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

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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 (Happe, 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 that 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 verses 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 medational 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, Wieibe & 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 beahviour 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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Chapter 4. Parental Locus of Control and Psychological Well-Being in of Mothers of Children with Intellectual Disabilities

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 Kausar 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, Pearsons' 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	*β*	*p*
Anxiety[1]	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[2]	Gender of child	-.033	.597
	Child behaviour problems	.272	<.001
	Hope agency	-.344	<.001
	Hope pathways	-.220	.008
	Hope interaction	.182	.004
Stress[3]	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[4]	Child mobility problems	.112	.065
	Child behaviour problems	-.148	.019
	Hope agency	.525	<.001
	Hope pathways	.146	.070
	Hope interaction	-.065	.290

[1] (R=.60, R^2=.35, F(9, 125)=7.60, p<.001), [2] (R=.71, R^2=.50, F(3, 133)=27.00, p<.001),

[3] (R=.63, R^2=.39, F(7,123)=11.39, p<.001, [4] (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	β	p
Anxiety[1]	Paternal job	.184	.152
	Hope agency	-.322	.037
	Hope pathways	-.071	.633
	Hope interaction	.110	.382
Depression[2]	Paternal age	.245	.037
	Hope agency	-.491	<.001
	Hope pathways	-.074	.594
	Hope interaction	.044	.693
Positive affect[3]	Age of child	-.235	.041
	Hope agency	.514	<.001
	Hope pathways	.079	.559
	Hope interaction	.056	.605

[1](R=.50, R^2=.23, F(4, 53)=3.95, p<.01), [2](R=.62, R^2=.38, F(4, 53)=8.27, p<.001),

[3] (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.

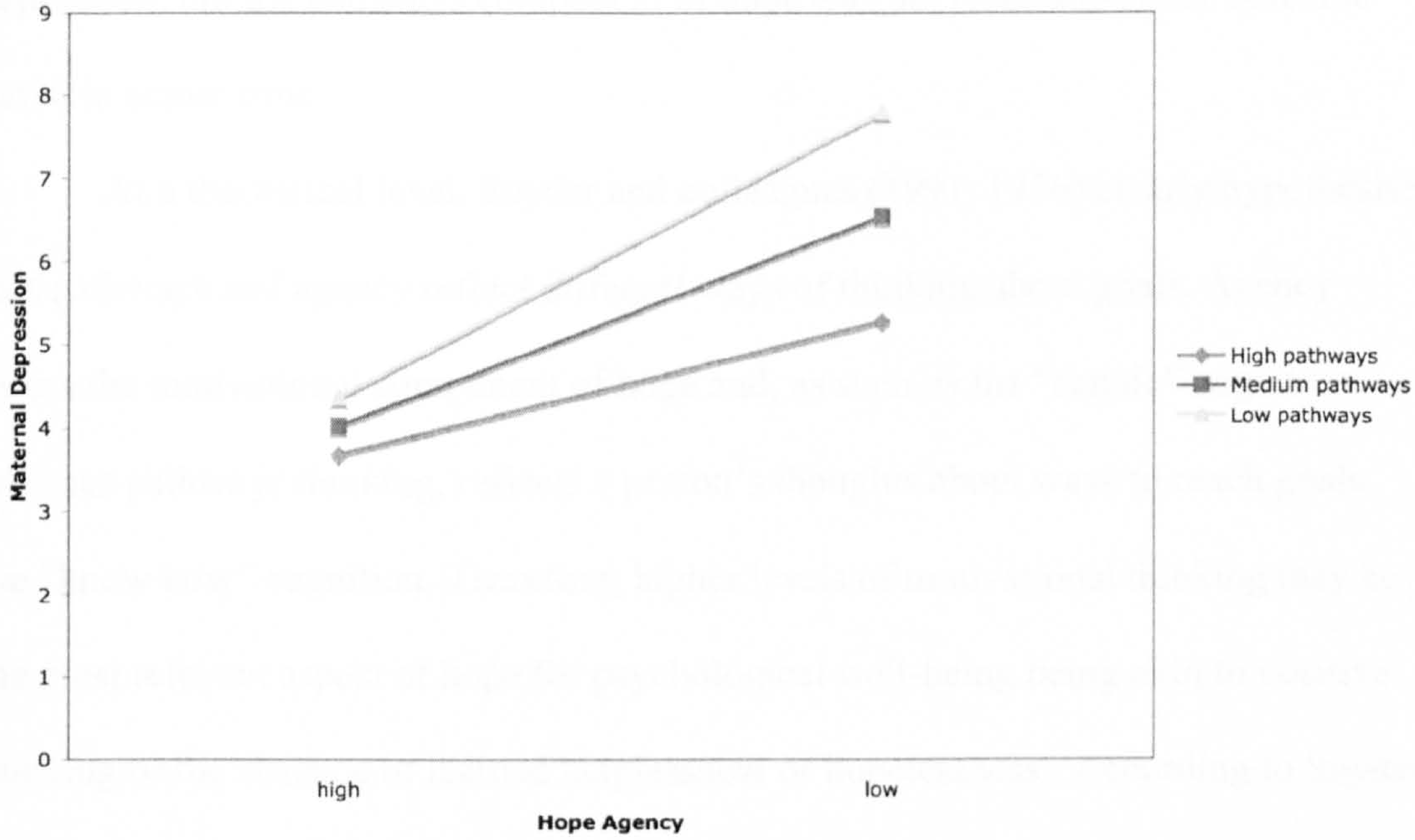

Figure 5.1. Interpretation of the interaction effect of hope agency and hope pathways on maternal depression.

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 Cronabch'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 of 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).

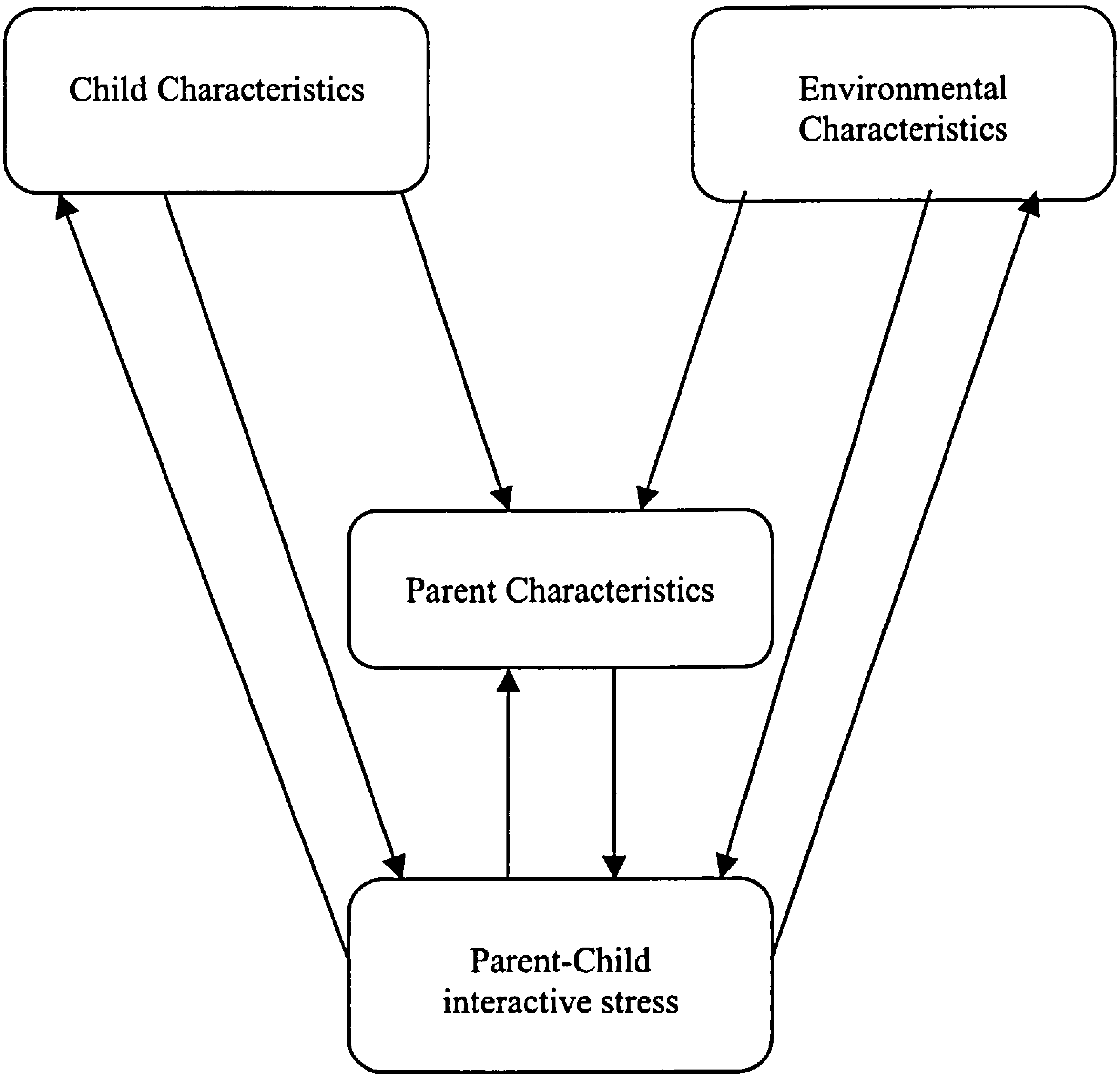

Figure 6.1. Mash and Johnston's (1990) model of stress in parent/child interactions.

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.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation, 109*, 237-254.

Abidin, R. R. (1986). *Parenting Stress Index: Manual.* Charlottesville, VA: Pediatric Psychology Press.

Aiken, L. S., & West, S. G. (1991). *Multiple Regression: Testing and interpreting interactions.* Thousand Oaks, CA, US: Sage Publications.

American Association on Intellectual and Developmental Disabilites (n.d.). *Frequently asked questions on the AAIDD definition.* Retrived June 1, 2008, from www.aaidd.org/Policies/faq_intellectual.disability.shtml

Anderson, C. R. (1977). Locus of control, coping behaviors, and performance in a stress setting: A longitudinal study. *Journal of Applied Psychology, 62*(4), 446-451.

Antonovsky, A. (1987). *Unraveling the Mystery of Health: How People Manage Stress and Stay Well.* Jossey-Bass Ltd. London.

APA (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th Ed. Revised). Washington D.C. American Psychiatric Association.

Arnau, R.C., Rosen, D.H., Finch, J.F., Rhudy, J.L., & Fortunado, V., J. (2007). Longitudinal effects of hope on depression and anxiety: A latent variable analysis. *Journal of Personality, 75*(1), 43-63.

Baer, R. A. (2003). Mindfulness training as a clinical intervention: A conceptual and empirical review. *Clinical Psychology: Science and Practice, 10*, 125-143.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation, 107*(6), 433-444.

Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 49*(8), 575-590.

Baker, B. L., Landen, S.J., & Kashima, K.J. (1991). Effects of parent training on families of children with mental retardation; Increased burden or generalized benefit? *American Journal on Mental Retardation, 96*, 127-136.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research. Special Issue on Family Research, 47*, 217-230.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215.

Barakat, L. P., Lutz, M. J., Nicolaou, D. C., & Lash, L. A. (2005). Parental locus of control and family functioning in the quality of life of children with sickle cell disease. *Journal of Clinical Psychology in Medical Settings, 12*(4), 323-331.

Baroff, G. S., & Olley, J. G. (1999). *Mental Retardation: Nature, Cause, and Management (3rd ed.).* Philadelphia, PA, US: Brunner/Mazel.

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality & Social Psychology, 51*, 1173-1182.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*(9), 702-714.

Beck, A., Daley, D., Hastings, R. P., & Stevenson, J. (2004). Mothers' expressed emotion towards children with and without intellectual disabilities. *Journal of Intellectual Disability Research, 48*, 628-638.

Behr, S.K., Murphy, D.L., & Summers, J.A. (1992). *User's Manual: Kansas Inventory of Parental Perceptions (KIPP).* Lawrence KS: Beach Centre on Families and Disability.

Benassi, V. A., Sweeney, P. D., & Dufour, C. L. (1988). Is there a relation between locus of control orientation and depression? *Journal of Abnormal Psychology, 97*(3), 357-367.

Beresford, B. (1996). Coping with the care of a severely disabled child. *Health & Social Care in the Community, 4*(1), 30-40.

Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation, 112*(5), 330-348.

Blacher, J., Shapiro, J., Lopez, S., & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation. *American Journal on Mental Retardation, 101*, 483-496.

Blackledge, J.T. & Hayes, S.C. (2006). Using Acceptance and Commitment training in the support of parents of children diagnosed with autism. *Child and Family Behavior Therapy, 28, 1-18.*

Blundo, R. (2001). Learning strengths based practice: Challenging our personal and professional frames. *Families in Society, 82*(3), 296-304.

Bond, F. W., & Bunce, D. (2000). Mediators of change in emotion-focused and problem-focused worksite stress management interventions. *Journal of Occupational Health Psychology, 5*, 156-163.

Brinker, R. P., Seifer, R., & Sameroff, A. J. (1994). Relations among maternal stress, cognitive development, and early intervention in middle- and low-SES infants with developmental disabilities. *American Journal on Mental Retardation, 98*(4), 463-480.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders - Social support, mental health status and satisfaction with services. *Autism, 8*(4), 409-423.

Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: Mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology, 84*, 822-848.

Bruce, A., & Davies, B. (2005). Mindfulness in hospice care: Practicing Meditation-in-Action. *Qualitative Health Research, 15*, 1329-1344.

Bugental, D. B., Johnston, C., New, M., & Silvester, J. (1998). Measuring parental attributions: Conceptual and methodological issues. *Journal of Family Psychology, 12*(4), 459-480.

Cahill, B. M., & Glidden, L. M. (1996). Influence of child diagnosis on family and parental functioning: Down syndrome versus other disabilities. *American Journal on Mental Retardation, 101(2)* 149-160.

Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The Parental Locus of Control Scale: Development and validation. *Journal of Clinical Child Psychology, 15*(3), 260-267.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*, 92-100.

Chadwick, P., Taylor, K. N., & Abba, N. (2005). Mindfulness Groups for People with Psychosis. *Behavioural and Cognitive Psychotherapy, 33*(3), 351-359.

Chang, E., C. (2003). A critical appraisal and extension of hope theory in middle-aged men and women: Is it important to distinguish agency and pathways components? *Journal of Social and Clinical Psychology, 22*(2), 121-143.

Coleman, P. K., & Karraker, K. H. (1998). Self-efficacy and parenting quality: Findings and future applications. *Developmental Review, 18*(1), 47-85.

Dahl, J., Wilson, K. G., & Nilsson, A. (2004). Acceptance and Commitment Therapy and the treatment of persons at risk for long-term disability resulting from stress and pain symptoms: A preliminary randomized trial. *Behavior Therapy, 35*, 785-801.

DeMaso, D. R., Campis, L. K., Wypij, D., Bertram, S., & et al. (1991). The impact of maternal perceptions and medical severity on the adjustment of children with congenital heart disease. *Journal of Pediatric Psychology, 16*(2), 137-149.

Didden, R., Duker, P. C., & Korzilius, H. (1997). Meta-analytic study on treatment effectiveness for problem behaviors with individuals who have mental retardation. *American Journal on Mental Retardation, 101*(4), 387-399.

Drach-Zahavy, A., & Somech, A. (2002). Coping with health problems: The distinctive relationships of Hope sub-scales with constructive thinking and resource allocation. *Personality and Individual Differences, 33*, 103-117.

Dragone, M. A., Bush, P. J., Jones, J. K., Bearison, D. J., & Kamani, S. (2002). Development and evaluation of an interactive CD-ROM for children with leukaemia and their families. *Patient Education and Counselling, 46*(4), 297-307.

Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism, 9*(4), 416-427.

Duggleby, W. D., Degner, L., Williams, A., Wright, K., Cooper, D., Popkin, D., et al. (2007). Living with Hope: Initial evaluation of a psychosocial hope intervention for older palliative home care patients. *Journal of Pain and Symptom Management, 33*(3), 247-257.

Dumas, J. E. (2005). Mindfulness-based parent training: Strategies to lessen the grip of automaticity in families with disruptive children. *Journal of Clinical Child and Adolescent Psychology, 34*, 779-791.

Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality, 2*(2), 97-110.

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39-52.

Dyson, L. L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. *American Journal on Mental Retardation, 98*, 207-218.

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*(9), 657-671.

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research, 47*, 385-399.

Emerson, E. (2005). Use of the Strengths and Difficulties Questionnaire to assess the mental health needs of children and adolescents with intellectual disabilities. *Journal of Intellectual & Developmental Disability, 30*, 14-23.

Emerson, E., Graham, H., & Hatton, C. (2006). The measurement of poverty and socioeconomic position in research involving people with intellectual disability. *International Review of Research in Mental Retardation, 32*, 77-108.

Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(2), 107-113.

Emerson, E., & Hatton, C. (2007a). Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal of Mental Retardation, 112*(2), 140-150.

Emerson, E., & Hatton, C. (2007b). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: A replication. *Journal of Intellectual Disability Research, 51*(11), 866-874.

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research, 50*(12), 862-873.

Eriksson, M., & Lindstrom, B. (2006). Antonovsky's Sense of Coherence Scale and the relation with health: A systematic review. *Journal of Epidemiology & Community Health, 60*(5), 376-381.

Factor, D. C., et al. (1990). Stress, social support, and respite care use in Families with autistic children. Brief report. *Journal of Autism and Developmental Disorders, 20*(1), 139-146.

Findley, M. J., & Cooper, H. M. (1983). Locus of control and academic achievement: A literature review. *Journal of Personality and Social Psychology, 44*(2), 419-427.

Fisman, S., & Wolf, L. (1991). The handicapped child: Psychological effects of parental, marital, and sibling relationships. *Psychiatric Clinics of North America, 14*(1), 199-217.

Flynt, S. W., & Wood, T. A. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation. Special Issue: Research on Families, 94*(3), 278-283.

Frankl, V.E. (1992). *Man's Search for Meaning: The Classic Tribute to Hope from the Holocaust.* London. Random House.

Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency, 88*, 41-48.

Friedrich, W. N., Wilturner, L. T., & Cohen, D. S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Retardation, 90*(2), 130-139.

Gammon, E. A., & Rose, S. D. (1991). The Coping Skills Training Program for parents of children with developmental disabilities: An experimental evaluation. *Research on Social Work Practice, 1*(3), 244-256.

Ganellen, R. J., & Blaney, P. H. (1984). Hardiness and social support as moderators of the effects of life stress. *Journal of Personality and Social Psychology, 47*(1), 156-163.

Gardner, F., Burton, J., & Klimes, I. (2006). Randomised controlled trial of a parenting intervention in the voluntary sector for reducing child conduct problems: outcomes and mechanisms of change. *Journal of Child Psychology and Psychiatry, 47*(11), 1123-1132.

Gifford, E. V., Kohlenberg, B. S., Hayes, S. C., Antonuccio, D. O., Piasecki, M. M., Rasmussen-Hall, M. L., et al. (2004). Acceptance-Based treatment for smoking cessation. *Behavior Therapy, 35*(4), 689-705.

Gill, M. J., & Harris, S. L. (1991). Hardiness and social support as predictors of psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental Disorders, 21*(4), 407-416.

Glidden, L. M., & Floyd, F. J. (1997). Disaggregating parental depression and family stress in assessing families of children with developmental disabilities: A multisample analysis. *American Journal on Mental Retardation, 102*, 250-266.

Glidden, L. M., & Schoolcraft, S. A. (2003). Depression: its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research, 47*(4-5), 250-263.

Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 38*, 581-586.

Grant, K. E., Compas, B. E., Stuhlmacher, A. F., Thurm, A. E., McMahon, S. D., & Halpert, J. A. (2003). Stressors and child and adolescent psychopathology: Moving from markers to mechanisms of risk. *Psychological Bulletin, 129*(3), 447-466.

Hagekull, B., Bohlin, G., & Hammarberg, A. (2001). The role of parental perceived control in child development: A longitudinal study. *International Journal of Behavioral Development, 25*(5), 429-437.

Hanson, M. J., & Hanline, M. F. (1990). Parenting a child with a disability: A longitudinal study of parental stress and adaptation. *Journal of Early Intervention. Special Issue: Families, 14*(3), 234-248.

Happe, F. (1994). *Autism: An Introduction to Psychological Theory*. Cambridge, MA, US: Harvard University Press.

Hassall, R., & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy, 33*(1), 71-88.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*, 405-418.

Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability, 27*(3), 149-160.

Hastings, R. P. (2003a). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders, 33*(2), 141-150.

Hastings, R. P. (2003b). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*, 231-237.

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(3), 269-275.

Hastings, R. P., & Beck, A. (2004). Practitioner Review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*, 1338-1349.

Hastings, R. P., Beck, A., Daley, D., & Hill, C. (2005). Symptoms of ADHD and their correlates in children with intellectual disabilities. *Research in Developmental Disabilities, 26*(5), 456-468.

Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities, 9*, 155-165.

Hastings, R. P., & Brown, T. (2002a). Behavioral problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107*(3), 222-232.

Hastings, R. P., & Brown, T. (2002b). Coping strategies and the impact of challenging behaviors on special educators' burnout. *Mental Retardation, 40*(2), 148-156.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and Expressed Emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111*, 48-61.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism The International Journal of Research and Practice, 9*, 377-391.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.

Hastings, R. P., Thomas, H., & Delwiche, N. (2002). Grandparent support for families of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities, 15*(1), 97-104.

Hatton, C. & Emerson, E. (2003). Families with a person with intellectual disabilities: Stress and impact. *Current Opinion in Psychiatry, 16*(5), 497-501.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour Research and Therapy, 44*, 1-25.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change.* New York: Guildford Press.

Haynes, S.N., (1992). *Models of Causality in Psychopathology: Toward Synthetic, Dynamic and Nonlinear Models in Causality In Psychopathology.* Des Moines; IA: Ayllon & Bacon.

Hedov, G., Anneren, G., & Wikblad, K. (2002). Swedish parents of children with Down's syndrome: Parental stress and sense of coherence in relation to employment rate and time spent in child care. *Scandinavian Journal of Caring Sciences, 16*(4), 424-430.

Hedov, G., Wikblad, K., & Anneren, G. (2006). Sickness absence in Swedish parents of children with Down's syndrome: Relation to self-perceived health, stress and sense of coherence. *Journal of Intellectual Disability Research 50(7), 546-552.*

Helff, C.M., & Glidden, L.M. (1998). More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation, 36,* 457-464.

Henderson, D., & Vandenberg, B. (1992). Factors influencing adjustment in the families of autistic children. *Psychological Reports, 71*(1), 167-171.

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*(12), 874-882.

Hillman, J. (2007). Grandparents of children with autism: A reveiw with recommendations for education, practice, and policy. *Educational Gerontology, 33*(6), 513-527.

Hodapp, R. M., Fidler, D., & Smith, A. (1998). Stress and coping in families of children with Smith-Magenis syndrome. *Journal of Intellectual Disability Research, 42*(5), 331-340.

Horner, R.H., Carr, E.G., Strain, P.S., Todd, A.W., & Reed, H.K. (2002). Problem behavior interventions for young children with autism: A research synthesis. *Journal of Autism and Developmental Disorders, 32*(5), 423-446.

Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46(4) 382-399.*

Hyman, P., & Oliver, C. (2001). Causal explanations, concern and optimism regarding self-injurious behaviour displayed by individuals with Cornelia de Lange syndrome: The parents' perspective. *Journal of Intellectual Disability Research, 45*(4), 326-334.

Janssens, J. M. A. M. (1994). Authoritarian child rearing, parental locus of control, and the child's behaviour style. *International Journal of Behavioral Development, 17*(3), 485-501.

Jones, J., & Passey, J. (2005). Family Adaptation, Coping and Resources: Parents Of Children With Developmental Disabilities and Behaviour Problems. *Journal on Developmental Disabilities. Special Issue on Families of Individuals with DD, 11*(1), 31-46.

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations, 47*(3), 263-268.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders, 27*(1), 39-57.

Katz, M. R., Kopek, N., Waldron, J., Devins, G. M., & Tomlinson, G. (2004). Screening for depression in head and neck cancer. *Psycho-Oncology, 13*(4), 269-280.

Kausar, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35-46.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*(5), 582-592.

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family centered caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of Pediatric Psychology, 24*, 41-53.

Konstantareas, M. M. (1991). Autistic, learning disabled and delayed children's impact on their parents. *Canadian Journal of Behavioural Science. Special Issue: Childhood disorders in the context of the family, 23*(3), 358-375.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*(4), 393-404.

Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*(4), 564-575.

Lam, L. W., & Mackenzie, A. E. (2002). Coping with a child with Down syndrome: The experiences of mothers in Hong Kong. *Qualitative Health Research, 12*(2), 223-237.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal and Coping.* New York: Springer.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172-183.

Leigh, J., Bowen, S., & Marlatt, G. A. (2005). Spirituality, mindfulness and substance abuse. *Addictive Behaviors, 30*(7), 1335-1341.

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), 37-48.

Lovejoy, M. C., Verda, M. R., & Hays, C. E. (1997). Convergent and discriminant validity of measures of parenting efficacy and control. *Journal of Clinical Child Psychology, 26*(4), 366-376.

Luthar, S. S., & Zigler, E. (1991). Vulnerability and competence: A review of research on resilience in childhood. *American Journal of Orthopsychiatry, 61*(1), 6-22.

Mak, W. W. S., Ho, A. H. Y., & Law, R. W. (2007). Sense of coherence, parenting attitudes and stress among mothers of children with autism in Hong Kong. *Journal of Applied Research in Intellectual Disabilities, 20*(2), 157-167.

Margalit, M., & Kleitman, T. (2006). Mothers' stress, resilience and early intervention. *European Journal of Special Needs Education, 21*(3), 269-283.

Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology. Special Issue: The stresses of parenting, 19*(4), 313-328.

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: the double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman & J. M. Patterson (Eds.), *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research.* New York: The Haworth Press.

Miech, R. A., & Shanahan, M. J. (2000). Socioeconomic Status and Depression over the Life Course. *Journal of Health and Social Behavior, 41*(2), 162-176.

Moes, D., Koegel, R. L., Schreibman, L., & Loos, L. M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports, 71(3)*, 1272-1274.

Murphy, K. R., & Davidshofer, C. O. (1994). *Psychological Testing: Principles and applications.* Englewood Cliffs, NJ, US: Prentice Hall, Inc.

National Autistic Society (n.d.). *Notes on the prevalence of autism spectrum disorders.* Accessed 02.06.08 from www.nas.org.uk/nas/jsp.

Neely-Barnes, S., & Marcenko, M. (2004). Predicting impact of childhood disability on families: Results from the 1995 National Health Interview Survey Disability Supplement. *Mental Retardation, 42*(4), 284-293.

Ng, T. W. H., Sorensen, K. L., & Eby, L. T. (2006). Locus of control at work: A meta-analysis. *Journal of Organizational Behavior, 27*(8), 1057-1087.

Nixon, C. D., & Singer, G. H. S. (2002). Group cognitive-behavioral treatment for excessive parental self-blame and guilt. *American Journal on Mental Retardation, 97*(6), 665-672.

Noble, M., Wright, G., Dibben, C., Smith, G.A.N., McLennan, D., Antilla, C. et al. (2004). *Indices of deprivation 2004* (Rep. to the Office of the Deputy Prime Minister). London: Neighbourhood Renewal Unit.

Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability, 31*(1), 1-12.

Oettingen, G., & Gollwitzer, P. M. (2002). Turning hope thoughts into goal-directed behavior. *Psychological Inquiry, 13*(4), 304-307.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 191-193.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research. Special Issue: Mental health and intellectual disability: IX, 45*(6), 535-543.

Olsson, M. B., & Hwang, C. P. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research, 46*(7), 548-559.

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research, 51*(9), 682-696.

Ostrander, R., & Herman, K. C. (2006). Potential cognitive, parenting, and developmental mediators of the relationship between ADHD and depression. *Journal of Consulting and Clinical Psychology, 74*(1), 89-98.

Padencheri, S., & Russell, P. S. S. (2002). Challenging behaviours among children with intellectual disability: The hope busters? *Journal of Learning Disabilities, 6*(3), 253-261.

Pakenham, K. I., Sofronoff, K., & Samios, C. (2004). Finding meaning in parenting a child with Asperger syndrome: Correlates of sense making and benefit finding. *Research in Developmental Disabilities, 25*(3), 245-264.

Patterson, J.M., (1988). Families experiencing stress I. The Family Adjustment and Response Model: II Applying the FAAR model to health-related issues for intervention and research. *Family Systems Medicine, 6*(2), 202-237.

Patterson, J.M., (2002). Integrating family resilience and family stress theory. *Journal of Marriage and the Family, 64*(2), 349-360.

Piven, J., Chase, G. A., Landa, R., Wzorek, M., & et al. (1991). Psychiatric disorders in the parents of autistic individuals. *Journal of the American Academy of Child & Adolescent Psychiatry, 30*(3), 471-478.

Quine, L., & Pahl, J. (1991). Stress and Coping in Mothers Caring for a Child with Severe Learning-Difficulties - a Test of Lazarus Transactional Model of Coping. *Journal of Community & Applied Social Psychology, 1*(1), 57-70.

Quittner, A. L., Glueckauf, R. L., & Jackson, D. N. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality and Social Psychology, 59*(6), 1266-1278.

Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities, 21*(1), 34-47.

Reiss, S., & Valenti-Hein, D. (1994). Development of a psychopathology rating scale for children with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 28-33.

Rimmerman, A. (1991). Parents of adolescents with severe intellectual disability in Israel: Resources, stress and the decision to apply for out-of-home placement. *Australia & New Zealand Journal of Developmental Disabilities, 17*(3), 321-329.

Roach, M. A., Orsmond, G. I., & Barratt, M. S. (1999). Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. *American Journal on Mental Retardation, 104*(5), 422-436.

Roberts, M. W., Joe, V. C., & Rowe-Hallbert, A. (1992). Oppositional child behavior and parental locus of control. *Journal of Clinical Child Psychology, 21*(2), 170-177.

Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. (1992). Psychosocial adaptation of fathers of children with autism, Down syndrome, and normal development. *Journal of Autism and Developmental Disorders, 22*(2), 249-263.

Roemer, L., & Orsillo, S. M. (2003). Mindfulness: A promising intervention strategy in need of further study. *Clinical Psychology: Science & Practice, 10*(2), 172-178.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs: General & Applied, 80*(1), 1-28.

Rotter, J. B. (1975). Some problems and misconceptions related to the construct of internal versus external control of reinforcement. *Journal of Consulting and Clinical Psychology, 43*(1), 56-67.

Rotter, J. B. (1990). Internal versus external control of reinforcement: A case history of a variable. *American Psychologist, 45*(4), 489-493.

Sandler, I. N., & Lakey, B. (1982). Locus of control as a stress moderator: The role of control perceptions and social support. *American Journal of Community Psychology, 10*(1), 65-80.

Sansome, C., Wiebe, D.J., & Morgan, C. (1999). Self-regulating interest: the moderating role of hardiness and conscientiousness. *Journal of Personality, 67*, 701-733.

Scheier, M. F., & Carver, C. S. (1985). Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. *Health Psychology, 4*(3), 219-247.

Schnyder, U., Buchi, S., Morgeli, H, Sensky, T., & Klaghofer, R. (2000). Sense of coherence - a mediator between disability and handicap? *Psychotherapy Psychsomatics,* 68(2), 102-110.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation, 38*(3), 195-206.

Scorgie, K., Wilgosh, L., & McDonald, L. (1999). Transforming partnerships: parent life management issues when a child has mental retardation. *Education and Training in Mental Retardation, 34,* 395-405.

Scorgie, K., Wilgosh, L., Sobsey, D., & McDonald, J. (2001). Parent life management and transformational outcomes when a child has Down Syndrome. *International Journal of Special Education, 16*(2), 57-69.

Seligman, M. E. (1975). *Helplessness: On Depression, Development, and Death.* Oxford, England: W. H. Freeman.

Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*(1), 5-14.

Singer, G. H. S. (2006). Meta-Analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111*(3), 155-169.

Singer, G.H.S., Ethridge, B.L. & Aldana, S.I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 357-369.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Fisher, B. C., Wahler, R. G., McAleavey, K., et al. (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders, 14*(3), 169-177.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Wahler, R. G., Singh, J., & Sage, M. (2004). Mindful caregiving increases happiness among individuals with profound multiple disabilities. *Research in Developmental Disabilities, 25*(2), 207-218.

Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism, 6(4), 2002, 397-409.*

Sloper, P., Knussen, C., Turner, S., & Cunningham, C. C. (1991). Factors related to stress and satisfaction with life in families of children with Down's syndrome. *Journal of Child Psychology and Psychiatry, 32*(4), 655-676.

Sloper, P., & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 34(2)* 210-223.

Smith, J. E., Richardson, J., Hoffman, C., & Pilkington, K. (2005). Mindfulness-based stress reduction as supportive therapy in cancer care: Systematic review. *Journal of Advanced Nursing, 52*(3), 315-327.

Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry, 71*(2), 257-261.

Snyder, C.R., (2002). Hope Theory: Rainbows in the mind. *Psychological Inquiry, 13* (4), 249-275.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Yoshinobu, L., Gibb, J., et al. (1991). The will and the ways: development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology, 60*(4), 570-585.

Snyder, C. R., Ilardi, S. S., Cheavens, J., Michael, S. T., Yamhure, L., & Sympson, S. (2000). The role of hope in cognitive-behavior therapies. *Cognitive Therapy and Research, 24*(6), 747-762.

Snyder, C. R., Rand, K., L., Sigmon, D.R. (2002). *Hope Theory: A Member of the Positive Psychology Family.* Chapter in C.R. Snyder & S.J. Lopez (Eds.). *Handbook of Positive Psychology.* New York. Oxford University Press.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., Borders, T. F., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the state hope scale. *Journal of Personality and Social Psychology, 70*, 321-335.

Sparrow, S.S., Balla, D. A., & Cicchetti, D.V. (1984). *The Vineland Adaptive Behavior Scale* (Interview edition survey form). Circle Pines, MN: American Guidance Service.

Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual & Developmental Disability, 23*(1), 57-70.

Stone, A.A., Schwartz, J.E., Neale, J.M., Shiffman, S., Marco, C.A. et al., (1998). A comparison of coping assessed by ecological momentary assessment and retrospective recall. *Journal of Personality and Social Psychology, 74*(6), 1670-1680.

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation, 43*(5), 339-350.

Sturmey, P. (2004). Cognitive therapy with people with intellectual disabilities: A selective review and critique. *Clinical Psychology & Psychotherapy, 11*(4), 222-232.

Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities, 37*(4), 410-420.

Taylor, S. E. (1983). Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist, 3*, 1161-1173.

Teasdale, J., Segal, Z., & Williams, M. (1995). How does cognitive therapy prevent depressive relapse and why should attentional control (mindfulness) training help? *Behavioural Research and Therapy, 35*, 25-39.

Treacy, L., Tripp, G., & Baird, A. (2005). Parent Stress Management Training for Attention-Deficit/Hyperactivity Disorder. *Behavior Therapy, 36*(3), 223-233.

Turnbull, A.P., Patterson, J.M., Behr, S.K., Murphy, D.L., Marquis, J.G., & Blue-Banning, M.J. (1993). *Cognitive Coping, Families and Disability.* Baltimore, MD. Paul H. Brookes Publishing Co.

Twohig, M. P., & Woods, D. W. (2004). A preliminary investigation of Acceptance and Commitment Therapy and habit reversal as a treatment for Trichotillomania. *Behavior Therapy, 35*(4), 803-820.

Wanamaker, C. E., & Glenwick, D. S. (1998). Stress, coping, and perceptions of child behavior in parents of preschoolers with cerebral palsy. *Rehabilitation Psychology, 43*(4), 297-312.

Wang, L.-Y., Kick, E., Fraser, J., & Burns, T. J. (1999). Status attainment in America: The roles of locus of control and self-esteem in educational and Occupational Outcomes. *Sociological Spectrum, 19*(3), 281-298.

Warfield, M. E., Krauss, M. W., Hauser-Cram, P., Upshur, C. C., & Shonkoff, J. P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Journal Of Developmental And Behavioral Pediatrics, 20*(1), 9-16.

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology, 54*(6), 1063-1070.

Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6*(1), 115-130.

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*(3), 181-190.

Wing, L., & Gould, J. (1978). Systematic recording of behaviors and skills of retarded and psychotic children. *Journal of Autism & Childhood Schizophrenia, 8*(1), 79-97.

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370.

Appendix A
Demographic Questionnaire

Appendix B
Strengths and Difficulties Questionnaire

Appendix C
Acceptance and Action Questionnaire

Appendix D

Mindful Attention Awareness Scale

Appendix E

Brief Cope - Active Avoidance Coping subscale

Appendix F
Kansas Inventory of Positive Perceptions
Positive Contributions Scale

Appendix G
Hospital Anxiety and Depression Scale

Appendix H

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

Appendix I
Ethical approval for study

Appendix J

Invitation to participate and initial contact form

Appendix K
Consent Form

Appendix L
Thank you letter

Appendix M
Reminder letter

Appendix N
Parental Locus of Control Scale

Appendix O
Reiss Scales for Children's Dual Diagnosis

Appendix P
Trait Hope Scale

Appendix Q

Positive and Negative Affect Scale – positive affect scale

Appendix S
Information letter for parents

Appendix T

Participant information sheet

Appendix U
Consent form

Appendix V
Reminder letter

Appendix W

Thank you letter