Mash and Johnston's (1990) model of stress in parent/child interactions.

According to the model, stress is influenced bi-directionally by the three types of characteristics. When applied to parenting a child with ID, child characteristics can include variables such as behaviour problems, child adaptive behaviour levels and child diagnosis; environmental characteristics could include such variables as social support, poverty and life events; and parent characteristics could include parental health and parental cognitions. As well as indicating direct effects, there is also room within this model for the consideration of mediational effects. Parental cognitions,

according to the model, may mediate the effect of child and environmental characteristics on parental stress.

The empirical findings from the three studies within this thesis lend support to Mash and Johnston's model. Acceptance, parental locus of control and hope are all cognitions that we have shown can predict parental distress. Furthermore, we have shown that acceptance has a bidirectional relationship with maternal depression and a change in internal/external locus of control has a bidirectional relationship with maternal stress. These findings fit well within the model. However, theory suggests that acceptance, locus of control and hope should all act as moderators, a factor that does not sit so well within the model. Mash and Johnston, however, claim that many cognitive variables are thought to be stable and trait-like within populations of parents of typically developing children, but that this may not be the case for parents of non-typical children (such as children with ID/autism) as the decisions parents make on a momentary basis may out-weigh the stability of cognitive variables.

More research needs to be conducted into whether parental cognitive variables have moderating or mediating effects on parental distress before conclusions can be made. Ideally, to achieve this, research would be needed that can show parental cognitions before parenthood and then again during parenthood. This would however, be an almost impossible task as it would be very difficult to find a large enough sample of people whose cognitions could be assessed before parenthood and who would then go on to have children with ID/autism.

The best way around this problem would be to assess cognitions specific to the parenting role. This would allow for tests of mediation that could then fit within this model. Mash and Johnston developed this model with a view to informing intervention research about the types of cognitions that could be changed during



intervention and so mediation would be of primary importance to the model. This does not mean however that moderation effects could not be incorporated into the model. By acknowledging that the relationships between child and parent characteristics and environmental and parent characteristics could potentially be bidirectional, the effects of moderation could be incorporated into the model. For example, theoretically it is possible that parental hope could moderate the effects of child behaviour on parental stress. Schematically, this factor could be incorporated into the model by the addition of double arrowheads from child and environmental characteristics to parent characteristics.

Another point that needs addressing within the model is that of the use of the model to predict parental distress only. We have shown in this thesis that cognitions are related to positive parental adjustment as well as negative outcomes. It is important that this be recognised within any model of parental adjustment and that, not only is parental stress recognised as an outcome, but parental well-being (happiness) should also be included as an outcome variable.

A final, more general, point that needs to be made regarding cognitions and stress modelling is that adjustment takes place at a familial level, not just from the perspective of the parents. Mash and Johnston's model is one which could easily be adapted to cover the perspective of siblings, grandparents or other extended family members. Future research could examine how the feelings and beliefs held by the parents of a child with ID may influence the well-being and cognitions of other family members. However, equally important to research is the fact that though each family member's cognitions could predict that family member's well-being, (i.e. a brother's cognitions could predict his own well-being) they could also affect the well-being of other family members. For example, a grandparent who is high in sense of coherence

and a sibling of a child with ID who is low in this construct may differ in their interactions with the child with ID, particularly when the child displays challenging behaviour. Research must now try to account for cognitions across family members and to do this new and more complex models may need to be developed.

All the parental cognitive variables discussed in this thesis would be amenable to study with other family members, for example, with grandparents and siblings, as well as other people who play a significant role in the child's life. If data were gathered from other family members, this would allow researchers to gain a full picture of how family cognitions affect well-being, a factor that would be of use to investigators using a family systems perspective. Since parenting does not occur in a vacuum, different levels of variables, from different family systems, need to be measured as predictor variables within models that account for parental distress and/or well-being. These variables could include socio-economic deprivation (societal level), parental cognitions (individual level) and child behaviour (family level). Mash and Johnston's (1990) model is one that could easily be applied to any of these recommendations and therefore shows much promise as a model that could be specifically tailored to for ID families research.

### *Practical implications*

Not only does the research described in his thesis have theoretical implications, there are also implications for the design of interventions for parents of children with ID/autism. In chapter 2, we described an intervention that aimed to change parents' cognitions by increasing acceptance (Blackledge & Hayes, 2006). The premise for this intervention was that by increasing acceptance, parental well-

being would also be increased. The findings of chapter 3 of this thesis lend support to the rationale for Blackledge and Hayes' intervention.

Acceptance is a cognitive variable with a large and rapidly growing evidence base. Acceptance-based therapies are used within many populations and for a variety of reasons (see chapter 3 for details). Similarly mindfulness-based therapies are increasingly becoming the therapy of choice for many mental health problems (Roemer & Orsillo, 2003). These currently include depression (Teasdale, Segal, & Williams, 1994), substance abuse problems (Leigh, Bowen, & Marlatt, 2005) and psychosis (Chadwick, Taylor, & Abba, 2005). As discussed in chapter 2, mindfulness-based therapies have also begun to be used with families and carers of children and adults with ID (Singh et al., 2006; Singh et al., 2004). Research now needs to discover the mechanisms by which these therapies are having their effects. It is not enough to show that these therapies are effective, evidence must be provided as to how the change in mental health and behaviour are brought about.

Whilst acceptance and mindfulness are therapies that are currently in use and aim to change cognitions, there are many other candidate variables that could also be changed by intervention. For example, in this thesis, we have provided empirical evidence to show that parental locus of control and hope are related to parental well-being. These variables could be addressed by interventions designed to change cognitions.

In fact, locus of control and hope are both variables that have been targeted during interventions to increase well-being. In an intervention designed to educate children aged 4 to 11 years with leukaemia and their families, Dragone, Bush, Jones, Bearison and Kamani (2002) developed a CD Rom package that aimed to increase health locus of control as well as educating children about their disease. Results

showed that, when compared with a group of children receiving education only, via a book about leukaemia, children in the CD Rom group showed increased feelings of control over their health (internal locus of control).

In an intervention designed to foster hope in elderly, terminally ill cancer patients, Duggleby et al. (2007) developed a video and activities to encourage hope. When compared with a control group, findings showed that those patients who had received the “Living with Hope” programme had statistically higher hope and quality of life scores on relevant measures.

Either of these types of designs could be useful for families of children with ID, both when the family has received a diagnosis for their child and as the child grows older. An adapted version of the CD Rom intervention may be particularly useful for young siblings of children with ID as it was aimed at children aged 4-11. Similarly, the “Living with Hope” intervention may be useful for parents of children who have a short life expectancy due to their condition.

When developing and testing new interventions for parents of children with ID, researchers need to take cognitions into consideration. If the aim of a specific intervention is to change parents’ thoughts or beliefs about a situation, then measures of cognitions must be taken pre- and post-intervention to establish by what mechanism the intervention is having its effect. We have highlighted here the fact that interventions that aim to change cognitions are used within other populations and that there are a limited number of interventions with this aim within families research in the field of ID. More research is now needed to provide an evidence base from which clinicians can work.

*Recommendations for future research*

Though this thesis has contributed significantly to the research area of parental cognitions in ID research, there remain many unanswered questions. We will now discuss the outstanding issues and suggest how future research may address these issues.

This thesis has looked at a wide range of cognitive variables and has reviewed those that have been investigated with respect to parental outcomes. However, other cognitive variables also require investigation. Future research now needs to extend its reach to cover areas such as parental guilt, denial, self-blame and mastery. As yet, very little research has been conducted into these areas and what little does exist lacks a theoretical basis. Research is needed to synthesise existing findings and address the issues of theoretical underpinnings and implications. Research needs to firmly establish whether there are other cognitive variables as yet unstudied within the ID families field and then attempt to investigate these in relation to parental well-being.

Though this research has gone some way to establishing the theoretical bases behind many parental cognitive variables, it remains unclear whether these cognitions come about as responses to stressors (state variables) or are already present within parents of children with ID before the occurrence of a stressor (trait variables). Theoretically, it is likely that some variables act as moderators and others as mediators, as well as showing main effects with well-being. Future research needs to establish the function of each cognitive variable in order to maximise the knowledge base and be able to inform intervention research. Parental cognitions may be important in changing behaviour during interventions aimed at this and so knowing the precise function of each of these variables in relation to its effect on parental well-

being is vital. Until this research is carried out, interventions that aim to change parents thoughts and beliefs will continue to lack an evidence base.

A final consideration that needs to be addressed is that of the role of parental cognitive variables as mechanisms of change. Lazarus and Folkman (1984) call for process-oriented research into coping. They also suggested that coping be studied over time to discover its function as stressors changed. We echo these suggestions here; parental cognitions need to be studied as potential mechanisms for change. In order to do this, cognitive variables now need to be studied from a longitudinal perspective to establish if, in fact, they are functioning as process variables. If this were found to be the case then we could say with more certainty that these variables would be amenable to change by intervention.

Interventions also need to look at parental cognitive variables from the perspective of resilience as well as risk. Interventions for families of children with disabilities primarily focus on alleviating distress. However, research has shown that this focus often misses the opportunity to use existing family strengths to foster and develop already existing resilience (Blundo, 2001). Using longitudinal methodologies, research is needed to determine whether cognitive variables may serve to protect parents from stress and to apply this knowledge to the design of interventions targeting cognitions as the mechanism for change.

### *Conclusions*

No single factor is solely responsible for parental distress or well-being in families of children with ID and /or autism. Therefore, research needs to focus on a variety of factors, both risk and resilience factors, in attempting to predict parental adjustment. The measurement of parental adjustment needs to include both measures

of well-being as well as measures of distress. This thesis has attempted to employ such research strategies when developing models of parental well-being and has added to the field of ID research by highlighting the most suitable methodologies for the study of parental cognitions and recommending future theoretical and applied research that is now needed. We have begun, with this thesis, to integrate disparate constructs under the umbrella term of parental cognitions and to investigate these variables in an attempt to account for the variability of experiences of parenting school-aged children with ID and/or autism.



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Appendix A  
**Demographic Questionnaire**

*Special Needs and Families Research Project*

For Office Use Only Code:
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*The following questions ask for background information about you, your child with special needs, and your family. Please tick the appropriate boxes or write in the spaces provided.*

1. Are you male or female? Male  Female

2. What was your age in years on your last birthday? \_\_\_\_\_

3. What is your current marital status?

Married, and living with spouse.....

Living with partner.....

Divorced/Separated/Single and NOT living with a partner.....

4. In total how many people currently live in your house?

Adults \_\_\_\_\_ Children \_\_\_\_\_

If there are other children living in the house how are they related to your child with special needs (e.g. biological brother, step brother) and how old are they? – Please list ALL children

.....

.....

.....

.....

5. Please tick the boxes next to all of the educational qualifications that you hold

No formal educational qualifications.....

GCSE, CSE, GCE, O Levels or equivalent.....

GCE, A Levels, HNC, GNVQ or equivalent.....

HND, other Diploma, or equivalent.....

Polytechnic/University ordinary or honours degree.....

Masters or Doctoral degree.....

6. Do you currently have a job outside of the home? Yes  No

*If no, please go to question 8, otherwise please answer following questions.*

What is your current job/occupation? (Please give a job title and a very brief description of your main duties).

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. Is your job/occupation full or part-time? Full-time  Part-time

8. If you are living with your spouse/partner, do they currently have a job outside of the home?

Yes  No

*If no, please go to question 10, otherwise please answer following questions.*

What is your spouse/partner's current job/occupation? (Please give a job title and a very brief description of their main duties).

\_\_\_\_\_  
\_\_\_\_\_

9. Is this job/occupation full or part-time? Full-time  Part-time

10. What is your relationship to your child with special needs (e.g., mother, father, stepmother, grandmother, adoptive parent)?

\_\_\_\_\_

11. How old is your child with special needs? \_\_\_\_\_ years \_\_\_\_\_ months

12. Is your child with special needs male or female? Male  Female

13. Please tick the boxes below to indicate any diagnoses/conditions that apply to your child with special needs

Learning Disability ("Intellectual Disability").....

Autism.....

Cerebral Palsy.....

Down Syndrome.....

Other syndrome (please specify) \_\_\_\_\_

**14. Does your child with special needs have sensory impairment that interferes with his/her day to day life?**

Yes                  No

*If yes, what is this impairment?*

Visual impairment?                  Yes

Hearing impairment?                  Yes

**15. Does your child with special needs currently suffer from epileptic fits?**

Yes                   No

**16. Does your child with special needs have problems with mobility that mean it is difficult for them to move around independently (e.g. needs to use a wheelchair)?**

Yes                   No

**17. Does your child with special needs have any other health problems not already mentioned?**

Yes                   No

If yes, then please specify \_\_\_\_\_

*18. Does your child with special needs normally live with you?*

Yes                   No



19. Recent data from research with families of children with special needs has shown that a family’s financial resources are important in understanding family member’s views and experiences. With this in mind, we would be very grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether those with high versus lower levels of financial resources have different experiences.

**What is your current total annual family income? Please include a rough estimate of total salaries and other income (including benefits) before tax and national insurance/pensions.**

Please tick one box only:

Less than £15,000.....	<input type="checkbox"/>
£15,001 £25,000.....	<input type="checkbox"/>
£25,001 £35,000.....	<input type="checkbox"/>
£35,001 £50,000.....	<input type="checkbox"/>
£50,001 £75,000.....	<input type="checkbox"/>
£75,001 £100,000.....	<input type="checkbox"/>
£101,001 £150,000.....	<input type="checkbox"/>
£151,001 £200,000.....	<input type="checkbox"/>
£201,001 or more.....	<input type="checkbox"/>

***Please complete each section as honestly you can, even if you are not absolutely certain or the item seems daft! Follow the instructions for each questionnaire.***

Appendix B  
**Strengths and Difficulties Questionnaire**

For each item, please circle Not True, Somewhat True or Certainly True. Please give your answers on the basis of your child with special needs' behaviour over the last six months.

Is your child.....

	Not True	Somewhat True	Certainly True
1. Considerate of other people's feelings	True	True	True
2. Restless, overactive, cannot stay still for long	True	True	True
3. Often complains of headaches, stomach-aches or sickness	True	True	True
4. Shares readily with other children (treats, toys, pencils etc)	True	True	True
5. Often has temper tantrums or a hot temper	True	True	True
6. Rather solitary, tends to play alone	True	True	True
7. Generally obedient, usually does what adults request	True	True	True
8. Many worries, often seems worried	True	True	True
9. Helpful if someone is hurt, upset or feeling ill	True	True	True
10. Constantly fidgeting or squirming	True	True	True
11. Has at least one good friend	True	True	True
12. Often fights with other children or bullies them	True	True	True
13. Often unhappy, down-hearted or tearful	True	True	True
14. Generally liked by other children	True	True	True
15. Easily distracted, concentration wanders	True	True	True
16. Nervous or clingy in new situations, easily loses confidence	True	True	True
17. Kind to younger children	True	True	True
18. Often lies or cheats	True	True	True
19. Picked on or bullied by other children	True	True	True
20. Often volunteers to help others (parents/teachers/other children)	True	True	True
21. Thinks things out before acting	True	True	True
22. Steals from home, school or elsewhere	True	True	True
23. Gets on better with adults than with other children	True	True	True

24. Many fears, easily scared	Not True	Somewhat True	Certainly True
25. Sees tasks through to the end, good attention span	Not True	Somewhat True	Certainly True

Appendix C  
**Acceptance and Action Questionnaire**

Below you will find a list of statements. Please circle the truth of each statement as it applies to you.

	Never true	Very Seldom true	Seldom true	Sometimes true	Frequently true	Almost true	Always true
1. I am able to take action on a problem even if I am uncertain what is the right thing to do.	1	2	3	4	5	6	7
2. When I feel depressed or anxious, I am unable to take care of my responsibilities.	1	2	3	4	5	6	7
3. I try to suppress thoughts and feelings that I don't like by just not thinking about them.	1	2	3	4	5	6	7
4. It's OK to feel depressed or anxious.	1	2	3	4	5	6	7
5. I rarely worry about getting my anxieties, worries, and feelings under control.	1	2	3	4	5	6	7
6. In order for me to do something important, I have to have all my doubts worked out	1	2	3	4	5	6	7
7. I'm not afraid of my feelings.	1	2	3	4	5	6	7
8. I try hard to avoid feeling depressed or anxious.	1	2	3	4	5	6	7
9. Anxiety is bad.	1	2	3	4	5	6	7
10. Despite doubts, I feel as though I can set a course in my life and then stick to it.	1	2	3	4	5	6	7
11. If I could magically remove all the painful experiences I've had in my life, I would do so.	1	2	3	4	5	6	7
12. I am in control of my life.	1	2	3	4	5	6	7
13. If I get bored of a task, I can still complete it.	1	2	3	4	5	6	7
14. Worries can get in the way of my success.	1	2	3	4	5	6	7
15. I should act according to my feelings at the time.	1	2	3	4	5	6	7
16. If I promised to do something, I'll do it, even if I later don't feel like it.	1	2	3	4	5	6	7
17. I often catch myself daydreaming about things I've done and what I would do differently next time.	1	2	3	4	5	6	7
18. When I evaluate something negatively, I usually recognize that this is just a reaction, not an objective fact.	1	2	3	4	5	6	7
19. When I compare myself to other people, it seems that most of them are handling their lives better than I do.	1	2	3	4	5	6	7

Appendix D  
**Mindful Attention Awareness Scale**

Please read each question carefully, then circle the number that corresponds to scale below.

	Almost Always	Very Frequently	Somewhat Frequently	Somewhat Infrequently	Very Infrequently	Never
1. I could be experiencing an emotion and not be aware of it until sometime later.	1	2	3	4	5	6
2. I break or split things because of carelessness, not paying attention, or thinking of something else.	1	2	3	4	5	6
3. I find it difficult to stay focused on what's happening in the present.	1	2	3	4	5	6
4. I tend to walk quickly to get where I am going without paying attention.	1	2	3	4	5	6
5. I tend not to notice feelings of physical tension or discomfort until they really grab my attention.	1	2	3	4	5	6
6. I forget a person's name almost as soon as I have heard it.	1	2	3	4	5	6
7. It seems I am "running on automatic" without much awareness of what I am doing.	1	2	3	4	5	6
8. I rush through activities without being really attentive to them.	1	2	3	4	5	6
9. I get so focused on the goal I want to achieve that I lose touch with what I am doing right now to get there.	1	2	3	4	5	6
10. I do jobs or talks automatically, without being aware of what I am doing.	1	2	3	4	5	6
11. I find myself listening to someone with one ear, doing something else at the same time.	1	2	3	4	5	6
12. I drive places on "automatic pilot" and then wonder why I went there.	1	2	3	4	5	6
13. I find myself preoccupied with the future or the past.	1	2	3	4	5	6
14. I find myself doing things without paying attention.	1	2	3	4	5	6
15. I snack without being aware that I am eating.	1	2	3	4	5	6



Appendix E  
**Brief Cope - Active Avoidance Coping subscale**

The following items focus on the ways in which you cope with having a child with special needs in your family. There are many ways in which people will deal with this situation, and different people will use different ways of coping. We are interested in how YOU cope with this situation. Each item says something about a particular way of coping. We want to know to *what extent* you do what the item says in order to cope with having a child with special needs. Please do not answer on the basis of whether these ways of coping seem to *work* or not, but simply whether or not you do what the item says. Try to rate each item separately in your mind from the others, and make your answers as true FOR YOU as you can. Select your response by placing a circle around the appropriate number next to each item.

	Not at all	A little	A medium amount	A lot
I use alcohol or other drugs to make myself feel better.	0	1	2	3
I give up trying to deal with it.	0	1	2	3
I say things to let my unpleasant feelings escape.	0	1	2	3
I use alcohol or other drugs to help me get through it.	0	1	2	3
I criticise myself.	0	1	2	3
I give up the attempt to cope.	0	1	2	3
I do something to think about it less, such as going to the cinema, watching TV, reading, daydreaming, sleeping or shopping.	0	1	2	3
I express my negative feelings.	0	1	2	3
I blame myself for things that happen.	0	1	2	3

Appendix F  
**Kansas Inventory of Positive Perceptions  
Positive Contributions Scale**

MY CHILD \_\_\_\_\_ IS:

The blank space after the word “child” is there to remind you to think only of your child with special needs when you answer each statement. Read each statement and circle the one response that best describes how much you agree or disagree with each statement.

### Part A

MY CHILD \_\_\_\_\_ IS:

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. the reason I attend religious services more frequently.	1	2	3	4
2. why I met some of my best friends.	1	2	3	4
3. the reason my life has better structure.	1	2	3	4
4. why I am a more responsible person.	1	2	3	4
5. the reason I've learned to control my temper.	1	2	3	4
6. responsible for my learning patience.	1	2	3	4
7. responsible for my increased awareness of people with special needs.	1	2	3	4
8. fun to be around.	1	2	3	4
9. the reason I am more realistic about my job.	1	2	3	4
10. responsible for my being more aware and concerned for the future of mankind.	1	2	3	4
11. kind and loving.	1	2	3	4
12. helpful to other family members, which saves time and energy for me.	1	2	3	4
13. a source of pride because of his/her artistic accomplishments.	1	2	3	4

### Part B

I CONSIDER MY CHILD \_\_\_\_\_ TO BE:

14. what gives me common ground with other parents.	1	2	3	4
15. helpful without having to be asked.	1	2	3	4
16. responsible for my increased sensitivity to people.	1	2	3	4
17. what gives our family a sense of continuity – a sense of history.	1	2	3	4
18. the reason I am more productive.	1	2	3	4
19. an advantage to my career.	1	2	3	4
20. the reason I budget my time better.	1	2	3	4
21. the reason I am able to cope better with stress and problems.	1	2	3	4
22. very affectionate.	1	2	3	4
23. what makes me realise the importance of planning for my family's future.	1	2	3	4
24. able to use good judgement.	1	2	3	4
25. a great help around the house.	1	2	3	4

**Part C**

THE PRESENCE OF MY CHILD \_\_\_\_\_:

26. is an inspiration to improve my job skills.	1	2	3	4
27. helps me understand people who are different.	1	2	3	4
28. is a source of pride because of his/her athletic achievements.	1	2	3	4
29. cheers me up.	1	2	3	4
30. confirms my faith in God.	1	2	3	4
31. gives a new perspective to my job.	1	2	3	4
32. renews my interest in participating in different activities.	1	2	3	4
33. is very uplifting.	1	2	3	4
34. is a reminder that all children, including those with special needs, need to be loved.	1	2	3	4
35. is a reminder that everyone has a purpose in life.	1	2	3	4
36. makes us more in charge of ourselves as a family.	1	2	3	4
37. helps me take things as they come.	1	2	3	4

**Part D**

BECAUSE OF MY CHILD \_\_\_\_\_:

38. my circle of friends has grown larger.	1	2	3	4
39. I have someone who shares responsibility for doing several tasks around the house.	1	2	3	4
40. my social life has expanded by bringing me into contact with other parents.	1	2	3	4
41. I am more compassionate.	1	2	3	4
42. I learned about mental retardation.	1	2	3	4
43. my family is more understanding about special problems.	1	2	3	4
44. I am grateful for each day.	1	2	3	4
45. our family has become closer.	1	2	3	4
46. I am more sensitive to family issues.	1	2	3	4
47. I have learned to adjust to things I cannot change.	1	2	3	4
48. my other children have learned to be aware of people's needs and their feelings.	1	2	3	4
49. I have many unexpected pleasures.	1	2	3	4
50. I am more accepting of things.	1	2	3	4

Appendix G  
**Hospital Anxiety and Depression Scale**

**This questionnaire focuses on how you feel about things. Please read each item and circle the reply underneath the item which comes closest to how you have been feeling in the past week. Do not take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.**

**1. I feel tense or “wound up”**

Most of the time	A lot of the time	Occasionally, from time to time	Not at all
------------------	-------------------	------------------------------------	------------

**2. I still enjoy the things I used to enjoy**

Definitely as much	Not quite so much	Only a little	Hardly at all
--------------------	-------------------	---------------	---------------

**3. I get a sort of frightened feeling as if something awful is about to happen**

Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
------------------------------------	------------------------	--------------------------------------	------------

**4. I can laugh and see the funny side of things**

As much as I always could	Not quite so much now	Definitely not so much now	Not at all.
------------------------------	-----------------------	-------------------------------	-------------

**5. Worrying thoughts go through my mind**

A great deal of the time	A lot of the time	From time to time but not too often	Only occasionally
-----------------------------	-------------------	--	----------------------

**6. I feel cheerful**

Not at all	Not often	Sometimes	Most of the time
------------	-----------	-----------	---------------------

**7. I can sit at ease and feel relaxed**

Definitely	Usually	Not often	Not at all
------------	---------	-----------	------------

**8. I feel as if I am slowed down**

Nearly all the time	Very often	Sometimes	Not at all
---------------------	------------	-----------	------------

**9. I get a sort of frightened feeling like “butterflies” in the stomach**

Not at all	Occasionally	Quite often	Very often
------------	--------------	-------------	------------

**10. I have lost interest in my appearance**

Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
------------	--	--------------------------------------	-------------------------------------

**11. I feel restless as if I have to be on the move**

Very much indeed	Quite a lot	Not very much	Not at all
------------------	-------------	---------------	------------

**12. I look forward with enjoyment to things**

As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
-----------------------	----------------------------	-----------------------------------	---------------

**13. I get sudden feelings of panic**

Very often indeed	Quite often	Not very often	Not at all
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**14. I can enjoy a good book, radio or TV programme**

Often	Sometimes	Not often	Very seldom
-------	-----------	-----------	-------------



Appendix H  
**Questionnaire on Resources and Stress Short Form –  
Parent and Family Problems subscale**

The following statements deal with your feelings about your child with special needs. There are many blank spaces on the questionnaire (\_\_\_\_\_). Imagine the name of your child with special needs in each of these blank spaces. Please give your honest feelings and opinions. Respond to all of the statements, even if they do not seem to apply. If it is difficult to decide “true” or “false”, answer in terms of what you or your family feel or do *most* of the time.

- |  |      |       |
|--|------|-------|
| 1. Other members of the family have to do without things because of _____  | TRUE | FALSE |
| 2. Our family agrees on important matters.   | TRUE | FALSE |
| 3. The constant demands for care for _____ limit growth and development of someone else in our family.             | TRUE | FALSE |
| 4. I have given up things I have really wanted to do in order to care for _____                                    | TRUE | FALSE |
| 5. _____ is able to fit into the family social group.  | TRUE | FALSE |
| 6. In the future, our family’s social life will suffer because of increased responsibilities and financial stress. | TRUE | FALSE |
| 7. I can go to visit friends whenever I want.  | TRUE | FALSE |
| 8. Taking _____ on a holiday spoils the pleasure for the whole family.   | TRUE | FALSE |
| 9. The family does as many things now as it ever did.  | TRUE | FALSE |
| 10. There are many places where we can enjoy ourselves as a family when _____ comes along.                         | TRUE | FALSE |
| 11. There is a lot of anger and resentment in our family.  | TRUE | FALSE |
| 12. The constant demands to care for _____ limit my growth and development.  | TRUE | FALSE |
| 13. I feel sad when I think of _____   | TRUE | FALSE |
| 14. Caring for _____ puts a strain on me.  | TRUE | FALSE |
| 15. Members of our family get to do the same kind of things other families do.                                     | TRUE | FALSE |

Appendix I  
**Ethical approval for study**

**Ysgol Seicoleg  
Prifysgol Cymru, Bangor**

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September 16, 2004

Dr. Richard Hastings, Dr. Alex Beck, Tracey Lloyd  
School of Psychology  
University of Wales  
Bangor, Gwynedd

Dear Colleagues

**Special Needs and Families Research Project II**

Your research proposal (referred to above and on the attached sheet) has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines.

However, our reviewer has drawn attention to two matters, as follows:

- i) The shaded questions on the questionnaires are difficult to read – please reconsider this format
- ii) It appears there is something missing between the end of page 3 and the beginning of page 4 – please clarify

If you wish to make any substantial modifications to the research project, please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Good luck with your research.

Kath Chitty  
Coordinator - School of Psychology Research Ethics Committee

C Fergus Lowe PhD, FRPS  
Athro a Phrosseth yf Ysgol • Professor and Head of School

Appendix J  
**Invitation to participate and initial contact form**

# The Special Needs and Families Research Project

## NEEDS YOUR HELP!

I know your time is valuable but if you can spare 20 minutes to help us understand the positive contributions your child makes to family life and why some families are more resilient than others, please complete the form at the end of this leaflet and return it (free post) to me. We will then send you a short questionnaire.

## Thank you

Any questions please contact Ms Tracey Lloyd

Phone: 01248 388436

E mail: [specialfamilies@bangor.ac.uk](mailto:specialfamilies@bangor.ac.uk)

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LL57 2AS

WALES

*This research project is funded by a grant from The Health Foundation who fund various health and social care research projects.*

## Information for Families

### 1. Study Title

Special Needs and Families Research Project.

### 2. Research Team

Dr Alexandra Beck (Research Officer)  
Dr Richard Hastings (Project Leader)  
Ms Tracey Lloyd (Doctoral Researcher)

### 3. What is the purpose of the study?

We are interested in how family members, especially parents/parental caregivers, adapt to the care of children with special needs (specifically, intellectual disabilities). There is already research on this topic, but we are aiming to explore issues that have received little attention by researchers and others to date:

- What kinds of positive experiences are there associated with the care of children with special needs, and how might these experiences help parents to adapt successfully?
- What characteristics of parents explain why some families cope well (i.e. are “realistic”) and some families find things much more difficult to deal with.

### 4. Invitation to participate

We are looking for families of children with special needs in Surrey and south London to participate in our research project. We would like primary parental caregivers to take part in our research. A primary parental caregiver is the parent who takes the main responsibility for the care of your child with intellectual disabilities. You may be a parent, foster carer or adoptive parent. Please read the remainder of this information sheet carefully and complete the form enclosed if you are interested in helping us with this research. If there is anything that is not clear, or you would just like more information before you decide, please contact us by mail, telephone or email (including your telephone contact number) and we will telephone you to discuss the project further and answer any questions that you may have.

As several organisations have agreed to help us distribute information about this research, you may receive a duplicate of this information sheet and invitation to participate in the study. *If so, you only need to respond once.* If you do not wish to take part, simply discard this information – thank you.

### 5. What are the benefits of taking part in the research?

The main benefits of this research relate to improving the knowledge that we have about families and how they adapt to caring for children with special needs. In particular, almost nothing is known about parents’ positive experiences and how these

might help families to cope effectively. We hope to use the information from this research in the future to develop support interventions for families that focus on recognition of positive experiences of caring for children with special needs. We think that existing support services sometimes focus too much on stressful aspects of life and that new interventions and services might prove helpful.

We plan to keep all families up-to-date with the project's progress and its findings through a regular newsletter.

## **6. What are the risks of taking part?**

We do not believe that you are at risk of any harm from taking part in this study. Whether or not you take part, we are not involved in providing services to families of children with special needs and so your decisions will not affect any services you might receive.

## **7. Do we have to take part?**

It is up to you to decide whether you want to take part. If you do decide to take part, or want further information, please sign the Initial Contact Form and return it in the envelope provided. You can keep this information sheet for your records. You are still free to withdraw from the research at any time, and without giving a reason.

## **8. What will happen to us if we take part?**

After you have returned the Initial Contact Form, we will go through the following contact process:

1. Telephone you to answer any questions (if you have requested this).
2. Send you a questionnaire pack in the mail to complete and return to us. This will include questions about your child and their special needs, yourself, and your family. Specifically, we will ask about your positive feelings and feelings of stress, the strategies you use to cope with problems, the support available to you, and your child's behaviour problems (if any). This pack will also include A Consent Form to sign to say that you are willing to participate in the research.  
The questionnaires take between 20 and 30 minutes to complete.
3. We will then telephone you to ask you some questions about your child. This should take about 20 minutes.
4. Send you information about the results of the study.

## **9. What do we have to do now?**

If, having discussed this information with you partner, friends and/or family, you would like to discuss the study further, or you would like to take part, then please return the Initial Contact Form. If you decide not to take part, please discard this letter. You do not need to make contact with us. We apologise if you receive any



more copies of this invitation. Just ignore these as we have no way of contacting you directly unless you return the Initial Contact Form to us.

All the information that you give us will be treated as strictly confidential, and will be kept securely locked in a filing cabinet without your names attached. None of the information that you provide will be used in any way that would identify you as a family. Results of the study will describe overall findings and not information about individual families.

## 10. Further details

If you want to contact the research team, our details are below:

Tracey Lloyd E-Mail [tracey.lloyd@hca.ac.uk](mailto:tracey.lloyd@hca.ac.uk)

If you have any complaints about the way that this research is being conducted, you are welcome to address unresolved concerns to:

This research project is funded by a grant from the Health Foundation who fund various health and social care research projects.

### Initial Contact Form

#### Special Needs and Families Research Project

Please read the following, place a tick in the appropriate boxes, then return the form in the stamped addressed envelope provided.

I would like more information before I decide to take part in the study. *Please give us a contact number.*

.....

I would like to take part in the study. *Please complete the information below.*

Your Name (please print):

\_\_\_\_\_

Your contact address:

\_\_\_\_\_

\_\_\_\_\_

Postcode

\_\_\_\_\_

Telephone Number:

\_\_\_\_\_

***Return this sheet to me at the university (in the freepost envelope provided) and I'll send you your questionnaire. Thank you for agreeing to participate in this research, Tracey Lloyd.***

Appendix K  
**Consent Form**

**Research Consent Form**

**Special Needs and Families Research Project**

For Office Use Only Code: No: Date:
---

*Please complete the following and delete as necessary:*

- 1) Have you read the Information for Families leaflet? YES/NO
- 2) Have you had an opportunity to telephone and ask questions about this study? YES/NO
  - Have you received satisfactory answers to all of your questions? YES/NO
- 3) Have you received enough information about this study? YES/NO
- 4) Do you understand that you are free to withdraw from this study:
  - ..at any time
  - ..without giving a reason for withdrawing
  - ..without affecting any treatment you receive? YES/NO

I am willing to participate in this study. YES/NO

Signature \_\_\_\_\_

Date \_\_\_\_\_

Name in block letters \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Telephone Number \_\_\_\_\_

Please let me know the best time to telephone you (please tick):

	Morning	Afternoon	Early evening	After 8.00pm
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				

Specific.....

Appendix L  
**Thank you letter**

Dear Parents or Guardians,

Thank you for the information you provided for the Special Needs and Families Research Project. Information gathered from you will be used to try and understand the positive experiences that having a child with a learning disability may bring to a family and why some families are more resilient than others. The long-term aim is to use what is learned to inform early intervention for families and develop coping strategies.

We will send you information from our study as we get it, informing you of our overall findings.

Once again, thank you for your time and commitment it is greatly appreciated.

Yours sincerely,

Tracey Lloyd  
Doctoral Researcher: Special Needs and Families Research Project.

Appendix M  
**Reminder letter**

Dear

I am writing with reference to the questionnaire(s) I sent to you from the Special Needs and Families Research Project. If you are still happy to complete the questionnaires then please send them to the address below. If you would now like more information about the study or help with completing the questionnaires please contact me and I will try to clarify any problems you may have. If you no longer wish to complete the questionnaires, please send them back in the envelope provided and I will not contact you again.

I look forward to hearing from you soon.

Tracey Lloyd

Doctoral Researcher: Special Needs and Families Research Project.



Appendix N  
**Parental Locus of Control Scale**

The following questions concern your beliefs about child rearing. Please circle the number which corresponds to the answer you agree with.

	Strongly Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree
1. When I set expectations for my child, I am almost certain that I can help him/her meet them.	1	2	3	4	5
2. I am often able to predict my child's behaviour in situations.	1	2	3	4	5
3. When my child gets angry I can usually deal with him/her if I stay calm.	1	2	3	4	5
4. What I do has little effect on my child's behaviour.	1	2	3	4	5
5. No matter how hard a parent tries, some children will never learn to be responsible.	1	2	3	4	5
6. My child usually ends up getting his/her way, so why try?	1	2	3	4	5
7. When something goes wrong between me and my child, there is little I can do to correct it.	1	2	3	4	5
8. Parents should address problems with their children because ignoring them won't make them go away.	1	2	3	4	5
9. It is not always wise to expect too much from my child because many things turn out to be a matter of good or bad luck anyway.	1	2	3	4	5
10. If your child throws tantrums no matter what you try, you might as well give up.	1	2	3	4	5
11. I am responsible for my child's behaviour.	1	2	3	4	5
12. Capable people who fail to become good parents have not followed through on their opportunities.	1	2	3	4	5
13. My child's behaviour problems are no one's fault but my own.	1	2	3	4	5
14. Parents whose children make them feel helpless just aren't using the best parenting techniques.	1	2	3	4	5
15. There is no such thing as good or bad children-just good or bad parents.	1	2	3	4	5
16. Parents who can't get their children to listen to them don't understand how to get along with their children.	1	2	3	4	5

17. Most children's behaviour problems would not have developed if their parents had had better parenting skills.	1	2	3	4	5
18. Children's behaviour problems are often due to mistakes their parents made.	1	2	3	4	5
19. When my child is well-behaved, it is because he/she is responding to my efforts.	1	2	3	4	5
20. The misfortunes and successes I have had as a parent are a direct result of my own behaviour.	1	2	3	4	5
21. I feel like what happens in my life is mostly determined by my child.	1	2	3	4	5
22. My child does not control my life.	1	2	3	4	5
23. Even if your child frequently has tantrums, a parent should not give up.	1	2	3	4	5
24. My child influences the number of friends I have.	1	2	3	4	5
25. When I make a mistake with my child I am usually able to correct it.	1	2	3	4	5
26. It is easy for me to avoid and function independently of my child's attempts to have control over me.	1	2	3	4	5
27. My life is chiefly controlled by my child.	1	2	3	4	5
28. Without the right breaks one cannot be an effective parent.	1	2	3	4	5
29. Heredity plays the major role in determining a child's personality.	1	2	3	4	5
30. Neither my child nor myself is responsible for his/her behaviour	1	2	3	4	5
31. Success in dealing with children seems to be more a matter of the child's moods and feelings at the time rather than one's own actions.	1	2	3	4	5
32. In order to have my plans work, I make sure they fit in with the desires of my child.	1	2	3	4	5
33. I'm just one of those lucky parents who happened to have a good child.	1	2	3	4	5
34. Most parents don't realise the extent to which how their children turn out is influenced by accidental happenings.	1	2	3	4	5
35. Being a good parent often depends on being lucky enough to have a good child.	1	2	3	4	5
36. I have often found that when it comes to my children, what is going to happen will happen.	1	2	3	4	5

37. Fate was kind to me-if I had had a bad child I don't know what I would have done.	1	2	3	4	5
38. It is not too difficult to change my child's mind about something.	1	2	3	4	5
39. My child's behaviour is something more than I can handle.	1	2	3	4	5
40. Sometimes I feel that I do not have enough control over the direction my child's life is taking.	1	2	3	4	5
41. I always feel in control when it comes to my child.	1	2	3	4	5
42. Sometimes I feel that my child's behaviour is hopeless.	1	2	3	4	5
43. It is often easier to let my child have his/her way than to put up with a tantrum.	1	2	3	4	5
44. I allow my child to get away with things.	1	2	3	4	5
45. I find that sometimes my child can get me to do things I really did not want to do.	1	2	3	4	5
46. My child often behaves in a manner very different from the way I would want him/her to behave.	1	2	3	4	5
47. Sometimes when I'm tired I let my children do things I normally wouldn't.	1	2	3	4	5

Appendix O  
**Reiss Scales for Children's Dual Diagnosis**

This test presents a list of maladaptive behaviours that could create problems in the lives of children with special needs. Each item on the list is defined. A few examples are given to help you understand the meaning of the definition. Your task is to read each item and tell us if you think that the item is currently **NO PROBLEM**, a **PROBLEM**, or a **MAJOR PROBLEM** in the child's life. Please keep in mind that we do not want to know simply if the behaviour occurs; what we would like is your opinion if the problem occurs with sufficient frequency, with sufficient intensity, or under sufficiently strange or inappropriate circumstances, so that the behaviour category is a problem or a major problem in the child's life.

**How to use the Rating Scale:**

**NO PROBLEM.** Use this rating if any of the following are true:

1. The behaviour category does not apply to the child you are rating. For example, the category of "lying" does not apply to a child who is non-verbal.
2. The child you are evaluating does not engage in the behaviour.
3. The behaviour does not occur with sufficient frequency, intensity, or severity to be considered a current problem in the life of the child you are evaluating.

**PROBLEM.** Use this rating if one or more of the following are true:

1. The behaviour causes a significant degree of discomfort and/or suffering for the child being evaluated.
2. The behaviour interferes with the child's social functioning.
3. The behaviour interferes with the child's school functioning.
4. The behaviour occurs often or with unusual degree of severity.

**MAJOR PROBLEM.** Use this rating if one or more of the following are true:

1. The behaviour causes a great deal of discomfort and/or suffering for the child you are evaluating.
2. The behaviour occurs with very high frequency or intensity.
3. The behaviour significantly interferes with the child's social adjustment.
4. The behaviour causes placement in a restrictive environment or increases the need for supervision.

**Now please answer the following questions:**

<b>1. Afraid of strangers.</b> Becomes fearful in the presence of adult strangers. e.g. resists going near an unfamiliar adult even when encouraged to do so under appropriate circumstances, cries when meeting an adult for the first time, cries in a crowd.	No Problem	Problem	Major Problem
<b>1. Angry.</b> Frequently feels hostile or mad. Example: gets mad easily, argues a lot, interrupts others when ignored, expresses anger in inappropriate ways.	No Problem	Problem	Major Problem
<b>3. Anxious.</b> Appears nervous or tense. e.g. nervous, overreacts to unexpected sounds or events, vigilant, worried.	No Problem	Problem	Major Problem
<b>4. Avoids by Illness.</b> False sickness, disability, or pain in order to avoid something he/she does not want to do. e.g. says he/she has a stomach-ache in order to avoid going to school, says he/she has a headache in order to avoid cleaning up room.	No Problem	Problem	Major Problem
<b>5. Avoids Peers.</b> Dislikes interacting with other children. e.g, prefers to play alone, avoids groups, parallel play only, pushes/hits others when approached.	No Problem	Problem	Major Problem



<b>6. Bizarre Ideas.</b> Expressed strange ideas. e.g. says that he/she is a sailor, says that he/she should collect as many rocks as possible.	No Problem	Problem	Major Problem
<b>7. Blank Stares.</b> Appears expressionless and emotionless. e.g. sometimes appears to be in a trance, gazes off into space.	No Problem	Problem	Major Problem
<b>8. Bodily Complaints.</b> Complains about aches and pains. e.g. headaches, stomach-aches, dizziness, constipation, diarrhoea, unexplained recurrent pains.	No Problem	Problem	Major Problem
<b>9. Bonding Problem.</b> Child or infant has not formed normal emotional attachments with parents/caregivers. e.g. does not seek closeness if caretakers enters room, does not calm when held by parents, does not respond to affection from parents/caretakers.	No Problem	Problem	Major Problem
<b>10. Bullies Others.</b> Controls others with threats, verbal abuse, or actual physical attack. e.g. intimidates smaller or weaker children, bosses around smaller or weaker children.	No Problem	Problem	Major Problem
<b>11. Changes In Sleep Behaviour.</b> A change in usual sleep habits. e.g. recent trouble falling asleep, wakes up in the middle of the night, has trouble waking in mornings.	No Problem	Problem	Major Problem
<b>12. Communication Problem.</b> Marked difficulty in communicating with others. E.g. makes up and uses own words for things, no mode of communication, abnormal gestures, marked speech problem, echolalia, stuttering.	No Problem	Problem	Major Problem
<b>13. Confusing Speech.</b> Poorly related or bizarre ideas or thoughts. e.g. speech makes no sense, thinking is hard to follow, expresses strange ideas, thoughts jump from one topic to another.	No Problem	Problem	Major Problem
<b>14. Crying Spells.</b> Periodic bouts of sobbing. E.g. easily moved to tears, cries more often than most children, cries for no apparent reason.	No Problem	Problem	Major Problem
<b>15. Destructive.</b> Deliberately damages property. E.g. breaks windows, deliberately destroys furniture, throws objects, turns over furniture.	No Problem	Problem	Major Problem
<b>16. Disobedient.</b> Does not follow rules or directions given by people in authority. E.g. does not listen to teacher, does not follow rules of group home/residence, does not follow simple requests.	No Problem	Problem	Major Problem
<b>17. Distracted.</b> Attention to a task is easily interrupted by extraneous or irrelevant stimuli. Example: short attention span, has trouble concentrating	No Problem	Problem	Major Problem
<b>18. Enuresis/Encopresis.</b> A child beyond the age of toilet training with inadequate bladder or bowel control. e.g. bed wetting, urinating on the floor, defecating in pyjamas or pants.	No Problem	Problem	Major Problem
<b>19. Excessive Need For Reassurance.</b> Frequently needs to be told that things are okay. E.g. excessive need to be told that he/she is loved or liked, excessive need to be told that he/she is doing a good job, repeatedly needs to be told that time of a schedule event or reassured that it will occur.	No Problem	Problem	Major Problem
<b>20. Excessive Sensitivity To Criticism.</b> Excessive or inappropriate reactions to criticism. E.g. reacts to failure by crying, quits easily, become angry.	No Problem	Problem	Major Problem
<b>21. Fearful.</b> Afraid of many objects or situations. E.g. afraid to go places, afraid to try new activities, afraid of many different things.	No Problem	Problem	Major Problem

<b>22. Feels Unloved.</b> Has perceptions that parents or significant others do not love or care about him/her. E.g. says that parents/caretakers do not love him/her, says that nobody cares about him/her, says that parents/caretakers love others (e.g. brother or sisters) more.	No Problem	Problem	Major Problem
<b>23. Gaze Avoidance.</b> Actively avoids eye contact. E.g. infrequent eye contact with others, becomes upset when face-to face contact is forced.	No Problem	Problem	Major Problem
<b>24. Hallucinations.</b> Experiences things that are not there. E.g. hears voices. Hears sounds, has visions, feels strange bodily sensations.	No Problem	Problem	Major Problem
<b>25. Headaches.</b> Complains about aches and pains in the head. E.g. says head hurts, has migraine headaches, has tension headaches.	No Problem	Problem	Major Problem
<b>26. Impatient.</b> Needs/demands must be met immediately. E.g. demanding, can't wait his/her turn, easily frustrated.	No Problem	Problem	Major Problem
<b>27. Impulsive.</b> Reacts quickly without first thinking about the likely consequences. E.g. makes decisions quickly, quick-tempered.	No Problem	Problem	Major Problem
<b>28. Inattentive.</b> Pays little attention to people or to events around him/her. E.g. pays little attention when spoken to, seems "spaced out".	No Problem	Problem	Major Problem
<b>29. Involuntary Motor movements.</b> Repetitive movements beyond the control of the person. E.g. excessive blinking, strange motor movements, frequent shrugs, hand flapping.	No Problem	Problem	Major Problem
<b>30. Irritable.</b> Easily annoyed or provoked. E.g. easily frustrated, becomes angry over minor annoyances, easily offended, feelings are hurt easily.	No Problem	Problem	Major Problem
<b>31. Isolated.</b> Spends a lot of time alone. E.g. has no friends, plays alone, is ignored or avoided by other children.	No Problem	Problem	Major Problem
<b>32. Lacks Enjoyment.</b> Does not seem to enjoy things anymore. E.g. has no fun, does not want to play anymore, does not want to do much of anything.	No Problem	Problem	Major Problem
<b>33. Lies.</b> Habitually says things that he/she knows are false or misleading. E.g. lies about getting into fights, fabricates incredible tales, lies about being late.	No Problem	Problem	Major Problem
<b>34. Negative Self-Image.</b> Dislikes self. E.g. he/she is stupid, says he/she is a bad person, says he/she is ugly.	No Problem	Problem	Major Problem
<b>35. Obese.</b> Excessively overweight. Example: perceived by others as being fat, eats too much.	No Problem	Problem	Major Problem
<b>36. Object Attachment.</b> Strong and persistent attachments to a particular object. E.g. Often wants to hold a particular ball, searches for missing objects, likes to carry a key chain and gets upset when the key chain cannot be found.	No Problem	Problem	Major Problem
<b>37. Overactive.</b> Excessive movement to the point where the person has difficulty staying still. E.g. appears to be in constant motion, excessive physical movement, pacing, constantly changing activity.	No Problem	Problem	Major Problem
<b>38. Pessimistic.</b> Has a negative view of the future. E.g. negative outlook, lacks hope, expects the worst, negative thinking.	No Problem	Problem	Major Problem
<b>39. Physically Aggressive.</b> Physically attacks others.	No Problem	Problem	Major Problem



E.g. fights, spits on others, hits others.

<b>40. Pica.</b> Tendency to eat non-edible objects. E.g. eats dirt, eats paint chips, eats paper, drinks cleaner solution.	No Problem	Problem	Major Problem
<b>41. Rebellious.</b> Defies authority and/or resists control from adults. e.g. defiant, refuses to co-operate with adults, hostile toward authority figures.	No Problem	Problem	Major Problem
<b>42. Runs Away.</b> Leaves without permission and without informing other people. E.g. runs away from home, residential facility, runs away from school.	No Problem	Problem	Major Problem
<b>43. Sad.</b> Displays frequent or excessive feelings of unhappiness. e.g. often gives appearance of unhappy child, has bouts of crying, rarely smiles.	No Problem	Problem	Major Problem
<b>44. Seeks Medical Care.</b> Frequently asks for or seeks out medical attention. E.g. asks for medicine, often needs medical care for one thing after another.	No Problem	Problem	Major Problem
<b>45. Self-Injury.</b> Repeatedly injures body on purpose. E.g. bites arm, hits self repeatedly, bangs head repeatedly.	No Problem	Problem	Major Problem
<b>46. Self-Stimulatory Behaviour.</b> Repetitive movements that are performed frequently and appear to be non-functional. E.g. body-rocking, object twirling, head rocking.	No Problem	Problem	Major Problem
<b>47. Separation Anxiety.</b> Afraid of being away from parent/caretaker. e.g. body-rocking, object-twirling, head-rocking.	No Problem	Problem	Major Problem
<b>48. Sets Fire.</b> Deliberately starts fires. Example: sets fire to room, sets fires in schools	No Problem	Problem	Major Problem
<b>49. Sexual Problem.</b> Repeatedly performs sexual behaviours that are socially disapproved. e.g. sexual expression at in appropriate times or places, masturbates in public.	No Problem	Problem	Major Problem
<b>50. Shy.</b> Uncomfortable in the presence of other people. e.g. dislikes being the centre of attention, bashful, ill at ease in groups, dislikes meeting new people.	No Problem	Problem	Major Problem
<b>51. Social Inadequacies.</b> Has difficulty relating to peers in appropriate or satisfying ways. e.g. has no friends, tends to be disliked, insensitive to the feelings of other people.	No Problem	Problem	Major Problem
<b>52. Steals.</b> Takes property that belongs to others. e.g. takes classmate's possessions, takes money for others.	No Problem	Problem	Major Problem
<b>53. Stomach aches.</b> Complains about stomach aches. e.g. says stomach is upset, feels nauseous, complains of gassy stomach.	No Problem	Problem	Major Problem
<b>54. Strange Behaviour.</b> Engages in behaviour that impresses many observers as unusual, peculiar, strange, or bizarre. e.g. hoards food in pockets or under bed, unusually wears several layers of clothes regardless of weather, always mutters things to self.	No Problem	Problem	Major Problem
<b>55. Suicidal Statements.</b> Thinks about, attempts, or threatens to kill himself/herself. e.g. says that he/she would like to die, intentionally cuts or hurts self, tries to get run over by cars.	No Problem	Problem	Major Problem
<b>56. Temper Tantrums.</b> Angry outbursts when frustrated or disappointed. e.g. shouts and yells when not given in to, has outburst when asks to do something he/she does not want to do.	No Problem	Problem	Major Problem

**57. Uncompleted Activities.** Marked tendency not to finish things. e.g. usually does not finish, goes from one uncompleted activity to another.      No Problem      Problem      Major Problem

**58. Unusual Vocalisations.** Makes strange or unusual sounds. e.g. grunts, barking noises, whispers words, sudden anger or swear words when not obviously angry.      No Problem      Problem      Major Problem

**59. Verbally Abusive.** Threatens or insults other people e.g. taunts, insults, threatens others, makes fun of other people, yells or shouts at others.      No Problem      Problem      Major Problem

**60. Withdrawn.** Avoids personal contact with other people. e.g. excessively shy, doesn't participate in group activities, prefers to be alone, socially isolated.      No Problem      Problem      Major Problem

Appendix P  
**Trait Hope Scale**

***Your Approach to Life***

Read each item carefully. Using the scale shown below, please select the number that best describes YOU and circle the corresponding number.

	Definitely false	Mostly false	Mostly true	Definitely true
1. I can think of many ways to get out of a jam.	1	2	3	4
2. I energetically pursue my goals.	1	2	3	4
3. I feel tired most of the time.	1	2	3	4
4. There are lots of ways around any problem.	1	2	3	4
5. I am easily beaten in an argument.	1	2	3	4
6. I can think of many ways to get the things in life that are most important to me.	1	2	3	4
7. I worry about my health.	1	2	3	4
8. Even when others get discouraged, I know I can find a way to solve the problem.	1	2	3	4
9. My past experiences have prepared me well for my future.	1	2	3	4
10. I've been pretty successful in life.	1	2	3	4
11. I usually find myself worrying about something.	1	2	3	4
12. I meet the goals that I set for myself.	1	2	3	4

Appendix Q  
**Positive and Negative Affect Scale –  
positive affect scale**

### Your Positive Feelings

*This scale consists of a number of words that describe different feelings and emotions. Read each item and circle the number which corresponds to what extent you feel this way right now, that is, at the present moment.*

	Very slight or not at all	A Little	Moderate	Quite a bit	Extremely
1.INTERESTED	1	2	3	4	5
2.EXCITED	1	2	3	4	5
3.STRONG	1	2	3	4	5
4.ENTHUSIASTIC	1	2	3	4	5
5.PROUD	1	2	3	4	5
6.ALERT	1	2	3	4	5
7.INSPIRED	1	2	3	4	5
8.DETERMINED	1	2	3	4	5
9.ATTENTIVE	1	2	3	4	5
10.ACTIVE	1	2	3	4	5

Appendix R  
**Ethical approval for study**

Ysgol Seicoleg  
Prifysgol Cymru, Bangor

Adeilad Brigantia, Ffordd Penrallt  
Bangor, Gwynedd LL57 2AS

Ffôn: (01248) 382211 - Ffacs: (01248) 382599  
e-bost: psychology@bangor.ac.uk  
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November 20, 2002

Dr. Richard Hastings, Alexandra Beck, Christopher Hill  
School of Psychology  
University of Wales  
Bangor  
Gwynedd LL57 2DG

Dear Colleagues

**Special needs and families research project**

Your research proposal (referred to above and on the attached sheet) has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines. I have been asked to point out, however, the spelling mistake on the final page of the risk assessment document – fourth word of first paragraph.

If you wish to make any substantial modifications to the research project, please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Good luck with your research.

Kath Chitty  
Coordinator -School of Psychology Research Ethics Committee



Appendix S  
**Information letter for parents**

## Initial Contact Form

### Special Needs and Families Research Project

Please read the following, place a tick in the appropriate boxes, then return the form in the stamped addressed envelope provided.

I would like more information before I decide to take part in the study. *Please give us a contact number below.*

I would like to take part in the study. *Please complete the information below.*

Please tell us if you are the child's primary or secondary parental caregiver:

I am the **primary parental caregiver** (parent, foster parent, adoptive parent etc., primarily responsible for the day-to-day care) of a child with special needs (age 4-17 years only)

I am the **secondary parental caregiver** (parent, foster parent, adoptive parent etc., involved in the child's care but not primarily responsible) of a child with special needs (age 4-17 years only)

Please tell us whether your child with special needs has another parental caregiver, and whether they would also be willing to participate in the research:

My child with special needs has another parental caregiver.

Yes  No

If yes, is this person willing to participate in the research?

Yes  No *If yes, please include their contact details below.*

**Your Name** (please print):

\_\_\_\_\_

Your contact  
address:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

**Your** telephone number:

\_\_\_\_\_

Best days to contact you are

\_\_\_\_\_

Best time of day to contact you is  Morning  Afternoon  Evening

specific times \_\_\_\_\_

**Name of other parental caregiver** (please  
print):

\_\_\_\_\_

**Their address** and telephone details (if different from above): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Telephone Number (if different from  
above):

\_\_\_\_\_

Best days to contact this person are

\_\_\_\_\_

Best time of day to contact this person is  Morning  Afternoon  Evening

specific times \_\_\_\_\_

Appendix T  
**Participant information sheet**

## Information for Families

**1. Study Title**

Special Needs and Families Research Project.

**2. Research Team**

Dr Alexandra Beck (Research Officer)

Dr Richard Hastings (Project Leader)

Tracey Lloyd (Doctoral Researcher)

**3. What is the purpose of the study?**

We are interested in how family members, especially parents/parental caregivers, adapt to the care of children with special needs (specifically, learning disabilities). There is already research on this topic, but we are aiming to explore two issues that have received little attention by researchers and others to date:

- What kinds of positive experiences are there associated with the care of children with special needs, and how might these experiences help parents to adapt successfully?
- How do changes over time affect the adaptation of parental caregivers, and do various positive experiences help parents to maintain a sense of satisfaction in their caring role?

**4. Invitation to participate**

We are looking for 150 families of children with special needs in the Wales and adjacent areas to participate in our research project. Ideally, families will be willing to participate in our research now and also agree to be involved in a follow-up data gathering phase in approximately 12 months time. Please read the remainder of this information sheet carefully and complete the form enclosed if you are interested in helping us with this research. If there is anything that is not clear, or you would just like more information before you decide, please contact us by mail, telephone or email (including your telephone contact number) and we will telephone you to discuss the project further and answer any questions that you may have.

As several organisations have agreed to help us distribute information about this research, you may receive a duplicate of this information sheet and invitation to participate in the study. *If so, you only need to respond once.*

### 5. What are the benefits of taking part in the research?

The main benefits of this research relate to improving the knowledge that we have about families and how they adapt to caring for children with special needs. In particular, almost nothing is known about parents’ positive experiences and how these might help families to cope effectively. We hope to use the information from this research in the future to develop support interventions for families that focus on recognition of positive experiences of caring for children with special needs. We think that existing support services sometimes focus too much on stressful aspects of life and that new interventions and services might prove helpful. Your participation in the research will contribute to these overall aims.

There are three more concrete benefits to participation in the research. First, the measures to be used in the research include an assessment of children’s adaptive skills (i.e., daily living skills, communication, and socialization skills). If you would like to receive one, we will provide you with a summary report of the findings from this assessment which you may wish to use to help identify appropriate service provision for your child.

Second, we appreciate that participation in research takes up valuable time and that it can be difficult to cover the costs of alternative care arrangements for your child. Therefore, we hope that you will feel able to accept a payment for participating in the research as outlined below. This payment would be made to you after your initial participation and then again if you agree to take part in our follow-up data collection in around 12 months time.

Receipt of data from Parent/Carer 1	Receipt of data from Parent/Carer 2	Receipt of follow-up data from Parent/Carer 1	Receipt of follow-up data from Parent/Carer 2	Maximum payment possible for family
£25	£10	£15	£10	£60

Finally, we plan several ways to keep all families up-to-date with the project’s progress and its findings, including:

- A regular newsletter.
- Access to a dedicated website about the project, including links to organizations offering advice and assistance to families of children with special needs.
- Facility to request full copies of research publications on families of children with special needs produced by members of the project team.

## **6. What are the risks of taking part?**

We do not believe that you are at risk of any harm from taking part in this study. Whether or not you take part, we are not involved in providing services to families of children with special needs and so your decisions will not affect any services you might receive.

## **7. Do we have to take part?**

It is up to you to decide whether you want to take part. If you do decide to take part, or want further information, please sign the Initial Contact Form and return it in the envelope provided. You can keep this information sheet for your records. You are still free to withdraw from the research at any time, and without giving a reason.

## **8. What will happen to us if we take part?**

After you have returned the Initial Contact Form, we will go through the following contact process:

5. Telephone you to answer any questions (if you have requested this).
6. Send you a questionnaire pack in the mail to complete and return to us. This will include questions about your child and their special needs, yourself, and your family. Specifically, we will ask about your positive feelings and feelings of stress, the strategies you use to cope with problems, the support available to you, and your child's behaviour problems (if any). This pack will also include another copy of this information sheet and a Consent Form to sign to say that you are willing to participate in the research. The questionnaires take between 60 and 75 minutes to complete.
7. Either telephone you to complete a short interview (our preferred option), or make a visit to your home or another place to carry out this interview (if you would rather). This interview for Parent/Carer 1 (approximately 25 minutes) will focus on how you see your relationship with your child with special needs and also completion of the adaptive behaviour assessment. For Parent/Carer 2, only the first part of the interview will be conducted (10 minutes).
8. If you are happy to let us make contact with them, we will also write to your child's school or nursery teacher and ask them to complete questionnaires about your child's pro-social behaviour and any behaviour problems your child may have in the school setting.
9. Send you a payment for helping us with the research.
10. Send you information about the initial results of the study.
11. 12 months later, we will write to ask you if you would be willing to help us with the follow-up data collection. This letter will include a fresh consent form for you to confirm that you are still willing to help. You will also be able to tell us at this point that you do not want to be included in this stage of the research.
12. Questionnaire and telephone contact, and payment will be made as before. However, the questionnaires (50-60 minutes) and interview (10 minutes only) will be shorter.

13. Send you final results of the study and let you know how you can access more detailed information.

## **9. What do we have to do now?**

If having discussed this information with you partner, friends and/or family you would like to discuss the study further, or you would like to take part, then please return the Initial Contact Form. If you decide not to take part, please discard this letter. You do not need to make contact with us. We apologise if you receive any more copies of this invitation. Just ignore these as we have no way of contacting you directly unless you return the Initial Contact Form to us.

All the information that you give us will be treated as strictly confidential, and will be kept securely locked in a filing cabinet without your names attached. None of the information that you provide will be used in any way that would identify you as a family. Results of the study will describe overall findings and not information about individual families.

If your preferred language is Welsh, we would like to apologise for the fact that the questionnaires and interview can be conducted in English only. It is not possible to translate them into Welsh without extensive testing of the measures due to potential problems in losing important aspects of their meaning through translation. We hope that you will be willing to participate in this research using English but understand that you may wish not to do so.

## **10. Further details**

If you want to contact the research team, our details are below:

Alex Beck or Tracey Lloyd: Special Needs and Families Research Project  
Mail - School of Psychology, Brigantia Building, University of Wales Bangor,  
Bangor, LL592AS. Telephone - 01248 388436. E-Mail  
[specialfamilies@bangor.ac.uk](mailto:specialfamilies@bangor.ac.uk)

If you have any complaints about the way that this research is being conducted you are welcome to address unresolved concerns to:

Professor Fergus Lowe  
Head of the School of Psychology  
University of Wales Bangor  
Bangor  
Gwynedd  
LL57 2AS

This research project is funded by a grant from the PPP Foundation who fund various health and social care research projects.



Appendix U  
**Consent form**

## Research Consent Form

### Special Needs and Families Research Project

*Please complete the following and delete as necessary:*

- |   |        |
|---|--------|
| 2) Have you read the Information for Families leaflet?                  | YES/NO |
| 5) Have you had an opportunity to ask questions and discuss this study? | YES/NO |
| 6) Have you received satisfactory answers to all of your questions?     | YES/NO |
| 7) Have you received enough information about this study?               | YES/NO |
| 5) Do you understand that you are free to withdraw from this study:     |        |
| ..at any time   |        |
| ..without giving a reason for withdrawing                               |        |
| ..without affecting any treatment you receive                           | YES/NO |

I am willing to participate in this study. YES/NO

Signature \_\_\_\_\_

Date \_\_\_\_\_

Name in block letters \_\_\_\_\_

Address \_\_\_\_\_  
 \_\_\_\_\_

Postcode \_\_\_\_\_

Please answer the following two questions:

1. If you are a member of staff of the University of Wales Bangor please tick this box

2. We would like to contact your child's teacher to ask them to complete a questionnaire about your child's behaviour in the school or nursery context. If you are happy for us to do this, please complete the information below.

Name of Teacher \_\_\_\_\_

Name and Address of School \_\_\_\_\_

Appendix V  
**Reminder letter**

Dear

I am writing with reference to the questionnaire(s) I sent to you from the Special Needs and Families Research Project. If you are still happy to complete the questionnaires then please send them to the address below. If you would now like more information about the study or help with completing the questionnaires please contact me and I will try to clarify any problems you may have. If you no longer wish to complete the questionnaires, please send them back in the envelope provided and I will not contact you again.

I look forward to hearing from you soon.

Tracey Lloyd  
Doctoral Researcher

Dear Parents or Guardians,

Thank you for the information you provided for the Special Needs and Families Research Project. Information gathered from you will be used to try and understand the positive experiences that having a child with a learning disability may bring to a family. The long-term aim is to use what is learned to inform early intervention for families and develop coping strategies.

We will send you another Christmas newsletter in November, this time informing you of our overall findings.

Once again, thank you for your time and commitment it is greatly appreciated.

Yours sincerely

Tracey Lloyd

Doctoral Researcher

Appendix W  
**Thank you letter**