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Resilience, Behavioural Problems and Well-being in Children with Intellectual and Developmental Disabilities and their Families.

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Summary

Behavioural problems exhibited by children with Intellectual and Developmental Disabilities (IDD) have been identified as a significant stressor for family members in both cross-sectional and longitudinal research. However, the extent to which family members are affected by child behavioural problems is variable which may be due to moderating factors between these relationships, including resilience. There is a lack of conceptual clarity in defining what resilience is in existing research, and it is unclear how resilience may improve well-being outcomes in this population.

This thesis presented four studies. One study investigated mothers' reporting on their child's resilience where it was found that maternal depression had a significant effect on child behavioural and emotional problems. The study found that child resilience functioned as a compensatory factor, being associated with fewer child behavioural problems. Three studies investigated resilience and related constructs in mothers of children with IDD. Social support was found to function as a protective factor between child behavioural problems and maternal depression, life satisfaction and when mothers reported the positive affect of having a child with IDD on themselves and their family. There was also some evidence of the role of practical coping and positive perceptions acting as protective factors between child behavioural and emotional problems and maternal well-being. Consistent evidence was found that maternal resilience functioned as a compensatory factor, improving maternal outcomes; including stress, anxiety, depression, perceptions of positive gain and family satisfaction. One study focused only on mothers of children with Autism Spectrum Disorder (ASD) where the severity of the child's current ASD symptoms was found to have a significant main effect on maternal depression. Longitudinally maternal resilience did not act as a significant predictor of maternal well-being outcomes over time. Finally, findings from the empirical studies were discussed along with their implications for future research and interventions.

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'*The life given to us by nature is short, but the memory of a life well spent is eternal*'- Cicero

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Chapter 1: Introduction and Overview

This thesis presents findings from four studies each investigating child behavioural and emotional problems, with a focus on the well-being in children and young people with Intellectual and Developmental Disabilities (IDD) and their mothers. The following four chapters of this thesis present quantitative data analyses that explore maternal and child resilience and associated factors (e.g., social support, coping style). This begins with chapter two (study one), a cross-sectional secondary data analysis conducted to explore perceived social support, coping and positive perceptions as moderating factors between child behavioural and emotional problems and maternal well-being. Chapter three (study two) and chapter four (study three) are cross-sectional studies which utilise the data collected during this PhD. This data collection was an UK wide, online survey, recruitment and promotion for the survey were carried out by Elizabeth Halstead, and the research was named as 'The ReAL Project' (Resilience and Life). Chapter three explores resilience in mothers of children with IDD through self-reporting, and chapter four explores child resilience by maternal report. Chapter five (study four) is the final of the studies in this thesis and is a second secondary data analysis, using data collected by Professor Naomi Ekas and her team at Texas Christian University, to explore resilience in mothers of children with Autism Spectrum Disorder (ASD) using both cross-sectional and longitudinal data. Study four was an opportunity for an international collaboration with another university and to explore resilience longitudinally and internationally, which expanded on the previous UK based cross-sectional studies presented in this thesis. The collaboration developed through an international IDD conference. Each of these chapters (chapters two to five) are designed and written as empirical papers to be published, therefore each chapter should be read independently and it should be noted there is an overlap of the information between the chapters due to this design. It should also be noted that in this thesis children with ASD are included in the term Intellectual and Developmental Disabilities as often there are comorbidities of diagnoses in this population, and children with ASD are relevant to this thesis as they often present with behavioural and emotional problems. The current chapter (chapter one) will now describe the background to the thesis and present a rationale as to why it is important to explore resilience, child behavioural and emotional problems, and well-being in children with IDD and their families. The chapter concludes by outlining subsequent chapters two to five in more detail and the introduction of chapter six which presents an overall discussion of the thesis.

Definition of Intellectual and Developmental Disabilities (IDD)

Intellectual and Developmental Disabilities (IDD): As defined by the American Association on Intellectual and developmental disabilities, "an *Intellectual disability* is a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour**,** which covers many everyday social and practical skills. This disability originates before the age of 18.**"**

Child behavioural and emotional problems as a risk factor to maternal well-being

It is well established that children with IDD display higher rates of child behavioural problems than their non-disabled peers (Baker et al., 2003; Einfeld, Ellis & Emerson, 2011; Totsika, Hastings, Emerson, Lancaster & Berridge, 2011). It is also established that mothers of children with IDD show increased levels of stress when compared to mothers of children without IDD (Emerson, 2003; Hastings & Beck, 2004). Child behavioural and emotional problems have been associated with poorer maternal health and well-being in cross-sectional research (e.g., Baker, Neece, Fenning, Crnic & Blacher, 2010; Totsika et al., 2013; Baker et al., 2003; Blacher & McIntyre, 2006; Emerson, 2003, Hastings, 2003; Lewis et al., 2006; Lecavalier et al. 2006; Hastings & Brown 2002; Saloviita, Itälinna, Leinonen et al., 2003). Child behavioural and emotional problems have also been shown to predict a decrease in maternal well-being (such as increased stress, tension, anxiety, and depression) over time in longitudinal research (e.g., Baker et al., 2003; Herring et al., 2006; Lecavalier, Leone, &

Wiltz, 2006; Zeedyk & Blacher, 2015; Emerson & Einfeld, 2011). Maternal well-being in mothers of children with IDD has also shown to vary and it is evident that not all mothers are highly stressed. Totsika, Hastings, Emerson, Lancaster and Berridge (2011) found that 60% of mothers of children with IDD did not report concerning clinical levels of their own emotional problems. This variability in mothers' well-being suggests there are additional factors affecting the relationship between child behavioural and emotional problems and maternal well-being. While negative parental outcomes are well established, positive parental outcomes are also associated with raising a child with IDD, such as personal growth, improved relationships with others, more patience, and more empathy (Hastings & Taunt, 2002; Pakenham, Sofronoff, & Samios, 2005; Scorgie & Sobsey, 2000). Therefore, this thesis introduces resilience and related influences (e.g., coping style) as potential factors which may have a positive effect on outcomes when included in this established relationship between child behavioural and emotional problems and family (child and mother) well-being.

Parenting a child with ASD has also been shown to be associated with a variety of parental positive and negative outcomes (see reviews by Glasbery, Martins, & Harris, 2007; Hastings, 2008). Research has identified that parents of children with ASD experience higher stress levels than parents of typically developing children or children diagnosed with other IDDs, including Down's Syndrome, Cerebral Palsy, and Global Developmental Delay (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010; Eisenhower, Baker & Blacher, 2005; Estes et al., 2009, 2013; Hayes, & Watson, 2013; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Zablotsky, Bradshaw, & Stuart, 2013; Giovagnoli, 2015). Also, parents of children with ASD also experience more symptoms of depression and use of avoidance coping than parents of typically developing children (Wei et al., 2015).

The behavioural symptoms of children with ASD and the severity of ASD symptoms have been explored in association with parental outcomes such as parental stress and depression in cross-sectional research (e.g., Eisenhower, Baker, & Blacher, 2005; Hastings & Johnson, 2001; Kasari & Sigman, 1997 Baker-Ericzen et al., 2005; Hastings & Johnson, 2001; Hastings et al., 2005; Hill-Chapman et al., 2013; Osborne & Reed, 2009) and over time (Firth & Dryer, 2013; Benson, 2010). It was noted by Smith et al. (2008) the literature explores mostly child ASD symptoms specifically and parental outcomes (such as Eisenhower, Baker, & Blancher, 2005; Ello & Donovan, 2005; Lecavlier, Leone, & Wiltz, 2006). However, the question remains if it is primarily due to ASD symptoms or child behavioural problems more generally (such as in Hastings, Kovshoff, Ward et al. 2005; Herring et al., 2006). Again, variability is present in parents' mental health and well-being when raising a child with ASD; some parents report significantly lower well-being and mental health problems than other parents (Benson, 2006; Benson & Karlof, 2009).

Moderators/ protective factors of maternal well-being

In studies on parental well-being in IDD literature, many child characteristics (such as behavioural problems) and parental resources variables (such as depression) have been explored. However, typically only the main effects of predictor variables on parental psychological well-being have been addressed, thus researchers have rarely looked beyond a simple main effect relationship between risk variables and parental-well-being. Theoretically, factors that are associated with positive outcomes may mediate or moderate this relationship, potentially explaining the variability in the outcomes. A mediator specifies how (or the mechanism by which) a given effect occurs (Holmbeck, 1997; Baron & Kenny, 1986; James & Brett, 1984). Stated more simply, “the independent variable causes the mediator which then causes the outcome" (Shadish & Sweeney, 1991, p. 883). A moderator affects the relationship between two variables, so that the nature of the impact of the predictor on the criterion varies according to the level or value of the moderator. A moderator “interacts with a predictor variable in such a way as to have an impact on the level of a dependent variable” (Holmbeck, 1997, p. 599).

Previous research on moderators and mediators

Mediated and moderated relationships between child behavioural and emotional problems and parental well-being outcomes have been explored in previous studies. For example, a study by MacDonald, Hastings, and Fitzsimons (2010) found psychological acceptance partially mediated the impact of child behavioural problems on paternal stress, anxiety, and depression.

In research with families of children with ASD, Weiss, Cappadocia, MacMullin, Viecili, and Lunsky (2012) found supporting evidence that maternal empowerment is a partial mediator between child behavioural problems and greater maternal distress in mothers of children with ASD. In this study empowerment is defined as a psychological process in which an individual is active in changing or eliminating potentially stressful events through applying knowledge and skill (Gutiérrez, 1994). Self-efficacy was found to moderate the effect of child behavioural problems on anxiety in fathers of children with ASD (Hastings & Brown, 2002).

Researchers found the level of social support experienced by mothers of children with IDD had a moderating effect on the relationship between key variables, such as child behavioural problems and level of parental stress (Plant and Sanders, 2007). Social support was also found to be a moderator between stressors (life events and parenting stress) and negative outcomes (e.g., depression, social isolation) (Dunn, Burbine, Bowers, & Tantledd-Dunn, 2001). Coping style (e.g., practical coping style and emotion based coping styles) has been found to be a moderator between stressors (life events and parenting stress) and negative parental outcomes (e.g., depression, social isolation) (Dunn et al., 2001). Suarez and Baker

(1997) found coping styles moderate the impact of externalising behaviour problems on parental stress in parents of children with IDD.

Resilience

One construct which could be important as a mediator or moderator of maternal well-being in families of children with IDD is resilience. Resilience is of growing interest in mainstream research. For example, researchers have recently reviewed the resilience literature and critiqued the variety of definitions, concepts and theories of psychological resilience (Fletcher & Sarkar, 2015). In disability research, it has been proposed to expand the current research agenda to consider resilience (and thus adaptation) of families caring for children with IDD to gain a greater understanding of the resources needed in family well-being (McConnell & Savage, 2015).

There is a lack of conceptual clarity in defining what resilience is in existing research and in particular what it means to children with IDD (Peer & Hillman, 2014). Definitions of resilience suggest “resilience is concerned with individual variations in response to risk. Some people succumb to stress and adversity whereas others overcome life hazards” (Rutter, 1987, p. 317). Resilience is also defined as “the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful” (Walsh, 1998, 2006, p. 263). The “most agreed upon definition” of resilience is proposed in a review and is described as the “successful adaptation to life tasks in the face of social disadvantage or highly adverse conditions” (Windle, 1999, p. 163). These definitions are based around a risk/stress – resilience framework: for resilience to be displayed, a stressor must be experienced. Resilience appears to have its roots from the risk, stress and coping literature and has mainly been developed into a concept in itself through findings with “resilient subgroups”. However, the advantage to this is it prophers an opportunity to identify factors relating to “resilience” and how to enhance reactions to stress and adversity positively through intervention work

(Garmezy, 1993; Luthar & Cicchetti, 2000; Luthar et al. 2000). It has been argued resilience should not be considered as a personality trait, or an adjective to describe an individual (Luthar & Zelazo, 2003) but as a process that involves contextual elements, such as the population of interest, the specific risk involved, and also the outcomes (Fergus & Zimmerman, 2005).

Research into resilience has very much focused on children and identifying outcome profiles of a risk group to identify protective factors associated with positive outcomes (Luthar et al. 2000). Most of the research focuses on the use of quantitative scales correlated to outcomes measures, and qualitative methods are seldom used (e.g. Rutter, 1993; Windle, 1999). There is inconsistency in approaches to defining and operationalising resilience, and therefore undermines the ability to compare study findings (Luthar and Cichetti, 2000; Windle, 1999). A need in the literature was identified to use interactive statistical models to explore underling mechanisms and processes of adaptation (Fergus & Zimmerman, 2005).

Very little is known about how resilience functions as a moderator variable, or as an additional factor in risk-outcome relationships. However, research into resilience often identifies resilience as a process and there are thus three main theoretical ways to think about resilience: as a compensatory factor (risk factors have a direct main effect, reducing negative outcomes directly), as a protective factor (reducing negative outcomes in the context of exposure to risk – a moderated effect), and finally the challenge model, which suggests that when exposed to low levels of risk, resilience builds over time (Fergus & Zimmerman, 2005; Brook, Whiteman, Gordon, & Cohen, 1986; 1989). In terms of the challenge model, it has been suggested that childhood adversities may protect against the effects of later life stress, as this produces “steeling effects” (Andrews, Page, & Neilson, 1993; Lyons & Parker, 2007; Oldehinkel & Ormel, 2014; Rutter, 2006; Seery, Holman, & Silver, 2010). That is “exposure to stresses or adversities may either increase vulnerabilities through a sensitization effect or decrease vulnerabilities through a steeling effect." (Rutter, 2012 p. 337). It appears there is some consensus that for resilience to be inferred positive adaptation much be present despite a risk (Luthar et al. 2000; Tusaie & Dyer, 2004). Each of these different conceptualisations of resilience leads to different predictions about maternal outcomes in IDD research. Therefore, in the current context resilience might be demonstrated when a parent experiences risk factors, such as child behavioural problems and still report good well-being outcomes. In general there is great variability in measures chosen to investigate resilience, however outcomes must be conceptually relevant to the risk encountered (Masten et al. 2006).

Resilience over time

It is important to discuss how defining resilience has changed over time due to the changes in social norms and developments in IDD research and the wider well-being research. Garmezy (1974, 1985) was a pioneer in the conceptualisation of resilience in the general population. It was identified by Garmezy (1974, 1985) that environmental factors, such as social support and family dynamics, as well as genetic factors, such as personality dispositions should be considered in resilience research. Rutter (1999) stated the effects of resilience would likely be shaped by social context, and therefore a common clear definition or explanation of resilience would not necessarily be found. This is relevant in today's context as policy makers in the UK are suggesting "resilience" can be improved, that resilience is quantifiable, and therefore funding is being provided to support resilience interventions. A wider trend in the literature has emerged from focusing only on risk and adversity to focusing on resilience within positive psychology, using the term resilience supports this positive change (Seligman & Csikszentmihalyi, 2014). Viewing resilience in this way has three main limitations (Rutter, 2012); it implies influences of resilience will be similar in non-stressed groups and in those suffering from extreme adversity; however, promotive factors can also apply outside of resilience directly but still contribute to resilience in the face of adversity.

Second; that outcomes will be explicable on the balance between risk and protective factors, and third, it assumes that most individuals will respond to stress and adversity in the same way. It is clear from this research and from previous research in the broader resilience field that resilience is very much an umbrella term for many factors (Rutter, 2012). In terms of measuring resilience over time, it cannot be assumed that the same combination of factors would be protective in relation to all risks, and therefore resilience cannot be measured as if it was a character trait. Resilience also may be better defined through qualitative research, as it may reflect the experience of the individual (Garmezy, 1973).

Resilience overlaps with other areas of psychological well-being research.

It is important to consider that resilience may be related to coping, support, positivity, and many other factors and traits. When looking at resilience, a common conceptualisation is the process of the interaction between risk and protective processes; this can be across time and across different concepts, such as well-being, coping or positive psychology. Protective processes in themselves are another central construct in theory within psychological well-being research, they can be seen as processes that contribute to better resilience, or are they part of resilience itself. Protective processes have been defined as “factors that modify the effects of risk in a positive direction” (Luthar & Cicchetti, 2000). Three levels of protective factors are generally widely accepted across the literature; individual level (e.g. positive temperament, self-esteem, self-efficacy, cognitive factors, coping strategies, social skills), family level (family cohesion, warmth, emotionally responsive care-giving, parent-child relationships) and community level (peer networks, supportive communities and the school environment). Another related construct to resilience is vulnerability factors. These are factors that exacerbate the negative effect of the risk condition (Luthar & Cicchetti, 2000), or traits that increase vulnerability to stress, for example low intelligence, disability (Blum, 1998). Family resilience is also a growing area of research and is where resilience is conceptualised as a group level construct, which is focused on family processes (Walsh, 2002). Resilience in education is an area that defines resilience as success in school despite adversities (Wang et al. 1999). The idea of resilience being developmentally appropriate and changing throughout life stages (Luthar et al. 2000; Rutter 1993) is one issue that has been raised within the protective processes literature, thus resilience can also be viewed as a contribution or factor to protective processes. In additional the protective processes literature suggests context is important, and how researchers might conceptualise IQ or self-esteem as indicators of resilient outcomes, whereas they are also identified as protective factors (Delfabbro & Harvey, 2004).

Resilience also overlaps into the more established coping literature, as established by literature reviewing. The transactional approach is applied in coping literature. This model suggests that coping is a continuous and dynamic process of person environment interaction, that it fluctuates over time in response to changing demands, and that it is situational as opposed to person specific (Aspinwall, 2004; Fields & Prinz, 1997; Moos & Holahan, 2003). Key stages in the coping processes are an appraisal of the adverse event, coping options, and the use of coping strategies to manage the effect of stress (Smith & Carlson, 1997; Pincus & Friedman, 2004). Stress is conceptualised as a situation clashing with an individual’s assessment of their resources to deal with this stressor, the literature base has explored: acute stressors, uncontrollable stressors, usual and unusual stressor and chronic stressors (Fields & Prinz, 1997). The literature in the coping field, much the same as the resilience literature, has brought together internal resources (such as problem solving skills) and external resources (such as social support) into these two main categories (e.g. Fields & Prinz, 1997). The transactional framework has been criticised for lacking in content of the stressor (Skinner &

Edge, 2002) and this is where the resilience literature may benefit understanding, despite the other, many clear overlaps between coping and resilience literature bases. Another difference identified is that the resilience approach uses indicators of how individuals cope generally with adaptive demands, the coping literature focuses very much on understanding and measuring coping responses (Moos & Holahan, 2003).

The psychoanalytic approach has also been identified within the well-being, coping, and resilience literatures. This model suggests personal factors are the reason behind coping strategies, such as personality, attitudes and cognitive characteristics. This approach has been generally accepted as compatible with the contextual approaches described in the coping literature (Frydenberg, 2002; Sandler et al. 1997). A criticism of this approach is that the psychoanalytic model does not address the successful or unsuccessful thoughts and behaviours of individuals when coping with problems (Sandler et al. 1997). Ideally the resilience literature or concept of resilience would fill these gaps identified in the coping and psychoanalytic approaches.

Salutogenesis, it a concept developed within the medical sociology area by Aaron Antonovsky. It an operational form it is “sense of coherence”, it looks at processes that move people towards, or keep people at this “health-ease” state, as oppose to “dis-ease” (Antonvosky, 1998). However, it is also argued that sense of coherence is referring to collective coping and the ability to mobilise resources, and therefore is not an individual concept (Taylor, 2004). Sense of coherence in general refers to the way we as humans make sense of the world, how we use resources to respond to it, and how we feel this responses are meaningful. The three elements include comprehensibility, manageability, and meaningfulness. General Resistance Resources are resources that may be internal; they can be material or none material in nature (Antonovsky, 1998; Hansson & Cederblad, 2004; Lindstrom & Eriksson, 2005). Sense of coherence is important in disability research, as much similar to the theory in poverty research; it refers to the fact that people in these situations often have very limited control over their circumstances (Antonovsky, 1998; Tayler, 2004).

All three literature bases of resilience, coping and salutogenesis focus on how people deal and respond to various stressors. The coping literature is focused on negative as well as positive coping, each of them all identify common resources which facilitative positive effects and positive outcomes. They are all agreeing on the perspective of a person and environment interaction although there are some differences between the three theoretical frameworks.

An identified difference in the resilience literature is that it appears to lack an established theoretical framework, as it is based largely on observational findings. The coping literature is very short in terms of processes and focuses on the more immediate effects, whereas resilience and salutogensis focuses on more long term processes.

As well as the theoretical overlaps there are factors that overlap in the literature bases. For example, *positive identifying factors,* (including, self-esteem, social identity, self-concepts), *beliefs,* (religion, optimism, motivation), and *skills* (intelligence, social skills). Some overlapping themes within the IDD literature and disability literature are explored below.

Awareness or acknowledgement of disability

This theme appeared in several papers including, Curtain and Clarke (2005), Miller, Admi (2007), Mulcahey (1992), Mundhenke et al. (2010).

In qualitative research by Curtain and Clarke (2005) a student who participated in the interviews identified themselves as just another young person, with the exception that she used a wheelchair, she was generally positive about her life, although at times she wished she did not have an impairment. Miller (2002) suggested the less resilient students were aware of their learning disabilities, however, often the students did not report effective ways of coping with their leaning disability, for example when completing homework. Admi (2007) identified that the participants who were diagnosed at an early age recalled a growing awareness of their disability whilst coping with problems which prevented them in participating in daily 'normal' activities with peers (e.g. participating in school trips or sport events). In the study by Admi (2007) children and young people described their acceptance of epilepsy, for example perceiving epilepsy as a temporary diagnosis and controllable, and their coping mechanisms mainly surrounded feelings of optimism. Their perceptions of themselves was also influenced by life events surrounding others, such as being dismissed from work, or feeling pressure to keep their disability a secret in the family. In addition their perceptions of themselves were often influenced by opinions of other 'healthy' people surrounding them. Students identified they felt they could not be like everyone else; they couldn't work or travel as they "had to be more careful about my choices". Mundhenke et al. (2010) identified that the participants expressed sadness about the thought of an increasing impairment in future, which would lead to further limitations.

Understanding of ones' learning disability was identified by Mishna (2003) as a protective factor. Curtain and Clarke (2005) identified that often participants with physical and/ or learning disabilities liked their independence, and sometimes did not mention being impaired. Participants could also identify what was 'good' and 'bad' about having their motor impairment. Participants identified that they did not like people feeling sorry for them as they did not see themselves as different to others. One participant identified that other children became "upset" and "tense" about his disability, and this caused him to feel depressed, he identified this was not a healthy way of viewing lives of being with a disability. Two participants did identify themselves as disabled, however both were accepting of their impairment and what it meant to them. Miller (2002) identified that having an acknowledgement of having a learning disability also demonstrated resilience.

Family Togetherness

Bayat (2007) identified, from surveys completed by parents of children with autism, the need to pull resources together and being connected as a family as two necessary factors for resilience. In additional 62% of families defined themselves as becoming closer as a result of having a child with a disability. It was also identified that families did not always find it easy to unite and work together. However, often families reported that ultimately having a child with disabilities has made them stronger (e.g. "*Autism has made us stronger and more cohesive, my children are very protective of their sister".)* The level of family togetherness can affect the child's ability to communicate problems they are having with their parents, for example children may not want to worry their parents (Bourke, 2010). Or children may feel embarrassed to speak to their parents, or experience fear they may make the bullying worse.

Family Support

Jemta et al. (2007) found that children or adolescents who reported that they often had an adult who cared for them used 'support seeking' to a greater extent than those who did not. Admi (2007) asked participants who they chose to tell about their illness (epilepsy). The results showed that this decision was based on the ability of the listener to be empathetic, the ability of the listener to cope with information, and the ability to maintain a relationship based on equality and reciprocity. Mundhenke et al. (2004) identified that children with intellectual disabilities found it hard to express how they felt to their older siblings in case it would upset them, even if the sibling had hurt their feelings. It was also identified in this paper the importance of social support from close relatives and friends. Berntsson (2007) stated support from family, friends, and health care professionals was essential to be acknowledged and feel confidence. The prerequisites for feeling good were; a good relationship with parents and parent's capacity for support, including being on hand when there was a need, it was also important that parents trusted their child, without over protecting, and seeing their child's capacity to manage different situations. In terms of living with diabetes, Graue (2005) noted that adolescents may experience a high degree of involvement from parents and supportive, making them feel protected and thus promoting psychosocial health and well-being.

Previous research of resilience in parents and families of children with IDD

Knowledge is increasing in research of factors (such as support, coping, self-esteem) that might predict parent and family responses to a stressor (such as child behavioural and emotional problems), and this is especially true in relation to families of children with IDD (Gertstein, Crnic, Blacher & Baker, 2009). When addressing the concept of resilience in parents of children with IDD, several potential resilience factors have been explored, such as hope (Lloyd & Hastings, 2009) and self-efficacy (Hastings & Brown, 2002). More recently, a systematic review by Peer and Hillman (2014) identified that coping style, optimism, and social support are all factors that may influence resilience in parents of children with IDD. Ruiz-Robledillo et al. (2014) found that resilience was associated with the overall general health of caregivers of children with ASD (stress levels examined using cortisol readings, somatic symptoms, insomnia, anxiety, depression and social dysfunction). However, more generally resilience has also been shown to be associated with mental health, such as anxiety, insomnia and depression in caregivers (Tang et al., 2013). The Resilience Scale for Adults (RSA; Friborg et al., 2006) has been used in a small population of parents of children with IDD, as part of a comparison between parents of children with IDD and parents of children with Sanfilippo syndrome (a degenerative disorder with a progressive decline in children's intellectual and physical functioning). It was found parents rated *social resources* as the highest protective factor important to them, and *planned future* as the lowest protective factor important to them (Grant et al., 2013). In a longitudinal study trajectories of daily parenting stress have been examined for parents of young children with IDD; this included specific risk and resilience factors that were deemed to affect these trajectories, such as psychological well-being, marital adjustment and positive parent-child relationships. This study found these factors did affect parenting stress differently in mothers and fathers, and it was suggested that parents affect each other's resilience (Gerstein, Crnic, Blacher, & Baker, 2009). Therefore, previous research does suggest factors which may be associated with resilience, and that resilience as a concept is related to a person's well-being. However, the function of resilience and the complexities of these relationships are not established.

What resilience might mean to parents of children with ID?

Parents will often focus on their child, therefore many of the questions may instinctively relate to their child with IDD when considering day to day adversity or stress. It may be important to separate out resilience in terms of parenting a child with IDD and resilience in terms of one's self, although they are likely linked. For parents of children with ID conceptualising resilience may mean, good grades in schools, achieving things their child wants to achieve, reducing challenging behaviour, or finding ways to communicate. It may also mean, keeping control in a situation, overcoming legal battles, overcoming societal attitudes, or finding meaning in their life.

Risk factors for child behavioural problems

Several risk factors for child behavioural and emotional problems have been found in research with children with IDD, including the social economic position of the family (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011), family climate (consisting of cohesiveness, expressiveness and conflict in the family), and family life events (Hatton & Emerson, 2004; Mitchel & Hauser-Cram, 2009). A recent study by Emerson et al. (2014) has shown the impact of social deprivation as a risk for child behavioural problems in a population study. Specifically, children with ASD were more likely to show persistent conduct problems when risk is experienced. Hatton and Emerson (2004) found associations between several life events and mental health and well-being in children with IDD: parental separation, parents having negative involvement with the police, death of a child's close friend, parental financial crisis, and the child experiencing hospitalisation due to illness were associated with high rates of emotional disorders. In addition, Saylor, Macias, Wohlfeiler, Morgan and Awkerman (2009) found children who were exposed to more life events, including children with IDD, had significantly more behavioural and emotional problems than children who were exposed to fewer life events. Children with IDD have been shown to experience more negative life events than children without IDD (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). Therefore studying life events as a risk factor for child behavioural and emotional problems is particularly important in this population. Family life events could therefore influence child behavioural and emotional problems and the well-being of the child with IDD and family.

Previous research of resilience in children with IDD

Resilience is difficult to define, as it can be subjective based on environment, personality and experiences, having a concept possibly reliant on other influences also makes resilience difficult to measure. Previous research such as Windle (2010) has interviewed older adults to establish their concept of resilience. However, this is a difficult approach to utilise with children with IDD as it is hard to measure a child's understanding of the word resilience and the meaning of resilience without prompting, as it is unlikely this word is well understood at a young age. Only three studies have been identified exploring resilience in children with IDD, thus showing the need for development in this research area. A study by Miller (2002) used open ended interviews to determine the sources of resilience in students with IDD. Resilience was described as a person experiencing achievement despite others having a low expectation of them. The student's themselves identified several attributes which they believed made them resilient such as, identifiable success experiences (e.g., having a job), areas of strength (e.g., being good at art/sport), having self-determination, special friendships and/or an encouraging teacher, and acknowledging their learning disability. Gilmore, Campbell, Shochet and Roberts (2013) compared resilience in children with IDD to their typically developing peers and included two resilience scales; the Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2007) and the Healthy Kids Resilience Assessment (HKRA; Constantine, Bernard & Diaz, 1999). It was found children with IDD reported lower levels of tolerance, fewer future goals and higher levels of emotional sensitivity in comparison to their typically developing peers. Although other identified resilience factors, such as optimism and self-esteem, were reported at a similar level to their typically developing peers.

Forte, Jahoda and Dagnan (2011) used interviews and two measures of self-efficacy and anxiety to explore resilience in young people with IDD. The aim of this research was to examine the content and salience of worries experienced by young people aged 17-20 years with an intellectual disability during transition into adulthood. Factors deemed to be related to resilience included bullying, bereavement, failure and friendship. Bullying as a worry for young people with IDD was reported reflecting on past experience, a few who still experienced bullying were worried about it happening again. The fear of losing someone close was a common fear in this study, and it was reported the concern of how the young person with IDD would cope by themselves. Fear of failure was an important worry, and often came from past experiences and the worry of it happening again. Friendship was a common concern, making and keeping friends and the fear of not fitting in with peers. Several factors of these resilience attributes identified by young people themselves, such as special friendships, acknowledgement of disability, encouraging teachers, are not identified in wider resilience literature as they are specific to children, and possibility even more specific to children with disabilities. It is clear the literature currently available on resilience is varied and minimal; therefore the studies in this thesis were developed with this as a consideration.

Background to the studies presented in this thesis

This PhD was funded by Bangor University through a 125 Scholarship and was initially grounded in Healthcare Sciences focusing on resilience in children and young people with all disabilities (see Appendix XXXVI for original study one protocol). However, the PhD was transferred to the School of Psychology as it was decided the thesis topic was a better conceptual fit with psychology and IDD research in this department. The four studies were then designed and conducted, which are included as the four chapters in this thesis. In order to develop the most reliable conceptualisation of resilience, it was necessary to focus in depth on the literature and methodologies investigating a specific population and research area. Therefore, the topic of the thesis during this transfer was narrowed to focus specifically on children with IDD as it there was a clear gap in the literature identified for this research to be developed further.

Structure of this thesis

Chapter 2 (Study 1) presents a secondary data analysis in which three potential protective factors (social support, coping mechanisms, and positive perceptions of mothers of children with IDD) were explored between previously identified risk factors (child behaviour and emotional problems) and both positive and negative maternal well-being outcomes. It was hypothesised that these three variables will work as protective factors and will improve overall well-being in mothers when child behavioural and emotional problems increase in severity.

Chapter 3 (Study 2) presents a paper which investigated resilience in mothers of children with IDD. To ground the examination of the function of maternal resilience in theoretical models, the aim was to compare predictions from protective and compensatory models within the same analysis models. Child behaviour problems were included as a risk factor likely to lead to overall lower maternal well-being including: stress associated with caring for the child with IDD, mental health problems (anxiety and depression), positive perceptions, and also mothers' perceptions of the family. If maternal resilience acted as a protective factor, it was expected that when mothers were exposed to more child behavioural problems their well-being would improve more when scoring highly on a measure of resilience. This would mean resilience was affecting maternal outcomes at high levels of risk (high child behavioural problems). If maternal resilience acted as a compensatory factor, it was expected that resilience would emerge as a significant independent predictor of maternal outcomes – an effect that was not interactive with behaviour problems as a risk factor.

Chapter 4 (Study 3) presents a paper which investigated the resilience of children with IDD as perceived by their parents. The aim was to compare predictions from protective and compensatory models within the same analysis models. Family life events and maternal depression were conceptualised as two risk factors likely to lead to higher levels of child behavioural and emotional problems. If child resilience acted as a protective factor, it was expected that child behavioural and emotional problems would reduce more when exposed to high levels of adverse life events or maternal depression.

Chapter 5 (Study 4) is the first study, to our knowledge to explore resilience longitudinally. First this study explored, using cross-sectional data, if the severity of ASD symptoms was associated with positive and negative maternal well-being outcomes when resilience was a moderator. Second, this study explored if resilience predicts later maternal well-being when controlling for earlier well-being in longitudinal data.

Chapter 6 concludes this thesis and discusses the studies' contribution to knowledge, in addition outlining future research and implications for clinical practice.

Chapter 2: Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities.

Abstract

Behavioural and emotional problems exhibited by children with intellectual and developmental disabilities (IDD) have been identified as significant stressors for family members in both cross-sectional and longitudinal research. However, there is variability in the extent to which family members are affected by behavioural and emotional problems. In the present study, we explored whether perceived social support, positive perceptions, or coping style explains some of this variability and specifically whether these three variables function as protective factors. One hundred and thirty mothers of children aged between four and 18 years old with IDD participated in a cross-sectional survey. Using moderated multiple regression models, we found consistent evidence that perceived social support functioned as a protective factor – having a significant interactive relationship with maternal depression, life satisfaction, and the positive affect of the experience of having a child with IDD. There was some evidence of the role of practical coping and positive perceptions as a protective factor between child behavioural and emotional problems and maternal well-being. Building social support and targeting child behavioural and emotional problems through parental interventions may result in improved well-being for mothers of children with IDD.

Key words: intellectual disability, developmental disability, autism, mothers, psychological well-being, support, coping, positive perceptions

Mothers of children with Intellectual and Developmental Disabilities (IDD) show increased levels of stress when compared with other mothers of children without IDD (Emerson, 2003; Hastings & Beck, 2004). However, it is also evident that not all mothers are highly stressed. Totsika, Hastings, Emerson, Lancaster and Berridge (2011) found that 60% of mothers of children with IDD did not report having clinical levels of emotional problems. Clear contributing factors to this variation in stress are child behavioural and emotional problems. Previous research has shown child behavioural and emotional problems to be a risk factor for lower levels of psychological well-being among mothers (Baker et al., 2003; Blacher & McIntyre, 2006; Emerson, 2003, Hastings, 2003; Lewis et al., 2006; Lecavalier et al. 2006; Hastings & Brown 2002; Saloviita, Itälinna, Leinonen et al., 2003), and this risk factor has been identified in longitudinal studies as a significant predictor for an increase in maternal problems over time (Baker et al., 2003; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Zeedyk & Blacher, 2015).

However, despite the relationship between child behavioural and emotional problems and maternal well-being consistently shown in research, there is evident variability in the maternal responses to their child’s behavioural and emotional problems; some report emotional difficulties, and some do not. Theoretically, additional factors may mediate or moderate this relationship.

A mediator specifies how (or the mechanism by which) a given effect occurs (Holmbeck, 1997; Baron & Kenny, 1986; James & Brett, 1984). Stated more simply, “the independent variable causes the mediator which then causes the outcome" (Shadish & Sweeney, 1991, p. 883). A moderator “interacts with a predictor variable in such a way as to have an impact on the level of a dependent variable” (Holmbeck, 1997, p. 599). In studies on parental stress in IDD literature, many child characteristics (such as behavioural and emotional problems) and parental resources variables (such as depression) have been explored. However, typically only the main effects of predictor variables on parental psychological well-being have been addressed, thus researchers have rarely looked beyond a simple main effect relationship between risk variables and parental well-being.

In a small number of studies, mediated and moderated relationships have been explored. Researchers found the level of social support experienced by mothers of children with IDD had a moderating effect on the relationship between key variables, such as child behavioural problems and level of parental stress (Plant and Sanders, 2007). Social support was also found to be a moderator between stressors (life events and parenting stress) and negative outcomes (e.g., depression, social isolation) (Dunn, Burbine, Bowers, & Tantledd-Dunn, 2001). Coping style (e.g., adaptive and maladaptive) has been found to be a moderator between stressors (life events and parenting stress) and negative outcomes (e.g., depression, social isolation) (Dunn et al., 2001).

The main effects of variables related to child behavioural and emotional problems and positive or negative well-being outcomes should be considered when identifying protective factors, thus exploring these relationships further. In main effect studies coping style and social support have been identified as impacting in various ways on parental well-being. A passive emotion-focused coping style (such as wishful thinking, self-blame, distancing, and self-control) has been found to have a negative relationship with adaption or well-being (Dykens & Hodapp, 2001; Smith, Selzer, Tager-Flusberg, Greenberg, & Carter, 2008). Generally, parents who report using problem solving copings styles also report more positive adjustment outcomes and lower levels of parenting stress (Abbeduto et al, 2004; Glidden, Billings, & Jobe, 2006; Smith et al. 2008). Therefore, previous literature suggests the type of coping style used can account to some extent for the variation seen in parental psychological outcomes.

Similarly, a parent’s perception of their level of received social support has been shown to have an impact on psychological outcomes. Parents of children with IDD who experience social support from their partners, family, friends, and social networks reported less stress and depression and generally more positive adjustment outcomes (e.g., Abbeduto et al, 2004; Hassall & Rose, 2005; Plant & Sanders, 2007; Glidden et al., 2006; Asberg, Vogel & Bowers, 2008). This study will test another potential protective factor (positive perceptions), coping style, and perceived social support to develop further understanding of how these variables function in their relationship with child behavioural and emotional problems and maternal well-being.

When exploring factors associated with increased maternal well-being as an outcome, positive perceptions regarding having a child with IDD have been found to act as a protective factor amongst parents and caregivers. Werner & Shulman (2013) found the strongest predictors of subjective well-being in caregivers of individuals with ASD were self-esteem and positive meaning in caregiving. Lickenbrock, Ekas, and Whitman (2011) found mothers who reported higher levels of positive perceptions of their child reported higher levels of positive interactions with their spouse and higher levels of well-being (such as mood). This suggests positive perceptions may act as a protective factor, however, existing research is limited which directed the focus in positive perceptions as a potential protective factor in the present study. Positive perceptions have been developed into a working model (Hastings & Taunt, 2002). The model is based on the assumption that positive perceptions help families of children with IDD to adapt or cope with the experiences of raising their child.

In this study, three potential protective factors -social support, coping mechanisms, and positive perceptions of mothers of children with IDD- are explored. Previous research into coping styles and social support as a protective factor is minimal, and in addition the literature has not fully explored positive perceptions as a protective factor. Therefore, this research will explore these variables as three protective factors between previously identified risk factors (child behaviour) and both positive and negative maternal outcomes. It is hypothesised that these three factors will work as moderating/ protective factors and interact between child behavioural and emotional problems and well-being outcomes in mothers of children with IDD. In addition, it is expected that a practical coping style will work better than a wishful coping style in improving maternal well-being.

Method

Participants

The participants were 138 mothers (129 biological mothers, four adoptive mothers, two foster mothers, one step-mother) of children aged between four and 18 years old (*M* = 10.11, *SD* = 4.11) with IDD. The mothers' age ranged from 23 to 57 years (*M* = 39.42, *SD* = 7.33); 107 of the mothers were currently married or living with a spouse or partner, and 138 of the children lived permanently in the family home. The children who did not live permanently with their mother as the primary carer (lived in a residential service or elsewhere some or all of the time) were excluded from the study.

Table 2.1.

Mothers' Demographic Information

Variable		*n*	*Per cent*
Education level of mother	No Formal Educational Qualification	22	16 %
	GCSE level or equivalent	46	33 %
	3 or more a levels (NVQ 3), or equivalent	21	15 %
	Foundation degree, HND, or equivalent	18	13 %
	University degree	29	21 %
	Masters or doctoral degree	2	1 %
Employment status of mother	No paid employment	70	51 %
	Part time	48	35 %
	Full time	20	14 %
Respite	Available	69	50 %
	Used	48	35 %

Table 2.2.

Child's Demographic Information

Variable	*n*	*Per cent*
Male	91	66 %
Autism	51	37 %
Various diagnoses and causes of their IDD*	40	29 %
Down's Syndrome	32	23 %
Cerebral Palsy	15	11 %
Comorbid secondary diagnosis given	51	37 %
Additional health problems (such as acid reflux)	44	32 %
Mobility impairment	39	28 %
Sensory impairment	29	21 %
Visual impairment	12	9 %
Hearing impairment	7	6 %
Visual and hearing impairment	10	7 %

*Examples include; no specific diagnosis such as SWAN- Syndrome Without A Name, genetic syndromes such as Fragile X Syndrome, and other diagnosis such as Global Developmental Delay

Measures

Eight measures plus a demographic questionnaire (see Appendix I) were utilised in the present study; all measures were completed by the mother of the child with IDD.

Demographic Questionnaire. Demographic information was gathered using a questionnaire developed by the research team and included questions about the mother (see Table 3.2. for details) and their child with IDD (see Table 3.1. for details). A Total Disability Severity Index was created which included several demographic variables for the purpose of determining if the child had additional diagnoses, as well as their IDD diagnosis. The four questions included in this new variable were whether the child had sensory problems, epilepsy, mobility problems, or any other health problem. Each were coded as 0 (*not present*), or 1 (*present*). Therefore, the new variable reflecting additional disabilities ranged from zero (*no additional disabilities*) to four (*several additional disabilities*) (see Table 3.3.).

This index was used in the analysis to give an indication of whether maternal well-being is affected differently when children experience more disabilities.

Table 2.3.

Total Disability Severity Index

Disability Severity Index Score	*n*	*Per cent*
No additional disabilities (score of 0)	59	43 %
Score of 1	36	26 %
Score of 2	26	19 %
Score of 3	10	7 %
High number of additional disabilities (score of 4)	7	5 %

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Maternal Psychological Well-being

Anxiety and Depression. The Hospital Anxiety and Depression scale (HADS: Zigmond & Snaith, 1983, see Appendix II) was used to measure the mother’s mental health over the past seven days. The measure includes a total of fourteen items, with seven depression items (e.g., I feel as if I am slowed down) and seven anxiety items (e.g., I get sudden feelings of panic). The total scores of the two subscales were used to assess depression and anxiety dimensionally. The HADS has been used with community samples of parents of children with disabilities (e.g., Hastings et al., 2005). The HADS has shown good psychometric properties (Hastings et al., 2005) and statistically good levels of reliability when used with mothers of children with IDD, with internal consistency coefficients between .79 and .84 for maternal anxiety (Hastings & Brown, 2002; Hastings, Daley, Burns, & Beck, 2006) and .78 for maternal depression (Jones, Hastings, Totsika, Keane, Rhule, 2014). In the present sample, Cronbach’s alpha coefficients were .80 for maternal depression and .82 for maternal anxiety.

Life Satisfaction. The Satisfaction with Life Short Scale (Diener, Emmons, Larsen & Griffin, 1985, see Appendix III) was developed to assess the respondents’ satisfaction with their life as a whole. The scale consists of five items which ask respondents the degree to which they agreed to statements, such as, “In most ways my life is close to my ideal”, and “I am satisfied with my life”. The responses are measured using a seven-point Likert scale ranging from, 1 (*strongly disagree*) to 7 (*strongly agree*), and a higher score is indicative of greater life satisfaction. The Satisfaction with Life Short Scale has been tested recently with mothers of children with IDD and was found to have a good Cronbach’s alpha coefficient of .81 (Cohen, Holloway, Dominguez-Pareto & Kuppermann, 2015). In the present study Cronbach’s alpha coefficient was .87 for mothers.

Positive Affect. The Positive Affect Scale (PAS, see Appendix IV) was used to measure current maternal well-being. The PAS is a ten-item subscale from the Positive and Negative Affect Schedule (PANAS: Watson, Clark & Tellegen, 1988). Participants were asked to report their feelings in the present moment responding to ten items (e.g., excited, strong, enthusiastic, inspired, and determined) by selecting a response from a five-point scale. The five-point scale ranged from 1 (*very slight or not at all)* to 5 (*extremely*). A total score is then calculated by summing the scores on the ten items, in which a high score is indicative of a high positive affect. In the present study Cronbach’s alpha coefficient was .91 for mothers.

Maternal Moderator Variables

Support. The Short Support Functions Scale (Dunst, Trivette & Deal, 1988, see Appendix V) was developed for families with children who have disabilities (IDD and none IDD) (Dunst et al., 1988) and assesses different types of perceived support from other people (e.g., “Someone to talk to about things that worry you”, “Someone to help take care of your child”, “Someone who loans you money when you need it”). The items ask about help in financial, emotional, instrumental, and informational support. The respondents answer 12 items in the short form version, which was used in this study, on a five-point Likert scale with answers ranging from 1 (*never)* to 5 (*quite often*). Higher overall scores indicate higher levels of perceived support by the respondent. In the present study Cronbach's alpha coefficient was .88 for mothers.

Coping. Maternal coping was measured using the Shortened Ways of Coping Questionnaire (Hatton & Emerson, 1995, see Appendix VI), which was developed for use with care staff working in learning disability services. The 14-item measure explores both positive and negative coping mechanisms (e.g., "I take it out on other people" or "I think up a couple of different solutions to problems"). There are two subscales; seven questions on wishful thinking (e.g., "I wish that I could change how I feel", "I have fantasies of wishes about how things might turn out") and seven questions on practical coping (e.g., "I try to analyse the situation in order to understand it better", "I make a plan of action and follow it"). The respondents are asked to answer each statement to indicate how often they use that coping mechanism on a four-point scale ranging from 1 (*not used*) to 4 (*used a great deal*). The two subscales are totalled separately to provide a wishful thinking coping score (emotion-based coping style) and a practical coping score (problem focused coping style). In this present study the two subscale totals were used and entered as individual moderator variables, therefore Cronbach's alpha coefficient was calculated for mothers in each subscale; the practical coping subscale was .79 and the wishful thinking subscale was .85.

Maternal Positive Perceptions. Mothers' perceptions of the positive contributions their child with IDD has made to them and their family was measured using the Positive Contributions Scale from the Kansas Inventory of Parental Perceptions (KIPP: Behr, Murphy, & Summers, 1992, see Appendix VII). The overall KIPP scale includes 50 items, which include the Positive Contributions Scale which explores the positive contributions the child has made to the mother in 13 items (e.g., "My child is…" "The reason my life has better structure", "Responsible for my learning patience"), and to the wider family (e.g., "Bringing the family closer together", "Helping other family members to become more understanding of other people”) and positive characteristics of the child themselves (e.g., “Kind and loving”, “Fun to be around”). The items are rated on a four-point agreement scale ranging from 1 (*strongly disagree*) to 4 (*strongly agree*). For the current study, a total score was calculated for mothers’ ratings of the positive impact of their child with IDD; a higher score indicated a higher level of perceived positive impact. In the current study Cronbach’s alpha coefficient for the PCS total score was .93.

Maternal Exposure to “Risk”

Child Behavioural and Emotional Problems. The behavioural and emotional patterns of the child with IDD were measured using the Reiss Scales for Children’s Dual Diagnosis (Reiss & Valenti-Hein, 1990, see Appendix VIII). The Reiss Scales included 60 items designed to assess psychopathology in children with IDD (REISS: Reiss & Valenti-Hein, 1990). The scales consist of ten subscales, each subscale scores particular behavioural and emotional patterns observed in the child with IDD (attention deficit, anger, anxiety/self-control, conduct disorder, depression, autism/pervasive, psychosis, poor self-esteem, somatoform behaviour and withdrawn behaviour) as well as a total score (the sum of all subscales). The respondent was asked to score each item on a three-point scale 1 (*no Problem*), 2 (*problem*), or 3 (*major problem*). The Reiss Scales have been previously shown to have good internal consistency with Cronbach’s alpha coefficients of .91 for the total score, and between .57 and .86 for the ten subscales (Reiss & Valenti-Hein, 1994). In the present study Cronbach’s alpha coefficient for the total score was .95 for mothers.

Procedure

The participants in the present study were 138 mothers from a larger survey which included 142 parents of children with IDD (Hastings, Beck, & Hill, 2005). Four mothers were excluded from this study due to their child not living full time with them as it is unclear how regularly the mother may spend time with their child in comparison to mothers who live with their child with IDD full time. This present study is a secondary data analysis, and therefore previously the families were recruited through Special Educational Needs schools in North Wales and North West England. Information packs were distributed to parents via schools; these included a response form and a business reply envelope addressed to the project team. Upon response forms being returned, a questionnaire pack and consent form were sent to the primary parental caregiver via post, marked for return to the University. Further details about recruitment methodology can be found in Hastings et al. (2005)

In each scale, when a missing value was found, this was inputted as a mean average of the other scores given in that particular subscale/scale by that participant. This followed the recommendation of each measure; for example, the REISS guidance suggests if two or more items are missing from a subscale, that participants' responses must be excluded from the REISS dataset. See Appendix IX for full details of missing values, replaced average items and excluded participants from the dataset prior to analysis. .

Demographic Variables

Demographic variables presented in Table 2.1 and 2.2 were recoded dichotomously: mothers' relationship status- which originally had four categories- was reduced to two (currently living with partner/spouse vs. not currently living with a partner/spouse), maternal employment was re-coded into two categories (no paid employment vs. employed), and education was coded into degree level and above versus lower than degree level. Other categories were dichotomously coded (e.g., male vs. female; autism present vs. no autism present etc.). This was necessary to establish which demographics were significant with maternal well-being outcomes; these significant variables could then be entered as control variables in the multiple regression analyses.

Results

To assess social support, coping (both wishful thinking and practical coping styles), and positive perceptions as moderators, multiple regression analyses were conducted for each of the four maternal psychological well-being measures (anxiety, depression, life satisfaction, positive affect) (see Table 3.4.). Relevant demographic variables were selected for inclusion in each of the four analyses from significant bivariate analyses (correlations or *t*-tests) with maternal outcomes. Mothers of children with IDD who were married or living with a partner had significantly lower anxiety than those mothers who were not ($t(137) = -2.21$, $p = .029$). Mothers of children who had Cerebral Palsy had lower levels of life satisfaction ($t(137) = -2.03$, $p = .044$) compared to mothers in the study whose children did not have Cerebral Palsy.

Pearson's correlations showed older mothers reported lower anxiety than younger mothers ($r = -.22$, $p = .011$). Mothers who reported their child as having more additional disabilities had increased positive affect (current positive affect experienced of having a child with IDD; measured in the PAS) compared to mothers who reported fewer additional disabilities ($r = .17$, $p = .042$). It should be noted that the *r* levels are all small and therefore representing low levels of shared variance.

The key predictor in each analysis was child behavioural and emotional problems and four moderators (type of coping style (a. wishful thinking, b. practical coping), perceived social support, and positive perceptions) were entered individually both as a main effect and as an interaction variable with child behavioural and emotional problems. The "PROCESS" custom dialogue box (Hayes, 2012) was installed into SPSS predictive analytics software for the moderated multiple regression analyses. Multicollinearity issues between variables were checked using the Variance Inflation Factor (VIF); and the variables showed no multicollinearity issues (all values < 10, average > 1, tolerance > 0.1) (Bowerman &

O’Connell, 1990; Myers, 1990). Predictor variables were automatically mean-centred when using PROCESS (the variable mean is subtracted from each value of the variable).

Table 2.4

Moderated Multiple Regression Analyses Models for the Four Maternal Psychological Well-being Measures

Moderator- support	Life Satisfaction R = .465, R^2 = .217 F= 8.291, *n* = 125		Maternal Anxiety R=.507, R^2 =.257 F= 8.163, *n* = 124		Maternal Depression R=.549, R^2 = .301 F= 17.500, *n* = 126		Positive Affect R= .489, R^2 = .239 F= 9.504, *n* = 126	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional disabilities							.911	.142
Age of mother			-.039	.380				
Cerebral Palsy present	-4.633	.009						
Living with partner/spouse			.860	**.017**				
Child behavioural and emotional problems (centred)	-.090	.008	.088	**<.001**	.075	**<.001**	-.084	**-.026**
Social support (centred)	.222	.<.001	-.031	.314	-.122	**<.001**	.285	**<.001**
Social support x child behavioural and emotional problems (interaction)	.007	**.042**	-.003	.071	-.003	**.036**	.010	**.011**

Moderator- practical coping	Life Satisfaction R = .378, R^2 = .143 F= 5.132, *n* = 128		Maternal Anxiety R = .480, R^2 = .230 F= 7.421, *n* = 130		Maternal Depression R = .472, R^2 = .223 F= 12.340, *n* = 133		Positive Affect R = .529, R^2 = .280 F= 12.454, *n* = 133	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional disabilities							.800	.129
Age of mother			-.070	.122				
Cerebral Palsy present	-4.017	**.030**						
Living with partner/spouse			.807	**.027**				
Child behavioural and emotional problems (centred)	-.116	**.001**	.087	**<.001**	.088	**<.001**	-.142	**<.001**
Practical coping(centred)	.405	**.009**	.012	.878	-.168	**.017**	.825	**<.001**
Practical coping x child behavioural and emotional problems (interaction)	.012	.170	-.001	.868	-.007	.058	.015	.063

Moderator- wishful thinking coping	Life Satisfaction R = .619, R^2 = .382 F= 19.087, *n* = 128		Maternal Anxiety R = .636, R^2 = .404 F= 16.819, *n* = 130		Maternal Depression R = .623, R^2 = .388 F= 27.210, *n* = 133		Positive Affect R = .450, R^2 = .202 F= 8.111, *n* = 133	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional disabilities							.607	.275
Age of mother			-.055	.159				
Cerebral Palsy present	-4.301	**.007**						
Living with partner/spouse			.549	.089				
Child behavioural and emotional problems (centred)	.001	.971	.047	**.008**	.039	**.010**	-.056	.152
Coping wishful thinking (centred)	-.958	**<.001**	.390	**<.001**	.386	**<.001**	-.502	**.003**
Coping wishful thinking x Child behavioural and emotional problems (interaction)	.004	.517	-.001	.867	<.001	.904	.007	.323
Moderator- positive perceptions	Life Satisfaction R = .371, R^2 = .138 F= 4.786, *n* = 125		Maternal Anxiety R = .479, R^2 = .230 F= 7.272, *n* = 128		Maternal Depression R = .442, R^2 = .195 F= 10.204, *n* = 130		Positive Affect R = .507, R^2 = .257 F= 10.795, *n* = 130	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional disabilities							.647	.248
Age of mother			-.067	.138				
Cerebral Palsy present	-3.840	**.038**						
Living with partner/spouse			.743	**.046**				
Child behavioural and emotional problems (centred)	-.055	.137	.090	**<.001**	.074	**<.001**	-.066	.083
Positive perceptions (centred)	.067	**.037**	.012	.464	-.029	.069	.172	**<.001**
Positive perceptions x Child behavioural and emotional problems (interaction)	.003	.063	<.001	.842	<.001	.620	.003	.161

Note: Significant ($p < .05$) associations between variables are in boldface.

Following the recommendation by Aitkin and West (1991), a simple slope analysis was conducted to aid interpretation of the three significant interactions (see values in bold on Table 3.4.). Plots were derived from the PROCESS output and show the relationship between high versus low child behaviour and emotional problems and the maternal outcome, with the moderator at three values- high, mean and low.

Support. Social support was the only proposed moderator which was a statistically significant moderator/interaction term. This occurred in three models; in the life satisfaction (p = .042), depression (p = .036), and positive affect models (p = .011). All three slope analyses show a classic protective factor pattern; this means better outcomes at high levels of risk (higher levels of behavioural and emotional problems) when the moderator is present at higher levels. In the three models, low levels of support were associated with three significant outcomes and had a different impact on the outcome variable in comparison to when support was high.

Coping. Child behavioural and emotional problems were a significant independent predictor in two of the four models (anxiety and depression) when wishful thinking coping was the moderator. Wishful thinking coping was also a significant independent predictor in all of the four models; anxiety (p <.001), depression (p <.001), life satisfaction (p <.001), and positive affect (p =.003). Wishful thinking coping was not significant as a moderator between child behavioural problems and maternal outcomes interaction term in any of the four analyses.

Child behavioural and emotional problems were a significant independent predictor in all four models when practical coping was the moderator. Practical coping was a significant independent predictor in three of the four models (life satisfaction, depression and positive affect) and was close to significance as a moderator/interaction term in the depression (p =

.058) and positive affect (*p* = .063) models, suggesting that the main effects in the depression and positive affect models could be interpreted in relation to an interaction effect.

Positive Perceptions. Child behavioural and emotional problems was a significant independent predictor in two of the four models (anxiety and depression) when positive perceptions was the moderator. Positive perceptions was a significant independent predictor in two of the four models (life satisfaction and positive affect) and also was close to significance as a moderator/interaction term in the life satisfaction (*p* = .063) model. This suggests that the main effects in the life satisfaction model could be interpreted in relation to an interaction effect.

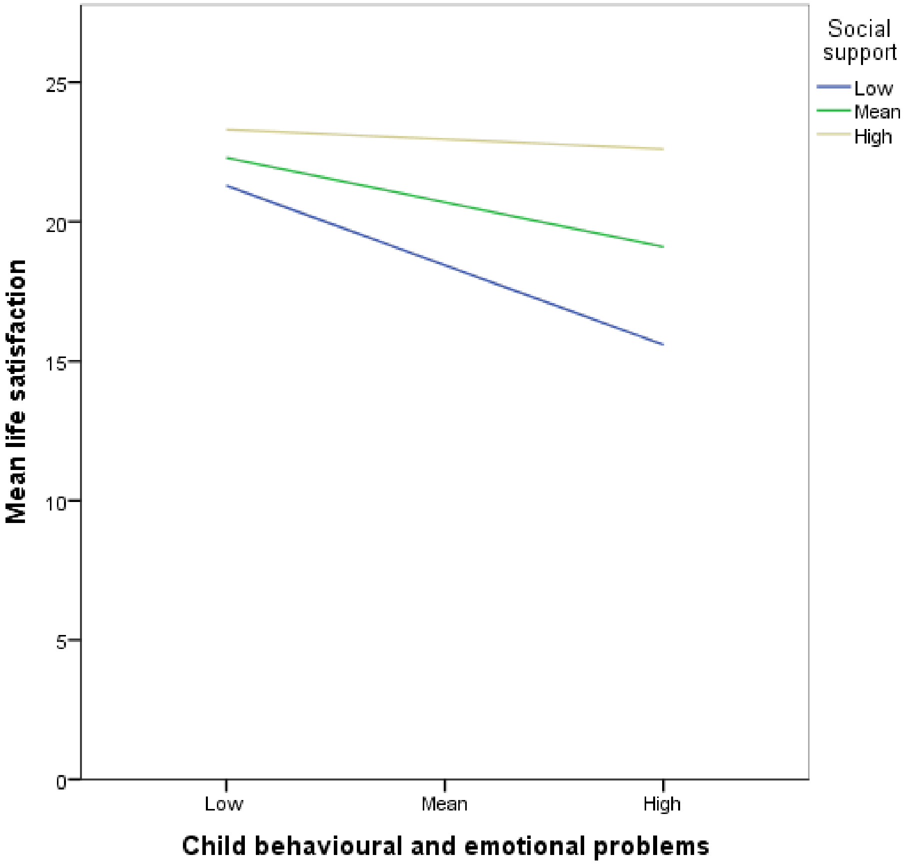

Figure 2. 1- simple slope graph for life satisfaction as the outcome variable. There was a negative relationship between child behavioural and emotional problems and life satisfaction at mid (*p* = .008) and low (*p* < .001) levels of social support, but not when social support was high (*p* = .704). However, higher levels of social support were associated with less of a decrease in life satisfaction.

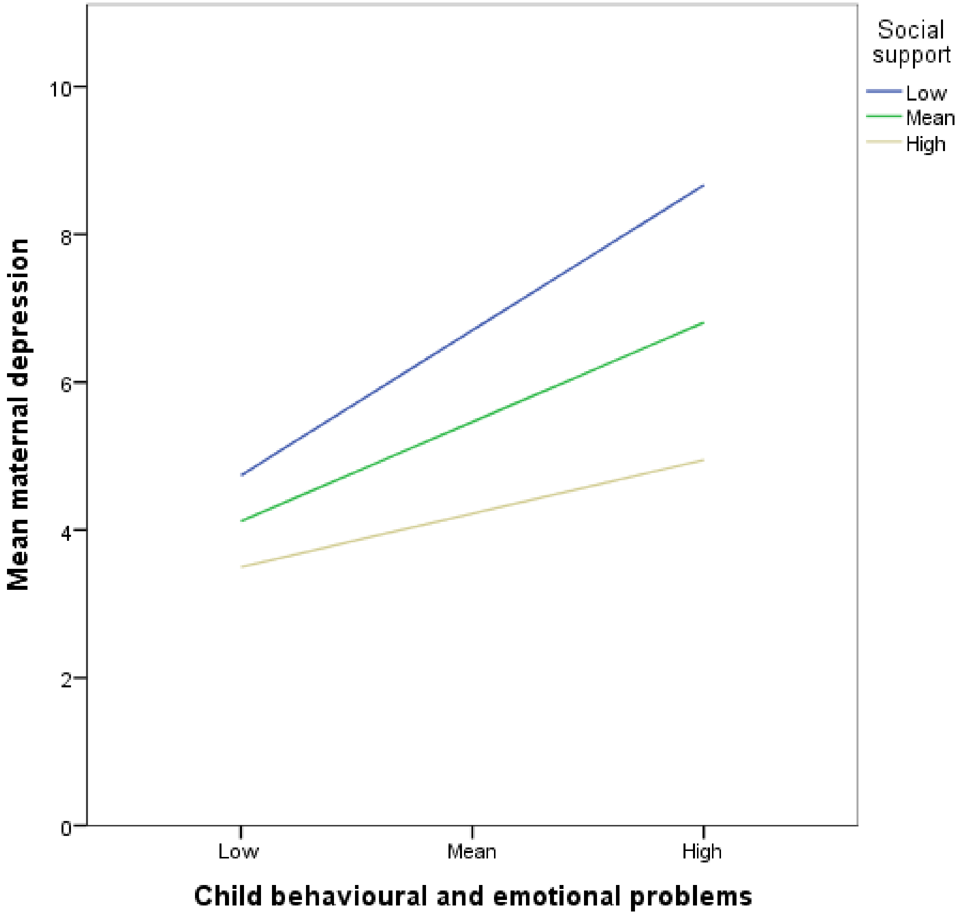

Figure 2. 2- simple slope graph for maternal depression as the outcome variable. There was a positive relationship between child behavioural and emotional problems and depression at mid (*p* = < .001) and low (*p* < .001) levels of social support, but not when social support was high (*p* = .094). However, higher levels of social support were associated with less of an increase in depression.

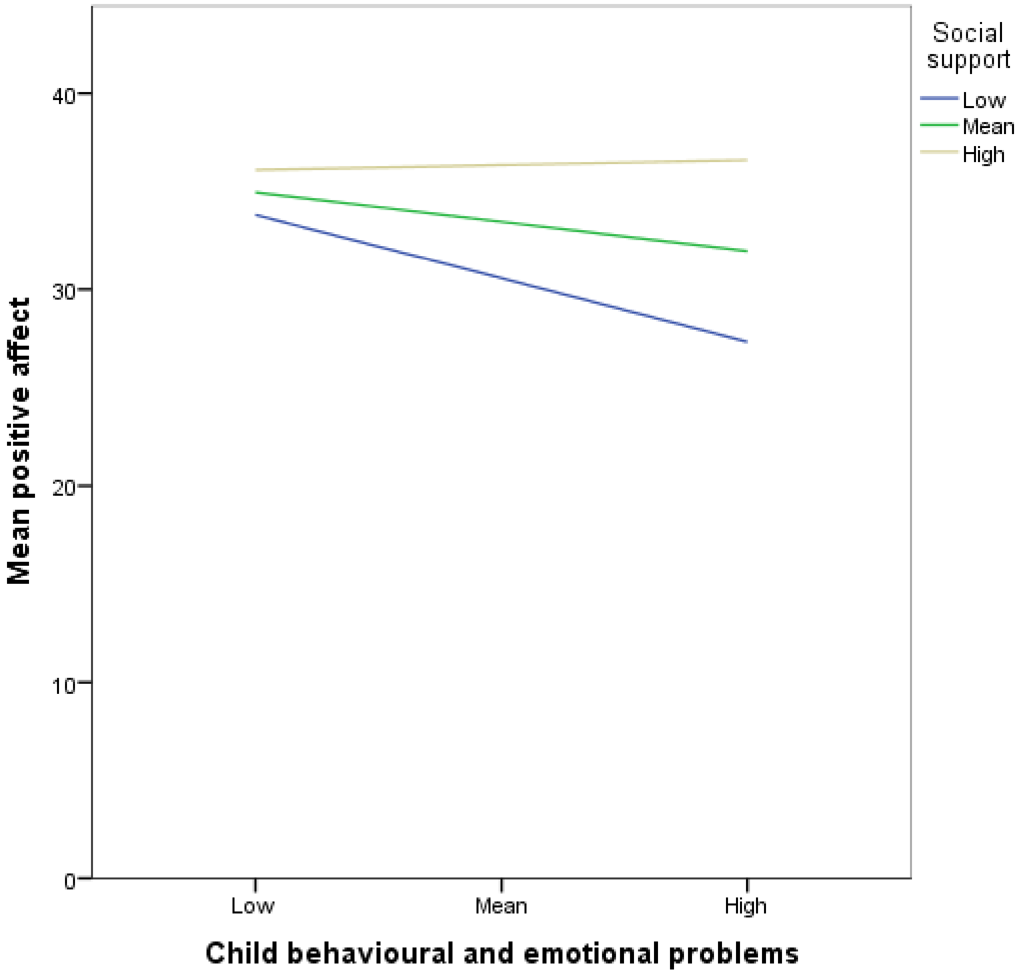

Figure 2. 3 – simple slope graph for positive affect experienced by mothers of having a child with IDD as the outcome variable. There was a negative relationship between child behavioural and emotional problems and positive affect at mid (*p* = .026) and low (*p* < .001) levels of social support, but not when social support was high (*p* = .805). However, higher levels of social support were associated with a slight increase, and no decrease in positive affect.

Discussion

Levels of social support consistently had a moderating effect on maternal well-being (depression, life satisfaction and positive affect). Social support as a moderator improved well-being outcomes when child behavioural and emotional problems were present; in particular, when child behavioural and emotional problems were at high levels. Therefore, we found the strongest evidence that social support works as a protective factor between child behavioural and emotional problems and maternal well-being. The relationship of child behavioural and emotional problems and maternal well-being outcomes was as hypothesised. Low levels of support showed a significant decrease in life satisfaction and the positive affect of having a child with IDD, and a significant increase in depression when child behavioural and emotional problems went from low levels to high levels. Having high levels of support (as opposed to having low levels of support) showed less of a decrease in the outcomes of maternal positive affect and life satisfaction, and less of an increase in maternal depression when behavioural and emotional problems increased in severity. Thus, these results show the importance of mothers experiencing they have good social support, as well as the negative effect on maternal well-being if they report low levels of social support. These findings are consistent with previous research as other studies have demonstrated that social support is related to psychological problems in parents of children with IDD (e.g., Smith, Greenberg, & Seltzer, 2012; Asberg et al., 2008; Glidden et al., 2006; Plant & Sanders, 2007).

Practical coping was identified as a potential moderating variable in two models; depression and positive affect. However, as they were not significant moderators, but were close to significance, these two models were run as single slope analysis so the way in which practical coping was functioning in this relationship could be seen clearly, and these figures are included in the appendices (see Appendix X, Figure 2.4 and Figure 2.5). The pattern of practical coping as a protective factor is the same as seen in the social support models (low levels of practical coping showed a decrease in positive affect and an increase in depression as child behavioural and emotional problems increased in severity). It is important to consider that practical coping is working in a similar way to social support, thus supporting the idea of practical coping as a protective moderating variable. High levels of practical coping reduced the decrease seen with low levels of practical coping in positive maternal outcomes (positive affect), and reduced the increase seen with low levels of practical coping in negative maternal outcomes (depression). Thus, these results show the potential importance of mothers having practical coping skills to improve aspects of their well-being.

Depression and practical coping could be viewed as a reciprocal relationship although the direction to which one affects the other is unclear. Additional regression analyses revealed that depression could arguably be shown as an independent predictor of coping levels, thus showing the relationship between depression and practical coping may not be a straight forward cause and effect relationship. Previous studies by Dunn et al. (2001) and Suarez and Baker (1997) found the coping style of being practical/adaptive moderates between parental stress as a risk factor and negative outcomes (e.g., depression), thus a practical coping style seems to improve overall parental well-being.

Wishful thinking was not found to act as a protective factor in this study. Wishful thinking is a different coping strategy to practical coping as it is emotion based. Differences in coping strategies have been explored in research, for example Hastings et al. (2005) suggested problem focused coping and active avoidance coping are reliable coping strategies. However, emotional coping, such as wishful thinking is not a reliable coping strategy. This could be why wishful thinking was not found to act as a moderator and successfully protect maternal well-being against risk in this study. In addition, Glidden, Billings, and Jobe (2006) found both mothers and fathers of children with developmental disabilities used more problem focused coping than emotion focused coping. Therefore, it is sensible to focus on problem based coping in future research, and developed this coping style as a tool to improve parental well-being.

As with the practical coping models discussed, positive perceptions also worked as a potential protective factor in one model; maternal depression increased as child behavioural and emotional problems increased in severity from low to high, positive perceptions at a high level were associated with lower depression levels than when positive perceptions was at a low level. However, as positive perceptions was not a significant moderator, but was close to significant, this model was not presented in the results, but was run as a single slope analyses, so the way in which positive perceptions was functioning in this relationship was clear, and this is included in the appendices (see Appendix X, Figure 2.6.).

There were several limitations to this study that need to be taken into account when interpreting these results. First, the generalizability of this sample to other studies may be limited, as most mothers were either married or living with a partner, and over a third had a university education. The mean age of mothers was 39.42 (*SD* = 7.33) years, therefore, it is unknown if this sample is reflective of younger or older mothers, or mothers who are one-parent families, or who have lower educational levels. In addition this study was dependent on mothers' self-report data and did not have any objective assessments. This is useful as mothers' perception of their family will best reflect their experience; however the perception of child behavioural problems may vary in a self-report measure as it is dependent on a mothers' interpretation, which can be influenced by their own well-being/ other factors being experienced at that time (e.g., financial stress, job stress, mental health).

Mothers did provide all the data in this study which means there was a lack of source variance; however this is common in IDD research due to recruitment approaches. To address this, future research will need to incorporate independent or multiple informant approaches for key constructs to address this potential limitation (e.g., child behavioural and emotional problems). Finally, the study is limited by its cross-sectional design. This is problematic since temporal precedence has not been established. For example, it may be the case that mothers with higher levels of psychological distress are less able to find support, or experience more support. Protective factors, such as coping and support, are often dependent upon personal circumstance and therefore measuring them at a single time point is not representative of the development, or idiosyncratic changes over time. Previous research has suggested moderators that could vary throughout a person's life and which can predict parental well-being, such as economic hardship, self-rated health (Olsson & Hwang, 2008), education, and optimism (Ellingsen, Baker, Blacher & Crnic, 2014).

Future research could also explore differences between mothers and fathers. Mothers of children with ASD often report higher levels of psychological problems than fathers in the same family (e.g., Dumas, Wolf, Fisman & Culligan, 1991; Gray & Holden; 1992; Dabrowska & Pisula, 2010). However, some studies report that mothers and fathers experience similar levels of psychological problems (e.g., Dyson, 1997; Hastings, 2003). Future research could also explore which factors act as moderators for fathers of children with IDD as there may be gender differences present.

The existing studies exploring positive perceptions are few; Hastings, Allen, McDermott and Still (2002) found that positive perceptions function as a coping mechanism for mothers of children with IDD. In addition, positive perceptions could be influenced by the sources of support parents receive, and also the positive attitude of those surrounding them (e.g., family professionals). Given this research which suggests support may influence positive perceptions, it may be beneficial in future research to explore positive perceptions as an additional maternal outcome (as opposed to a moderator as in this study) with support kept as a moderator/ protective factor.

Our findings have potential practical implications. In particular, it would be beneficial to directly try to monitor perceived social support in mothers of children with IDD, and to encourage mothers to find support in local support groups provided by charities or local services, to improve their well-being. Secondly, practical coping and social support could be explored further in terms of an intervention to improve well-being; however, literature is very minimal in interventions in parents of children with IDD so this would require further development and validation. Though, interventions to directly improve child behavioural and emotional problems in children with IDD have been identified. These have included providing parents with materials on child behavioural and emotional problems, such as information, workbooks, videotapes, and instructions from therapists. Parental stress was shown to decrease, and parental satisfaction was shown to increase (e.g. Hudson et al., 2003).

Alternative interpretations of findings

Parents' perception of their social support could be altered by other factors, such as positivity or depression. There may be a difference between parents' actual level of support and the support they feel to have. If parents feel depressed, then likely they will feel like they have less support, and similarly this would correlate with levels of reported life satisfaction. In this study it is clear that from a practical point of view, parents perceiving they have social support has a relationship with their other well-being outcomes. This measure of social support did not measure practical support received from professionals. In terms of behaviour, practical professional support may be more useful in altering well-being outcomes when child behavioural problems are the risk. It is important to build a picture of the correlation in a parent between their perception of their child's behavioural problems, depression, life satisfaction, and support to see if a parent scores low on all of these, which could be due to alternative factors, for example, having a positive perception in life, can also be related to optimism, resilience, and the experience of past coping strategies.

Similarly, practical coping gives mothers an instant response, rather than wishful thinking coping. The results can be seen immediately in practical coping strategies, and therefore the situation is dealt with much quicker. Can a parent have high levels of depression and still have high levels of practical coping skills?

To conclude, there may be something much more complex occurring within a parent’s attitude towards themselves and others around them. These may or may not be all linked together, and be generalised as sense of coherence.

Chapter 3: Does resilience function as a protective or compensatory factor for the well-being of mothers of children with intellectual and developmental disabilities?

Abstract

Behavioural and emotional problems exhibited by children with Intellectual and Developmental Disabilities (IDD) have been identified as a significant stressor for family members in both cross-sectional and longitudinal research. However, there is variability in the extent to which family members are affected by child behavioural and emotional problems. In the present study, we explored whether maternal resilience explains some of this variability and specifically whether resilience functions as a protective or compensatory factor. Three hundred and twelve mothers of children aged between four and 15 years old with IDD participated in a cross-sectional online survey. Using moderated multiple regression models, we found consistent evidence that maternal resilience functioned as a compensatory factor – having a significant independent main effect relationship with maternal stress, anxiety, depression, perceptions of positive gain and family satisfaction. There was little evidence of the role of resilience as a protective factor between child behavioural and emotional problems and maternal well-being. Building maternal resilience may result in improved well-being for mothers of children with IDD.

Key words: intellectual disability, developmental disability, autism, mothers, psychological well-being, resilience

Research showing higher levels of stress in mothers of children with Intellectual and Developmental Disabilities (IDD) compared to mothers of typically developing children is well established (Emerson, 2003). However, there is variability in how mothers respond to the stress of raising a child with IDD. In analysis of a population-based sample, Totsika, Hastings, Emerson, Lancaster and Berridge (2011) found that 40% of mothers of children with IDD reported experiencing concerning clinical levels of emotional problems, and 60% did not. Previous research has shown behaviour problems exhibited by children with IDD explain some of this variation in maternal outcomes. Indeed, child behavioural problems are a risk factor for lower levels of maternal psychological well-being and have been identified in several longitudinal studies as a significant predictor for an decrease in maternal psychological well-being over time (Baker et al., 2003; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Zeedyk & Blacher, 2015).

Despite the relationship between child behavioural and emotional problems and maternal well-being consistently shown in existing research, there is still variability in mothers' well-being in response to their child's behaviour problems. Not all mothers whose child has significant behaviour problems report increased psychological distress or lower levels of well-being. This variability in mothers' well-being suggests that there are additional factors affecting the relationship between this and child behavioural problems. In theoretical terms, these factors may mediate or moderate the relationship between child behavioural problems and maternal well-being. A moderator affects the relationship between two variables, so that the nature of the impact of the predictor on the criterion varies according to the level or value of the moderator. A moderator "interacts with a predictor variable in such a way as to have an impact on the level of a dependent variable" (Holmbeck, 1997, p. 599). A mediator specifies how (or the mechanism by which) a given effect occurs (Holmbeck, 1997;

Baron & Kenny, 1986; James & Brett, 1984). Stated more simply, “the independent variable causes the mediator which then causes the outcome" (Shadish & Sweeney, 1991, p. 883).

Many studies of parental stress in IDD research have incorporated a broad range of measures, including child characteristics and parental resource variables. However, researchers have typically addressed the main effects of predictor variables on parental psychological well-being. There are currently few studies which look beyond a simple main effect relationship between a number of predictors or risk variables and parental well-being, however, mediators and moderators in this relationship have begun to be explored. For example, a study by MacDonald, Hastings, and Fitzsimons (2010) found psychological acceptance partially mediated the impact of child behavioural problems on paternal stress, anxiety, and depression. In addition, Weiss, Cappadocia, MacMullin, Viecili, and Lunsky (2012) found supporting evidence that maternal empowerment is a partial mediator between child behavioural problems and greater maternal distress in mothers of children with ASD. Empowerment is defined as a psychological process in which an individual is active in changing or eliminating potentially stressful events through applying knowledge and skill (Gutiérrez, 1994). Self-efficacy was found to moderate the effect of child behavioural problems on anxiety in fathers of children with ASD (Hastings & Brown, 2002).

One construct which could be important as a mediator or moderator of maternal well-being in families of children with IDD is resilience. Resilience is of growing interest in mainstream research. For example, researchers have recently reviewed the resilience literature and critiqued the variety of definitions, concepts and theories of psychological resilience (Fletcher & Sarkar, 2015). In disability research, research has proposed expanding the current research agenda to consider the resilience, and thus adaptation, of families caring for children with IDD; through greater understanding of the resources needed to meet everyday challenges (McConnell & Savage, 2015). In terms of research addressing resilience in parents of children with IDD several potential resilience factors have been explored. These include hope (Lloyd & Hastings, 2009) and self-efficacy (Hastings & Brown, 2002). More recently, a systematic review by Peer and Hillman (2014) identified that coping style, optimism, and social support are all factors that may influence resilience in parents of children with IDD.

Although some research exists on the resilience of parents of children with IDD, there is a lack of conceptual clarity regarding its definition (Peer & Hillman, 2014). Nevertheless, influential factors of resilience have previously been identified. Rutter (1987) argued that "resilience is concerned with individual variations in response to risk. Some people succumb to stress and adversity whereas others overcome life hazards" (p. 317). Resilience is also defined as "the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful" (Walsh, 1998, 2006, p. 263). These two definitions are based around a risk/stress – resilience framework: for resilience to be displayed, a stressor must be experienced. Therefore, in the current context resilience might be demonstrated when mothers report good levels of well-being despite raising a child with IDD who has high levels of behaviour problems.

In the broader literature on resilience, there are three main theoretical ways to consider resilience: as a compensatory factor (risk factors have a direct main effect, reducing negative outcomes directly), as a protective factor (reducing negative outcomes in the context of exposure to risk – a moderated effect), and finally the challenge model, which suggests that when exposed to low levels of risk, resilience builds over time (Fergus & Zimmerman, 2005; Brook, Whiteman, Gordon, & Cohen, 1986; Brook, Whiteman, Gordon, & Cohen 1989). In terms of the challenge model, Andrews, Page, and Neilson (1993) suggest that childhood adversities may protect against the effects of later life stress, as this produces "steeling effects" (Lyons & Parker, 2007; Oldehinkel & Ormel, 2014; Rutter, 2006; Seery, Holman, & Silver, 2010).

Each of these different conceptualisations of resilience leads to different predictions about maternal outcomes in IDD research. To address the limitations in existing research and to ground the examination of maternal resilience in alternative theoretical models, our aim was to compare predictions from protective and compensatory models within the same analysis models. As this study is cross-sectional in design we were unable to test the challenge model, since this explicitly refers to a build-up of resilience over time following exposure to lower levels of stress. We also examined a range of maternal well-being measures: stress associated with caring for a child with IDD, mental health (anxiety and depression), positive perceptions of raising a child with IDD, and also mothers' perceptions of family satisfaction. In the current study, we conceptualise child behavioural and emotional problems as a risk factor likely to lead to lower maternal well-being. If maternal resilience acted as a protective factor, we would expect maternal well-being to be less affected when exposed to high levels of child behavioural and emotional problems if they also score high on a measure of resilience, meaning resilience is affecting maternal outcomes at high levels of risk (high levels of child behavioural problems). If maternal resilience acted as a compensatory factor, we would expect resilience to emerge as a significant independent predictor of maternal outcomes – an effect that is not interactive with child behavioural and emotional problems as a risk factor.

Method

Participants

The participants were 312 mothers (300 biological mothers, nine adoptive mothers, and three foster mothers) of children aged between four and 15 years old (*M* = 10.02, *SD* = 3.08) with IDD, 308 of whom reported they were the primary carer of their child. The mothers' ages ranged from 23 to 67 years (*M* = 42.50, *SD* = 7.13) and 252 were currently living with a spouse or partner.

Table 3.1.

Mothers' Demographic Information

Variable		*n*	*Per cent*
Postcode deprivation quintile	1 – Least Deprived	68	22 %
	2	48	15 %
	3	42	14 %
	4	56	18 %
	5- Most Deprived	69	22 %
Education level	No formal educational qualification	11	4 %
	Fewer than 5 GCSE's/ or levels or equivalent	21	7 %
	3 or more a levels (NVQ 3) or equivalent	43	14 %
	University degree	124	40 %
	Masters or doctoral degree	51	16 %
Employment Status	No paid employment	125	40 %
	Part time	125	40 %
	Full time	32	10 %
	Self -employed (full/part time)	30	10 %
Ethnicity	White British	262	84 %
	White Irish	5	2 %
	White Welsh	24	8 %
	Other White background	10	3 %
	Mixed White and Asian	2	1 %
	Other Mixed background	3	1 %
	Black/ Black British- Caribbean	1	<1 %
	White and Black Caribbean	1	<1 %
	Asian/Asian British (Bangladeshi),	1	<1 %
	Asian/Asian British (Indian)	1	<1 %
	Other Asian background	2	1 %

Table 3.2.

Children's Demographic Information

Variable	*n*	*Per cent*
Male	227	73 %
Autism	171	55 %
Various diagnoses and causes of their IDD*	93	30 %
Down's Syndrome	48	15 %
Disability from birth rather than acquired	263	84 %
Additional health condition	162	52 %
Secondary diagnosis given	123	39 %
Can feed themselves/ feed themselves with help	295	95 %
Can dress themselves or dress with help	259	83 %
Can walk upstairs without help/ by themselves	256	82 %
Can wash themselves or wash with help	252	81 %
Hearing impairment or deaf	55	18 %
Children did not use speech	39	13 %

*Examples include; no specific diagnosis such as SWAN- Syndrome Without A Name, genetic syndromes such as Fragile X Syndrome, and other diagnosis such as Global Developmental Delay

Measures

Six measures plus a demographic questionnaire (see Appendix XI) were used in this analysis; all measures were completed by the mother of the child with IDD.

Demographic Questionnaire. Demographic information was gathered using a questionnaire developed by the research team and included questions about the mother (see Table 3.2. for details) and their child with IDD (see Table 3.1.). Socio-Economic Position (SEP) has been associated with maternal well-being in several studies (e.g., Totsika et al., 2011), and so we gathered relevant data and combined several indicators into an index of deprivation. The first indicator was neighbourhood deprivation; each participant's postcode was entered into the relevant and latest UK country databases (England, Scotland, Wales and Northern Ireland). The Multiple Index of Deprivation for the relevant country (Wales, England, Scotland, Northern Ireland) was used. The deprivation level for each postcode is rank ordered into quintiles across the country concerned. The quintiles rank from high to low and those postcodes in the lowest quintile are considered to be living in the most deprived geographical areas; a cut off quintile for "low deprivation level" from the Department for Statistics in the UK was used. Each indicator was scored dichotomously; educational level was scored 0 (*college education or below*), or 1 (*university education or above*). Employment status was scored 0 (*no employment*) or 1 (*employment, full or part time*). Postcode deprivation was scored 0 (*low quintile)* or 1 *(not deemed low quintile)*. For example, the highest score of three indicated living in a low quintile neighbourhood, without a paid job, and with educational qualifications below degree level (see Table 3.3.).

Table 3.3.

Total Deprivation Summed Score for Mothers

	n	*Per cent*
Low Deprivation (score of 0)	141	45 %
Score of 1	122	39 %
Score of 2	44	14 %
High Deprivation (score of 3)	5	2 %

Maternal Psychological Well-Being

Stress. General parenting stress related to having a child with a disability was measured using a shortened seven-item version of the Parent and Family Problems scale from the Questionnaire on Resources and Stress- short Form (QRSF7: Griffith et al., 2011, see Appendix XII). The seven-item scale was developed by Griffith et al. (2011) from the Questionnaire on Resources and Stress Form (QRS-F: Friedrich, Greenberg, & Crnic, 1983). Examples of the scale items "Caring for N puts a strain on me," "Other members of the family have to do without things because of N," "In the future, our family's social life will suffer because of the increased responsibilities and financial stress". Using this seven-item scale, parents were asked to circle either "True" or "False" for each item based on whether the item applied to their family. A total stress score is derived by summing the number of negatively endorsed items (i.e. positively worded items are reverse scored). In the present study a Kuder–Richardson coefficient for the seven-item scale of .90 was obtained.

Maternal Positive Perceptions. The Positive Gain Scale (PGS: MacDonald et al., 2010; Pit-ten Cate, 2003, see Appendix XIII) assesses the positive aspects of raising a child with a disability. The measure consists of seven items about raising a child with intellectual disability (e.g., “Since having this child I have a greater understanding of other people”) including two focusing on what the family has gained (e.g., “Since having this child, my family has become more tolerant and accepting”). The seven items are rated using a five-point Likert scale from 0 (*strongly agree*) to 4 (*strongly disagree*). Preliminary research findings indicated that the PGS has face and content validity and a Cronbach’s alpha coefficient of .79 (Pit-ten Cate, 2003). Previous research has indicated good levels of internal consistency for the PGS with mothers of children with IDD (Griffith et al., 2011; MacDonald et al., 2010) and mothers of children with autism (Cronbach’s alpha coefficient .86: Jones, Hastings, Totsika, Keane, & Rhule, 2014). The PGS total score was used in the current study (with lower scores indicating higher levels of positive gain). Cronbach’s alpha coefficient for the present sample of mothers was .85.

Anxiety and Depression. Maternal anxiety and depression symptoms over the past seven days were measured by the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983, see Appendix II). The measure includes a total of fourteen items, seven depression items (e.g., “I feel as if I am slowed down”) and seven anxiety items (e.g., “I get sudden feelings of panic”). The total scores of the two subscales were used to assess depression and anxiety dimensionally. The HADS has been used with community samples of parents of children with IDD (e.g., Hastings et al., 2005). The HADS has shown good psychometric properties (Hastings et al., 2005) and good levels of reliability when used with mothers of children with IDD, with internal consistency coefficients between .79 and .84 (Hastings & Brown, 2002; Hastings, Daley, Burns, & Beck, 2006) and .85 for maternal anxiety and .78 for maternal depression (Jones et al., 2014). In the present sample, Cronbach's alpha coefficients for mothers were .85 for depression and .86 for anxiety.

Family Satisfaction Scale. Family satisfaction was measured by the Family Satisfaction Scale (FSS: Olson & Wilson, 1982, see Appendix XIV), a 14-item scale designed to measure satisfaction on the dimensions of family cohesion and family adaptability (flexibility). The response is a five-point Likert scale ranging from 1 (*extremely dissatisfied*) to 5 (*extremely satisfied*). The original reliability and validity of the scale was based on university students, married couples, and adolescents (Olson & Wilson, 1982). Cronbach's alpha coefficient for mothers in this present study, for the total family satisfaction score, including both the cohesion and adaptability subscales was .94.

Maternal Moderator Variable

Resilience. The Brief Resilience Coping Scale (Sinclair & Wallston, 2004, see Appendix XV) is designed to assess an adult's ability to recover from stress. The original measure was designed to test resilience in a sample of women with rheumatoid arthritis. The four questions in this scale include: "I actively look for ways to replace losses I encounter in life", "I believe that I can grow in positive ways by dealing with difficult situations", "I look for creative ways to alter difficult situations", "Regardless of what happens to me, I believe I can control my reaction to it". The response scale is a Likert response ranging from 0 (*does not describe me at all*) to 5 (*describes me very well*). The maximum score is 20, and a higher score indicates greater resilience. According to Sinclair and Wallston (2004) low resilience subjects are those who obtain scores lower than 13, while those who scored above 17 are considered highly adaptable. The pooled Cronbach's alpha coefficient in the original study was .69 and with a test retest reliability of .71 ($n = 87$, $p <.001$). Cronbach's alpha coefficient in the present study was .73 for mothers.

Maternal Exposure to "Risk"

Child Behavioural and Emotional Problems. The behavioural and emotional problems of the child with IDD were measured using the Strengths and Difficulties Questionnaire (SDQ: Goodman et al., 1997, 1998, see Appendix XVI). This measure is for parents of children aged between four and 16 years. There are 25 items scored using a three point scale from 1 (*not true)* to 3 (*certainly true).* The SDQ has five subscales including four problem behaviour subscales assessing; Conduct disorder (e.g., "often has temper tantrums"), Emotional Symptoms (e.g., "many worries, often seems worried"), Hyperactivity (e.g., "easily distracted"), Peer Problems (e.g., "has at least one good friend") and one Pro-social Behaviour subscale (e.g., "has at least one good friend"). A total difficulties score is produced by totalling the four problem behaviour subscales, giving a scale with a range of scores from zero to 40. The SDQ is a well validated instrument and research with children with IDD and their parents suggests good levels of reliability (Beck et al., 2004a, 2004b; Hastings et al., 2006; Iizuka et al., 2010). Jones et al. (2014) reported good internal consistency (Cronbach's alpha coefficient .78) with mothers of children with autism. Cronbach's alpha coefficient for the total difficulties score was .86 in this present study.

Procedure

We received approval from an institutional research ethics review board and an external National independent Research Ethics Committee and local Research and Development offices that are part of the National Health Service (NHS) in the UK; Reference number 14/WA/1032 (see Appendix XVII). Participants were recruited to complete an online survey through a multi-point recruitment method, which included emailing online links, distributing flyers (see Appendix XVIII) and information sheets (see Appendix IX for Welsh and English versions) to General Practice (GP) surgeries and secondary care services whose focus was to provide a service for children with IDD, UK charities relevant to children with IDD, and IDD parent support groups. Special Educational Needs schools in North Wales and the North West of England were sent flyers and information sheets to distribute to parents (see Appendix XX for examples of cover letters sent to schools and services). Online recruitment via social media (Twitter and Facebook) and online blogs was also on-going throughout the recruitment period. Several participants requested hard copies of the survey and returned completed surveys by post. As all mothers completed all questions, there was no missing data in this dataset. The Bristol Online Survey (BOS) system (https://www.onlinesurveys.ac.uk/) was used as the online survey system to collect data (see Appendix XXI for online survey consent). In total, 355 parents responded to the survey. Of the 326 mothers who completed the survey, nine were excluded as their child was not aged between four and 16 (the age range selected from the use of the SDQ measure age limits), and three were excluded because their children did not live with them full time. The fathers who participated in the survey were excluded from this analysis due to the differences seen in previous IDD research between mothers and fathers (e.g., Jones, Totsika, Hastings, & Patalas, 2013). Furthermore, it was unknown if the fathers came from the same family as the mothers. Due to the nature of the recruitment methods, we are unable to determine the overall response rate for this survey.

Demographic Variables

Demographic variables presented in Table 3.1. and 3.2. were re-coded dichotomously: children's physical and sensory abilities, which originally had three categories, were reduced to two, (e.g., 1. able to walk/ able to walk with help, and 2. unable to walk without help was reduced to able to walk with or without help, or unable to walk), maternal employment was re-coded into two categories (no paid employment vs. employed), ethnicity was coded as white British versus all other categories, and education was coded into degree level and above versus lower than degree level. All other demographic variables were dichotomously coded such as (male vs. female; autism present vs. no autism present, Down's Syndrome present vs. no Down's Syndrome present, Cerebral Palsy present vs. no Cerebral Palsy present, and IDD present vs. no IDD present). This was necessary to establish which demographics were significant with maternal well-being outcomes; these significant variables could then be entered as control variables in the multiple regression analyses.

Results

To assess maternal resilience as a moderator or as a compensatory factor, multiple regression analyses were conducted for each of the five psychological well-being measures (anxiety, depression, family satisfaction, positive perceptions and resources and stress) (see Table 3.4.). Relevant demographic variables were selected to be included in each of the five analyses from bivariate analyses (correlations or t-tests). Mothers of children with Down's Syndrome reported significantly less stress than other mothers ($t(310) = 6.49$, $p < .001$), as well as significantly less anxiety ($t(310) = 4.45$, $p < .001$), and less depression ($t(310) = 3.89$, $p < .001$), and more family satisfaction ($t(310) = 2.95$, $p = .003$), than mothers in the study whose child did not have Down's Syndrome. Mothers of children who had a diagnosis of autism also had higher stress levels ($t(310) = - 4.18$, $p < .001$), higher anxiety ($t(310) = -4.52$, $p < .001$), higher levels of depression ($t(310) = -3.72$, $p < .001$), and lower family satisfaction ($t(310)= 3.16$, $p = .002$), than mothers of children who did not have an autism diagnosis.

Mothers of male children reported higher stress levels than mothers of female children ($t(310) = 2.49$, $p = .013$). Mothers of white British ethnicity reported more anxiety ($t(310) = 2.46$, $p = .014$), and less family satisfaction ($t(310) = .25$, $p = .012$) than mothers of other ethnicities.

Pearson's correlations showed mothers from families with higher SEP reported higher family satisfaction than those mothers from a lower SEP ($r = .12$, $p = .033$), also families with lower SEP reported lower stress levels ($r = .14$, $p = .014$), lower anxiety levels ($r = .11$, $p = .045$), and lower depression levels ($r = .21$, $p < .001$), than mothers from families with higher SEP. Older mothers also reported less anxiety ($r = -.17$, $p = .002$) and less depression ($r = -.13$, $p = .026$) than younger mothers. It should be noted that the r levels are all small and therefore representing low levels of shared variance.

The key predictor variable in each analysis was child behavioural and emotional problems; resilience was entered as a main effect variable, and as an interaction variable with child behavioural and emotional problems. The "PROCESS" custom dialogue box (Hayes, 2012) was installed into SPSS predictive analytics software for the moderated multiple regression analyses. Multicollinearity issues between variables were checked using the Variance Inflation Factor (VIF) and the variables showed no multicollinearity problems (all values < 10, average > 1, tolerance > 0.1) (Bowerman & O'Connell, 1990; Myers, 1990). Predictor variables were automatically mean-centred when using the PROCESS dialogue box (the variable mean is subtracted from every value of the variable).

Table 3.4.

Moderated Multiple Regression Analyses Models for the Five Maternal Psychological Well-being Measures

n = 312	Maternal Stress		Family Satisfaction		Maternal Anxiety		Maternal Depression		Positive Perceptions	
	R = .611		R=.535		R=.502		R= .524		R= .394	
	R^2 = .374		R^2 = .286		R^2 = .252		R^2 = .275		R^2 = .155	
	F= 19.480		F= 12.645		F= 10.590		F= 11.203		F= 5.305	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Age of mother	.012	.432	-.199	.004	-.066	.056	-.029	.432	.093	**.042**
Autism present	-.309	.208	-.654	.533	.446	.479	.237	.693	.183	.871
Down's Syndrome present	-.823	**.030**	.762	.616	-.678	.353	-.538	.464	.590	.559
Gender of child	-.449	.063	-.013	.989	-.517	.329	.249	.637	.036	.955
SEP	.247	.070	-1.185	**.039**	.369	.253	.946	**.003**	.333	.394
White ethnicity	.368	.258	-2.419	**.033**	1.509	**.027**	.423	.540	.442	.526
Child behaviour problems (centred)	.130	**<.001**	-.293	**<.001**	.169	**<.001**	.160	**<.001**	.094	**.024**
Maternal resilience (centred)	-.079	**.004**	.849	**<.001**	-.270	**<.001**	-.385	**<.001**	-.412	**<.001**
Maternal resilience x Child behavioural and emotional problems (interaction)	.007	**.035**	-.035	.058	.005	.621	.003	.767	-.008	.295

Note: Significant (p<.05) associations between variables are in boldface.

The moderated multiple regression analysis showed that child behavioural and emotional problems and maternal resilience each had a significant independent effect on maternal well-being outcomes in all five models. There are two potentially relevant interaction terms, one statistically significant ($p < .05$) (maternal stress) and one close to significance ($p = .058$) (family satisfaction) suggesting that the main effects could be interpreted in relation to an interaction effect. Following the recommendation by Aiken and West (1991), a simple slope analysis was conducted to aid interpretation of these two interactions. Plots were derived from the values provided in the PROCESS output and show values of stress for the three values of the moderator by high versus low child behaviour and emotional problems.

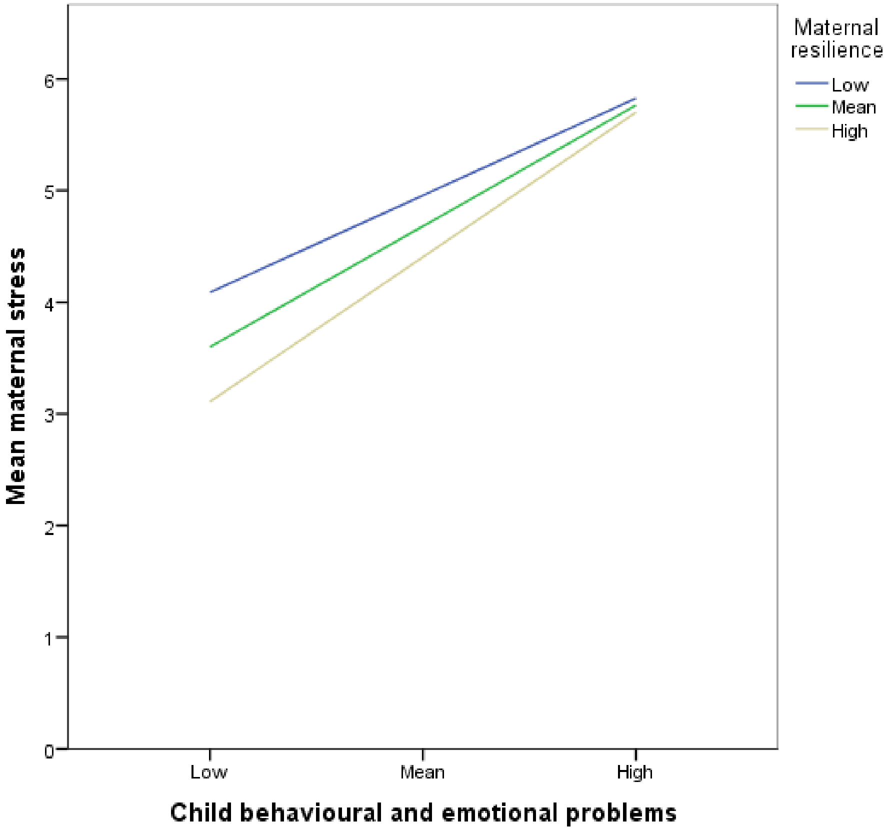

Figure 3. 1 – single slope graph for maternal stress as the outcome variable. There was a positive relationship between child behavioural and emotional problems and maternal stress at all three levels of maternal resilience (all *p*s < .001). Thus, the nature of the interaction effect was unclear. From the plot itself, it is clear that higher levels of maternal resilience were associated with lower maternal stress when child behavioural and emotional problems were at low levels.

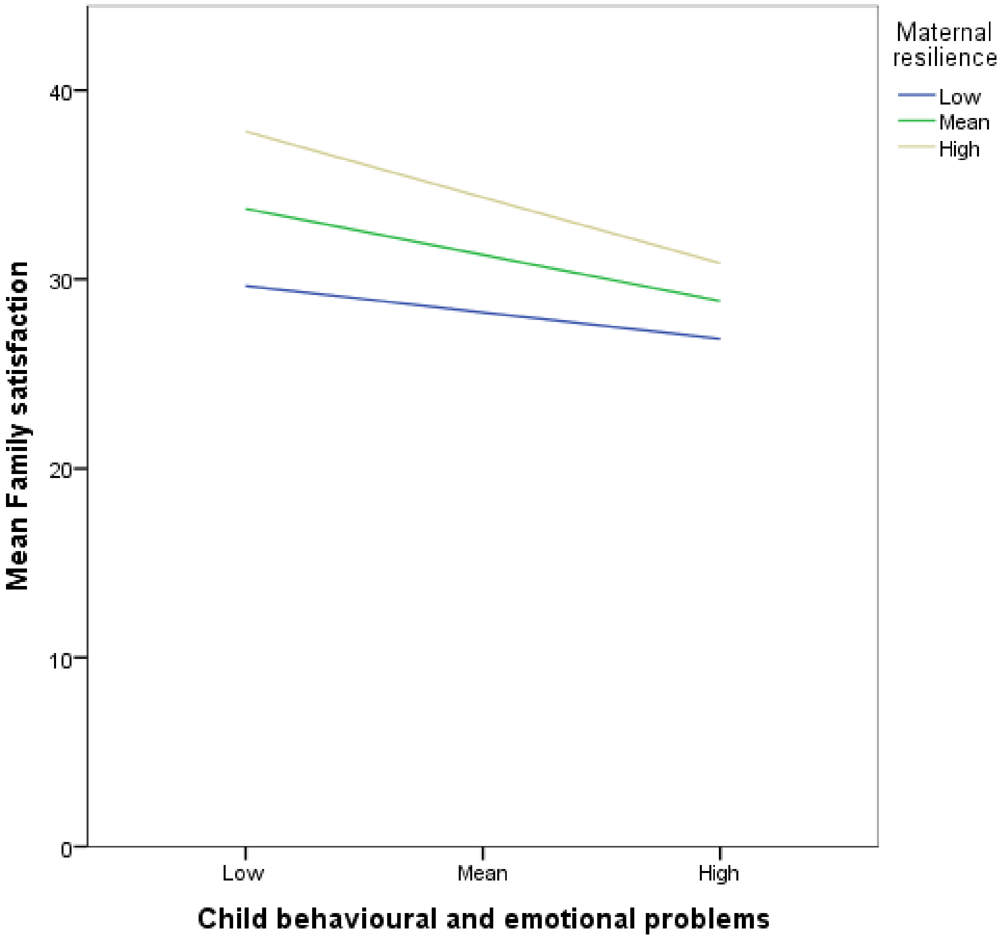

Figure 3. 2 – single slope graph for family satisfaction as the outcome variable. There was a negative relationship between child behavioural and emotional problems and family satisfaction at mid and high levels of maternal resilience (*p*s < .001), but not when maternal resilience was low (*p* = .109). This suggested that higher levels of resilience were associated with increased family satisfaction and had a different impact on family satisfaction to when resilience is low. However, again, higher levels of maternal resilience were associated with less of an increase in family satisfaction, but this only occurred when child behavioural and emotional problems were at low levels.

Discussion

Levels of maternal resilience consistently had a significant independent effect on maternal positive and negative well-being outcomes when child behavioural and emotional problems were present; therefore, we found the strongest support for a compensatory model of resilience. As discussed previously, the compensatory model is where risk factors have a direct main effect, reducing negative outcomes directly, thus overall the presence of resilience in a mother of a child with IDD has a positive impact on their well-being. Although there were interaction terms (one significant, and one borderline significant) that potentially support a protective factor/moderation model of resilience, the resulting relationships did not follow the predicted pattern of resilience affecting maternal outcomes at high levels of risk (high child behavioural and emotional problems). Instead, we found higher levels of resilience were associated with better maternal outcomes at low levels of child behavioural and emotional problems.

The unexpected findings in relation to the regression models for stress and family satisfaction may relate to the third theoretical perspective on resilience introduced earlier- the challenge model. It is possible that in a sample of mothers of children with IDD, “low risk child behavioural problems” is the equivalent of “high risk child behavioural problems” when compared to families of children without IDD. Therefore, high risk in the current study might constitute “extremely high risk” (having a child with IDD and with significant levels of behaviour problems). Ongoing exposure to risk in these families may have increased their resilience over time and this may be reflected in the data from this cross- sectional study, however, at this point the families may have already build up significant resilience at a high or extremely high risk in terms of their child’s behaviour. Of course, an alternative explanation for the findings in relation to the interactions (only one of which was actually statistically significant even in a reasonably large sample) is that the results are spurious and thus if replicated in the analyses are replicated in future, different results may be found.

There are several limitations to this study. First, upon examining the resilience measures available it was clear there is no resilience measure available that clearly pinpointed the concept of resilience from the definitions and evidence available. However, this is not a direct limitation of the study design but comes from a much broader issue of the difficulty in defining and measuring resilience. The resilience measure selected was a short four question measure which may have reduced the internal consistency; however the internal consistency was still acceptable (.73) within statistical recommendations (Hayes, 2012). The definitions of resilience in previous literature include the idea of bouncing back “the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful” (Walsh, 1998, 2006, p. 263). The questions addressed in the measure of resilience seem to address factors associated with resilient outcomes, such as handling stress in an adaptive manner. The resilience measure for this study was selected as it best reflected the core concept of resilience and past definitions, it also scored highly in a reliability and validity assessment (Windle, 2010). However, it was clear there is a gap to further develop resilience measures in future research, based on current definitions.

Mothers did provide all the data in this study which means there was a lack of source variance; however this is common in IDD research due to recruitment approaches. To address this, future research will need to incorporate independent or multiple informant approaches for key constructs (e.g., child behavioural and emotional problems). Finally, the study is limited by its cross-sectional design. This is problematic since temporal precedence has not been established. For example, it may be the case that mothers with higher levels of psychological distress become less resilient. Furthermore, the lack of longitudinal data meant that the challenge model of resilience could not be tested. As identified previously the idea of building up resilience over time could be an explanation for the unexpected findings, and thus looking at resilience in a challenge model may reflect resilience as a process better and produce clearer results.

Our findings may have some practical implications. In particular, it would be beneficial to directly try and build resilience in mothers to improve their well-being. The challenge model of resilience suggests that resilience increases over time when an individual is exposed to risks repeatedly, and one future research question is if living with a child with IDD exposes you to ‘risk’ and therefore mothers of children with IDD do build their resilience in this way. However, this is difficult to address as it is currently not clear how resilience can be built, therefore future research is needed to explore how this may lead to suitable interventions to help increase resilience. One aspect that can currently be explored further is that it is important to examine attributes of “resilient mothers”, for example through the measure questions where mothers scored highly compared to other mothers, group comparisons can be made between different disabilities or with a group of mothers with typically developing children. This can also be explored further qualitatively to gain descriptive information on what mothers of children with IDD think makes them resilient. As one aspect of resilience addresses mothers’ positivity, this could potentially be a related variable to explore. A meta-analysis showed that a number of interventions have been successful in the general population in improving positivity, and therefore well-being (Sin & Lyubomirsky, 2009). Several positive psychology interventions were found to be effective in improving well-being, such as a person identifying their strengths and using their signature strengths in new ways (Seligman, Steen, Park, & Peterson, 2005); cognitive strategies for example replaying positive experiences and self-monitoring well-being (Fava, Rafanelli, Cazzaro, Conti, & Grandi, 1998); and practicing emotional skills such as mindfulness and acceptance (BÉdard et al., 2003; Grossman, Tiefenthaler-Gilmer, Raysz, & Kesper, 2007). It may be that the previous research into what we suspect to be aspects of resilience, such as positivity, may help form a resilience intervention, which would also help develop a clear concept of resilience. Exploration of these types of interventions which focus on aspects of resilience for families of children with IDD is needed in future research.

Alternative interpretations of findings

To discuss some of the findings and data collection further, one of the potential limitations of this research was the use of an online survey to collect data. This was discussed during the ethics board meeting when gaining ethical approval for the online survey, and this issue was addressed by providing a hard copy of the survey to parents if requested, and also by the principal investigator (PhD Student, Elizabeth Halstead) attending many parent meetings to provide the hard copies to be completed at that time. However, it was noted the attraction to complete the survey in general might be from proactive, supported parents as they would be accessing the survey probably through a parent group or charity. This is an interesting discussion for the wider recruitment in IDD research. Frequently this is how recruitment occurs but arguably this may not reflect a true sample of parents of children with IDD. This sample was well educated and also likely interested and would know of the benefits of research. This is a tentative suggestion, however, it may be worth exploring different ways to recruitment, for example approaching parents through GP surgeries. In studies two and three recruitment was conducted by flyers being advertised in NHS services and with parent groups, however, it is important to perhaps have the opportunity to encourage parents who would be less likely to pick up a flyer and complete the survey, to participate in research. During recruitment several parent groups were attended by the researcher to discuss the survey face to face; this also encouraged parents who would not have completed the survey when it was sent out via email, to participate in the research.

The resilience measure for mothers in this study was selected after careful consideration as there was no clear choice of measure to use due to their being no resilience measures used with parents of children with IDD. Windle, Bennett and Noyes (2011) provided a review of resilience measures and scored the current resilience measures available on their reliability and validity using the Terwee measure (Terwee et al, 2007). The resilience measure selected for this study was one of the measures to score highly on the Terwee validation measure. Length of the measure was also a consideration; this measure was included in an online survey with measures of child behavioural and emotional problems, and maternal well-being, which were essential to test the function of resilience as a moderator. The length of the survey was therefore an overall consideration, and it was discussed that given the extensive reading around resilience prior to the survey design and the conclusion that it was unclear how the measures available captured resilience specifically, a short, well-validated measure based on previous literature was selected. Several parents in the parent groups who participated in the research across the UK commented on how difficult it was to answer the questions in the resilience measure about their child, and especially if their child was severely disabled. It was suggested that having more practical questions would work better, for example- Is your child resourceful in situations? Does your child deal with difficult situations well? Then examples can be given- such as a hospital visit, or bullying in school.

One limitation is that all the data reported in this research was dependent on mothers' self-report data and did not have any objective assessments. This is important as mothers' perception of their family best reflects their experience; however, the perception of child behaviour may vary in a self-report measure as it is dependent on a mothers' interpretation.

In terms of the problems with resilience measures, it is clear there is as problem with validity and well as comparability. Risk and adaptation is different in every person, and most outcome measures reflect normative judgements and social values dominant in individualist culture, not much attention has been paid to cultural contexts or subjective definitions (Delfabbro & Harvey, 2004; Ugnar, 2003). Measures of resilience have been criticised for lacking a theoretical base (Kaplan, 1999) and simply listing moderating variables does little to increase understandings of the underlying causes of the outcome variables (Kaplan, 1999; Luthar & Cicchetti, 2000; Luthar et al. 2000; Sandler, 2001). The role of qualitative research clearly has its place to add to learning about the underlying mechanisms in the risk-resilience relationship (Ungar, 2003), to establish what resilience means to parents of children with IDD.

Chapter 4: Maternal depression and family life events as risk factors for behavioural and emotional problems in children with intellectual and developmental disabilities and the function of child resilience as a compensatory factor in this relationship.

Abstract

In the present study, we conceptualise family life events and maternal depression as two risk factors likely to lead to higher levels of child behavioural and emotional problems. Child resilience may act as a protective factor in this relationship and thus we would expect child behavioural and emotional problems to be less affected when exposed to high levels of adverse life events or maternal depression. Three hundred and twelve mothers of children with IDD aged between four and 15 years old completed a cross-sectional online survey. Using multiple regression models, we found maternal depression and child resilience to both be associated with child behavioural and emotional problems, and maternal depression to act as a risk factor for child behaviour and emotional problems, specifically emotional symptoms and conduct problems. Levels of child resilience were found to have a significant independent effect on child behavioural and emotional problems when maternal depression was present. Child adverse life events were not a significant risk factor in any of the models.

Key words: intellectual disability, developmental disability, autism, mothers, psychological well-being, resilience

Children with intellectual and developmental disabilities (IDD) are more likely to demonstrate behaviour problems than children without IDD, and the presence of these behaviour problems have been shown to have a negative association with child outcomes, such as social ability and academic achievements (Campbell, 2003; Kaiser et al., 2007; Baker et al., 2003; Einfeld & Tonge, 1996). Mitchel and Hauser-Cram (2009) found several environmental predictors of child behavioural problems in children with IDD, such as stressful life events and family climate (consisting of cohesiveness, expressiveness and conflict in the family). In the current research we focus on two potential risk factors for child behaviour problems: maternal depression and child life events.

There is a well-established relationship between adverse or stressful life events and psychopathology amongst the general population (e.g., Goodyer, Wright & Altham, 1990). This association has also begun to be explored among the child IDD population. Hatton and Emerson (2004) found that children with IDD were more likely to experience a greater range of adverse life events than children without IDD, which were partly accounted for by family poverty. Hatton and Emerson (2004) found associations between several life events and mental health and well-being in children with IDD: parental separation, parents having negative involvement with the police, death of a child’s close friend, parental financial crisis, and the child experiencing hospitalisation due to illness were associated with high rates of emotional disorders. This study by Hatton and Emerson (2004) also found a cumulative effect on the psychopathology of children with IDD from life events experienced. In a population based study by Totsika, Hastings, Emerson, Lancaster and Berridge (2011) negative life events were included in the family’s socioeconomic status (none vs. one or more) to account for some of the variability in child behavioural problems. It was found that children with IDD were significantly more likely to have experienced at least one negative life event compared to children without IDD. Saylor, Macias, Wohlfeiler, Morgan and Awkerman

(2009) found children with special needs experienced more potentially traumatic life events than their typically developing peers. These potentially traumatic life events were likely related to the special needs of the child (school problems or hospitalisations) but others, such as vehicle accidents, were still reported as higher in children with special needs. Children who were exposed to more life events had significantly more behavioural and emotional problems.

Although it has been shown in the wider child development literature, a less well researched relationship is whether maternal well-being is predictive of child behavioural problems in children with IDD (Zeedyk & Blacher, 2015). The influence of maternal depression on child outcomes is cause for concern in children with IDD as behavioural problems are more common than among their typically developing peers (e.g., Abbeduto et al., 2004). In the wider literature, children of depressed parents are at increased risk for mental health and behavioural problems (e.g., Goodman et al. 2011; Civic & Holt, 2000; Einfeld & Tonge, 1996). The relationship between maternal well-being and child behavioural problems has been shown in families with and without IDD in cross-sectional research (e.g., Beck, Hastings, Daley, & Stevenson, 2004; Blacher, Baker, & Crnic, 2002) whilst the direction of effects between maternal well-being and child behavioural problems has been explored in longitudinal studies (Orsmond, Seltzer, Krauss, & Hong, 2003). However, in longitudinal IDD research it has been found that maternal depression is stable over time despite a decrease in child behavioural and emotional problems (Grey et al., 2011). This evidence suggests that even when risk factors such as life events and maternal depression are present, not every child has high levels of behavioural and emotional problems.

One construct which could be important in explaining this variability is resilience. Resilience may alter child behavioural and emotional problems as an outcome as it may act as a moderator between risk factors and child behavioural and emotional problems. In this study two different potential risk factors from previous research have been identified; maternal depression and negative life events. Some children with IDD may be more resilient than others when exposed to risks.

There is a lack of conceptual clarity in defining what resilience is in existing research and in particular what it means to children with IDD (Peer & Hillman, 2014). Definitions of resilience include “resilience is concerned with individual variations in response to risk. Some people succumb to stress and adversity whereas others overcome life hazards” (Rutter, 1987, p. 317). Resilience is also defined as “the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful” (Walsh, 1998, 2006, p. 263). These two definitions are based around a risk/stress – resilience framework: for resilience to be displayed, a stressor must be experienced. Therefore, in the current context resilience might be demonstrated when a child experiences risk factors, such as adverse life events or maternal depression.

A study by Miller (2002) investigated resilience in students with IDD. The students themselves identified several attributes which they believed made them resilient: 1) identifiable success experiences- such as having a job, 2) areas of strength- being good at art/sports, 3) self-determination, 4) distinctive turning points in their life, 5) special friendships, 6) encouraging teaching and 7) acknowledgement of their learning disability. In a study by Gilmore, Campbell, Shochet, and Roberts (2013) resilience in children with IDD was compared to their typically developing peers. Gilmore et al. found children with IDD reported lower levels of tolerance, fewer future goals and higher levels of emotional sensitivity, although other identified resilience factors in children with IDD, such as optimism and self-esteem, were reported at a similar level to that of their typically developing peers. To the best of our knowledge, no research studies have studied whether resilience measures predict positive or negative outcomes for children with IDD.

In the broader literature on resilience, there are three main theoretical ways to think about resilience: as a compensatory factor (risk factors have a direct main effect, reducing negative outcomes directly), as a protective factor (reducing negative outcomes in the context of exposure to risk – a moderated effect), and finally the challenge model, which suggests that when exposed to low levels of risk, resilience builds over time (Fergus & Zimmerman, 2005; Brook, Whiteman, Gordon, & Cohen, 1986; 1989**).** In terms of the challenge model, Andrews, Page, and Neilson (1993) suggest that childhood adversities may protect against the effects of later life stress, as this produces "steeling effects" (Lyons & Parker, 2007; Oldehinkel & Ormel, 2014; Rutter, 2006; Seery, Holman, & Silver, 2010).

Our aim was to compare predictions from protective and compensatory models within the same analysis models. We conceptualise family life events and maternal depression as two risk factors likely to lead to higher levels of child behavioural and emotional problems. If child resilience acted as a protective factor, we would expect child behavioural and emotional problems to be less affected when exposed to high levels of adverse life events or maternal depression.

Method

Participants

Mothers provided data about 312 children with IDD aged between four and 15 years old (M = 10.02, SD = 3.08). The mothers' ages ranged from 23 to 67 years (M = 42.50, SD = 7.13) and 252 were currently living with a spouse or partner. Most mothers (308) were the primary carer for their child. Further Demographic information about mothers is presented in Table 4.2.

Table 4.1.

Children's Demographic Information

Variable	*n*	*Per cent*
Male	227	73 %
Autism	171	55 %
Various diagnoses and causes of their IDD*	93	30 %
Down's Syndrome	48	15 %

*Examples include; no specific diagnosis such as SWAN- Syndrome Without A Name, genetic syndromes such as Fragile X Syndrome, and other diagnosis such as Global Developmental Delay

Table 4.2.

Mothers' Demographic Information

Variable		*n*	*Per cent*
Postcode deprivation quintile	1 – Least Deprived	68	22 %
	2	48	15 %
	3	42	14 %
	4	56	18 %
	5- Most Deprived	69	22 %
Education level	No formal educational qualification	11	4 %
	Fewer than 5 GCSE's/ or levels or equivalent	21	7 %
	3 or more a levels (NVQ 3) or equivalent	43	14 %
	University degree	124	40 %
	Masters or doctoral degree	51	16 %
Employment Status	No paid employment	125	40 %
	Part time	125	40 %
	Full time	32	10 %
	Self -employed (full/part time)	30	10 %

Measures

Four measures plus a demographic questionnaire (see Appendix XI) were used in this analysis; all measures were completed by the mother of the child with IDD.

Demographic Questionnaire. Demographic information was gathered using a questionnaire developed by the research team. This included the following child variables: gender, age, whether additional disabilities or health conditions were present, how independent the child was in regards to feeding and dressing themselves and being independently mobile, whether the child went to respite care, and whether they lived with the primary carer . Socio-Economic Position (SEP) has been associated with maternal well-being in several studies (e.g., Totsika et al., 2011), and so we gathered relevant data and combined several indicators into an index of deprivation (See Table 4.2.). The first indicator was neighbourhood deprivation; each participant's postcode was entered into the relevant and latest UK country databases (England, Scotland, Wales and Northern Ireland). The Multiple Index of Deprivation for the relevant country (Wales, England, Scotland, Northern Ireland) was used. The deprivation level for each postcode is rank ordered into quintiles across the country concerned. The quintiles rank from high to low and those postcodes in the lowest quintile are considered to be living in the most deprived geographical areas; a cut off quintile for "low deprivation level" from the Department for Statistics in the UK was used. Each indicator was scored dichotomously; educational level was scored 0 (*college education or below*), or 1 (*university education or above*). Employment status was scored 0 (*no employment*) or 1 (*employment, full or part time*). Postcode deprivation was scored 0 (*low quintile)* or 1 *(not deemed low quintile).* For example, the highest score of three indicated living in a low quintile neighbourhood, without a paid job, and with educational qualifications below degree level (see Table 4.3.).

Table 4.3.

Total Deprivation Summed Score for Families

	n	*Per cent*
Low Deprivation (score of 0)	141	45 %
Score of 1	122	39 %
Score of 2	44	14 %
High Deprivation (score of 3)	5	2 %

The demographic variables presented in Table 4.1. were recoded dichotomously: children's physical and sensory abilities, which originally had three categories, were reduced to two, (able to feed by themselves with or without help vs. feed with help, independently mobile, or help required vs. unable to walk, able to dress themselves with or without help vs. unable to dress themselves without help, hearing impairment vs. no hearing impairment, speech impairment vs. no speech impairment, secondary diagnosis present vs. no secondary diagnosis present, additional health condition present vs. no additional health condition present). In addition to creating a new variable of Socio-Economic status, a Total Disability Severity Index was created. A Total Disability Severity Index was created which included several demographic variables for the purpose of determining if the child had additional diagnoses, as well as their IDD diagnosis. The four questions included in this new variable were whether the child had sensory problems, epilepsy, mobility problems, or any other health problem. Each were coded as 0 (*not present*), or 1 (*present*). Therefore, the new variable reflecting additional disabilities ranged from zero (*no additional disabilities*) to four (*several additional disabilities*) (see Table 4.4.). In this index variable, a high score meant the child was considered to have a more severe disability than those children who scored lower. All other demographic variables were dichotomously coded such as (male vs. female; autism present vs. no autism present, Down's Syndrome present vs. no Down's Syndrome present, Cerebral Palsy present vs. no Cerebral Palsy present, and IDD present vs. no IDD present). This was necessary to establish which demographics were significant with maternal well-being outcomes; these significant variables could then be entered as control variables in the multiple regression analyses

Table 4.4.

Total Disability Severity Index

	n	*Per cent*
Low Severity (score of 0)	72	23 %
Score of 1	124	40 %
Score of 2	111	36 %
High Severity (score of 3)	5	2 %

Maternal Report on Behaviour Outcomes

Child Behavioural and Emotional Problems. The behavioural and emotional problems of the child with IDD were measured using the Strengths and Difficulties Questionnaire (SDQ: Goodman et al., 1997, 1998, see Appendix XVI). This measure is for parents of children aged between four and 16 years. There are 25 items scored using a three point scale from 1 (*not true)* to 3 (*certainly true)*. The SDQ has five subscales including four problem behaviour subscales assessing; Conduct disorder (e.g., “often has temper tantrums”), Emotional Symptoms (e.g., “many worries, often seems worried”), Hyperactivity (e.g., “easily distracted”), Peer Problems (e.g., “has at least one good friend”) and one Pro-social Behaviour subscale (e.g., “has at least one good friend”). A total difficulties score is produced by totalling the four problem behaviour subscales, giving a scale with a range of scores from zero to 40. The SDQ is a well validated instrument and research with children with IDD and their parents suggests good levels of reliability (Beck et al., 2004a, 2004b; Hastings et al., 2006; Lizuka et al., 2010). Jones et al. (2014) reported good internal consistency (Cronbach’s alpha coefficient .78) with mothers of children with autism. Cronbach’s alpha coefficient for the total difficulties score was .86 in the present study.

Child Proxy Moderator Variable

Resilience. The Wagnald and Young Resilience Scale (1993) was originally designed to identify the degree of resilience an individual possesses. The measure is derived from interviews with “resilient” individuals, the original resilience scale has 14 items and measures personal attributes associated with resilience. It has good psychometric properties and has been used successfully in many studies involving adults and adolescents (Wagnild, 1993; Wagnild, 2009). An adapted five-item version of the measure was used for this study as there was no suitable proxy resilience measure found. This five-item version was replicated from the resilience subscale of the well-being measure, used in the “Feelings Count” survey, conducted by the New Philanthropy Capital (NPC) charity. The NPC survey was a self-report survey for children to assess their well-being. Therefore, the measure was adapted to be used as a proxy report for parents of children with IDD. This five-item resilience measure included five perspectives on resilience, namely equanimity, perseverance, self- reliance, meaningfulness and existential aloneness. The words in the five questions were adapted to directly ask the mother about their child. The questions in the present study included “My child usually manages one way or another”, “My child keeps interested in things”, “My child feels their life has a sense of purpose”, “My child finds life really worth living”, “My child believes their life has meaning” (see Appendix XXII). In the original study by Wagnild & Young (1993) factor loadings (I) for four items were: “Manage one way of another” (.79); I”I keep interested in things” (.56); “Keeping interested in things is important” (.66); “My life has meaning” (.39), the final question was not included in the original scale. All items are scored on a seven-point Likert scale from 1(*disagree*) to 7 (*agree*). In this study, Cronbach’s alpha coefficient for mothers’ scores on the five-items used was .84.

Child Exposure to “Risk”

Life Events. Child and family life events were measured using life event questions from the Millennium Cohort Study (2012, see Appendix XXIII). A total of eight questions were asked. The life event questions referred to possible life events in the past 12 months of the child with IDD and their family life. Question included were relating directly to the child such as illness, moving house, and being absent from school or changing school. In addition, the scale captured any illness or separation of parents and/or spouses. Mothers responded "yes" or "no" to questions one to seven to indicate if the life event had occurred. The last question was an open-ended question to note any other life events not previously captured.

Depression. Maternal depression symptoms over the past seven days were measured by the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983, see Appendix II). The measure includes a total of 14 items, seven depression items (e.g., "I feel as if I am slowed down") and seven anxiety items. The total score of the depression subscale was used in this study. The HADS has been used with community samples of parents of children with IDD (e.g., Hastings et al., 2005). The HADS has shown good psychometric properties (Hastings et al., 2005) and good levels of reliability when used with mothers of children with IDD, with internal consistency coefficients between .79 and .84 (Hastings & Brown, 2002; Hastings, Daley, Burns, & Beck, 2006), .85 for maternal anxiety and .78 for maternal depression (Jones et al., 2014). In the present sample, Cronbach's alpha coefficient for depression in mothers was .85.

Procedure

We received approval from an institutional research ethics review board and an external National independent Research Ethics Committee and local Research and Development offices that are part of the National Health Service (NHS) in the UK; Reference number 14/WA/1032 (see Appendix XVII). Participants were recruited to complete an online survey through a multi-point recruitment method, which included emailing online links, distributing flyers (see Appendix XVIII) and information sheets (see AppendixIX for Welsh and English versions) to General Practice (GP) surgeries and secondary care services whose focus was to provide a service for children with IDD, UK charities relevant to children with IDD, and IDD parent support groups. Special Educational Needs schools in North Wales and the North West of England were sent flyers and information sheets to distribute to parents (see Appendix XX for examples of cover letters sent to schools and services). Online recruitment via social media (Twitter and Facebook) and online blogs was also on-going throughout the recruitment period. Several participants requested hard copies of the survey and returned completed surveys by post. As all mothers completed all questions, there was no missing data in this dataset. The Bristol Online Survey (BOS) system (https://www.onlinesurveys.ac.uk/) was used as the online survey system to collect data. As all mothers completed all questions, there were no missing data in this dataset. In total, 355 parents responded to the survey. The fathers who participated in the survey were excluded from this analysis due to the differences seen in previous IDD research between mothers and fathers (e.g., Jones, Totsika, Hastings, & Petalas, 2013). Of the 326 mothers who completed the survey, nine were excluded as their child was not aged between four and 16 (the age range selected from the use of the SDQ measure age limits), and three were excluded because their children did not live with them. Due to the nature of the recruitment methods, we are unable to determine the overall response rate for this survey.

Demographic Variables

The demographic variables presented in Table 4.1 and Table 4.2 were re-coded dichotomously; children's physical and sensory abilities, which originally had three categories, were reduced to two, (e.g., 1. able to walk/ able to walk with help, and 2. unable to walk without help was reduced to able to walk with or without help, or unable to walk), maternal employment was re-coded into two categories (no paid employment vs. employed), ethnicity was coded as white British versus all other categories, and education was coded into degree level and above versus lower than degree level. Other categories were dichotomously coded, such as male versus female, autism present versus no autism present, Down's Syndrome present versus no Down's Syndrome present, Cerebral Palsy present versus no Cerebral Palsy present, and IDD present versus no IDD present.

Results

To examine child resilience as a moderator or as a compensatory factor, multiple regression analyses were conducted for each of the five child behavioural and emotional problem subscales (Emotional Symptoms, Child Conduct Problems, Hyperactivity, Peer Problems and Pro-social Behaviour) and the total score of child behavioural and emotional problems (see Table 4.5). Life events and maternal depression were entered in the regression models as risk variables.

Demographic variables that were significantly associated with the SDQ scores from bivariate analyses (correlations or *t*-tests) were selected to be included in each of the six analyses. Mothers of boys with IDD reported significantly more pro-social behaviour than mothers of girls ($t(310) = 2.90$, $p = .004$). Mothers of children with autism reported significantly higher levels of child behavioural and emotional problems than mothers of children with no autism diagnosis in all SDQ subscales: emotional symptoms ($t(310) = -8.27$, $p < .001$); conduct problems ($t(310) = -4.27$, $p < .001$); hyperactivity ($t(310) = -4.26$, $p < .001$); peer problems ($t(310) = -6.50$, $p < .001$); total difficulties score ($t(310) = -8.29$, $p < .001$), and also lower levels of pro-social behaviour ($t(310) = -2.90$, $p = .004$). Mothers of children with Down's Syndrome reported significantly lower child behavioural and emotional problems than mothers of children without Down's Syndrome in all SDQ subscales: emotional symptoms ($t(310) = 6.96$, $p < .001$); conduct problems ($t(310) = 4.28$, $p < .001$); hyperactivity ($t(310) = 4.48$, $p < .001$); peer problems ($t(310) = 6.27$, $p < .001$), $p < .001$); total difficulties score ($t(310) = 9.23$, $p < .001$), and also lower levels of pro-social behaviour ($t(310) = 6.40$, $p < .00$)).

Pearson's correlations conducted showed mothers from families with higher SEP reported higher levels of child emotional problems ($r(.131) = .017$, $p = .020$), and more total behavioural and emotional problems ($r(.132) = .017$, $p = .020$) than those mothers from a lower SEP. Younger children were reported as having significantly more child conduct problems (r(-.125) = .016, p = .027), and more child hyperactivity (r(-.135) = .018, p = .-017) than older children.

No other demographic variables showed statistically significant associations with the SDQ scores of the children with IDD.

The “PROCESS" custom dialogue box (Hayes, 2012) was installed into SPSS predictive analytics software for the moderated multiple regression analyses. Multicollinearity issues between variables were checked using the Variance Inflation Factor (VIF) and the variables showed no multicollinearity problems (all values < 10, average > 1, tolerance > 0.1) (Bowerman & O’Connell, 1990; Myers, 1990). The life events variable was slightly positively skewed. A square root transformation was conducted on this variable, and the regression analyses were re-run. However, the pattern of results remained the same and so these additional analyses are not reported here. Predictor variables were automatically mean-centred when using the PROCESS dialogue box (the variable mean is subtracted from every value of the variable).

Table 4.5.

Moderated Multiple Regression Analyses Models for the Total Child Behavioural and Emotional Problems Total and Five Subscales

	Total		Subscales									
n = 312	Total Difficulties Score		Emotional Symptoms		Child Conduct Problems		Hyperactivity		Peer Problems		Pro-social Behaviour	
	R = .703		R=.591		R=.513		R= .402		R= .502		R= .507	
	R^2 = .494		R^2 = .349		R^2 = .263		R^2 = .162		R^2 = .259		R^2 = .257	
	F= 30.174		F= 23.470		F= 10.261		F= 6.736		F= 9.915		F= 10.788	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Age of child	-.161	.157	.063	.146	-.099	**.013**	-.101	**.007**	.056	.113	-.160	.158
Autism present	3.237	**<.001**	1.787	**<.001**	.366	.176	.535	.053	.867	.001	3.237	**<.001**
Down's Syndrome present	-5.085	**<.001**	-1.190	**.003**	-.454	.151	-.715	.103	-.778	.046	-1.949	**<.001**
Gender of child	-.652	.407	.860	**.010**	-.299	.243	-.179	.527	-.162	.530	-.872	**.004**
SEP	.210	.633	.148	.441	-.021	.891	.086	.576	-.031	.826	.229	.601
Child/Family Life events (centred)	.062	.840	.101	.434	-.032	.732	-.018	.856	.050	.636	-.039	739
Child Resilience (centred)	-.830	**<.001**	-.198	**<.001**	-.154	**<.001**	-.101	**.001**	-.137	**<.001**	-.239	**<.001**
Maternal Depression (centred)	.259	**.005**	.259	**.005**	.116	**<.001**	.043	.137	.045	.092	-.009	.797
Resilience x Life events (interaction)	-.029	.686	-.004	.867	-.021	.397	.024	.239	-.035	.406	-.003	.924
Resilience x Maternal depression (interaction)	.012	.470	-.008	.271	.001	.879	.007	.116	.006	.290	.006	.467

Note: Significant associations between variables are in boldface.

The moderated multiple regression analyses showed that child resilience was a significant independent predictor of child behavioural and emotional problems in all six of the models (all *p*s < .001 or = .001), and maternal depression was a significant independent predictor of child behavioural and emotional problems in three of the six models (all *p*s < .05) (total difficulties score, emotional symptoms and conduct problems). Contrary to predictions, exposure to more negative life events was not significantly associated with child behavioural and emotional problems. There were no significant interaction terms in any of the six models run, either in interaction one (resilience x life events) or two (resilience x maternal depression).

Discussion

This study has shown firstly that maternal depression and child resilience are both associated with child behavioural and emotional problems. Secondly, maternal depression was found to act as a risk factor for child behaviour and emotional problems (specifically emotional symptoms and conduct problems). Thirdly, levels of child resilience consistently had a significant independent effect of child behavioural and emotional problems when maternal depression was present; therefore, we found the strongest support for a compensatory model of resilience. The compensatory model explores whether risk factors have a direct main effect, reducing negative outcomes directly, thus overall the presence of resilience in a child with IDD has a positive impact on their behavioural and emotional problems. Fourthly, child adverse life events were not found to be a significant risk factor in any of the models.

In addition to child resilience acting as a compensatory factor, the finding that maternal depression acts as a risk factor to child behavioural and emotional problems fits with our hypothesis. However, the complexities of this relationship and what exactly makes maternal depression a risk factor remain unclear. In literature focused on mothers of children with disabilities, 89% of showed a significant relationship between child behavioural and emotional problems and maternal depression (Bailey, Golden, Roberts & Ford, 2007). Consequently the relationship between child behavioural and emotional problems and maternal depression is well established in cross-sectional research. Research has also explored this relationship as bi-directional, for example, how maternal depression can lead to negative parenting behaviours, which in turn can then influence child outcomes (Lovejoy, Graczyk, O'Hare, & Neuman, 2000).

In this study adverse life events did not act as a risk factor of child behavioural problems, although some previous research has found a link between these two factors (Mitchel and Hauser-Cram, 2009). A possible explanation for this lack of consistency with previous research is that the current findings may be due the life events scale used, which is not specific to children with IDD or their families. The life events scale was selected as the items were used in a large scale cohort study across the UK. It captured the main life events identified in other life events measures explored for use in this present study, and it also captures life events specifically relating to a child. In the context of having a disability it may have been more meaningful to ask the individual to rate their perception of the life event (see Bramston & Fogarty, 1995; Esbensen & Benson 2006). Self-report scales measuring life events among adults with IDD have been successfully used. The Bangor Life Events Schedule for Intellectual Disabilities (BLESID-SR: Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011), is designed as a measure of significant life events occurring in the life of someone with IDD. In the BLESID-SR an interviewer uses a semi-structured interview to guide the conversation and reflect in the scoring what the individual has said about their life events. In future research about child life events, an adaption of this scale may be a valuable tool and prove more useful than the proxy tool completed by parents in the current study.

Mothers did provide all the data in this study which means there was a lack of source variance; however this is common in IDD research due to recruitment approaches. To address this potential limitation, future research could incorporate independent or multiple informant approaches for key constructs, such as for child behavioural and emotional problems. As with the BLESID-SR, it is important to provide individuals with IDD the opportunity to self-report, and therefore there is also a possibility for future research to develop a self-report resilience measure in children/individuals with IDD. In addition, this study is limited by its cross-sectional design. Negative life events were measured asking mothers to think of life events of the past 12 months and as such provide an element of results reported over time, however overall this cross-sectional design is problematic because temporal precedence has not been established. For example, it may be the case that children with IDD who have higher levels of behavioural and emotional problems become less (or more) resilient over time. It would be beneficial in future research to explore child and maternal outcomes at various points in time in order to look at these possible changes. In addition future research could explore positive life events as well as negative life events to build a picture of balance in the life of the child with IDD.

As the research suggests that resilience in a child with IDD and maternal depression have a relationship with child behavioural and emotional problems, a potential route for future interventions would be to examine both maternal depression and reducing behavioural and emotional problems directly by developing the skills and ability to adapt to situations to facilitate resilience in the child with IDD. Developing child resilience to reduce child behavioural and emotional problems could however prove a difficult task. There is currently no agreed definition of resilience, and arguably resilience is subjective and dependent on many factors. Therefore, resilience is complex to measure and it would be difficult to currently use a measure of resilience to assess resilience over time in an intervention study. It seems the proxy measure developed and chosen for this study does begin to capture some ‘resilience’ in children with IDD that is consistent with the hypothesis of how resilience might work in a compensatory model. In addition, Cronbach’s alpha coefficient was also good for this measure in this study (.84). Clearly, there is a possibility for a proxy resilience measure to be developed further. In future research it would be useful to compare a parent’s report of resilience in their child, with the child’s report of their own resilience, as these two reports may vary. The measure that was used for resilience has also been used in a large cohort study with children without IDD, and therefore future research could be conducted to be able to compare these resilience scores from children with IDD to children without IDD. This would develop the concept of resilience further and begin to shape what resilience means to children with IDD, along with some of the differences or similarities between parent and child reports. This could then start to build a picture around family resilience.

There has been research investigating the development of a family approach to promote child resilience. Shapiro (2002) reported a case study intervention to promote family resilience with a child with chronic health problems and IDD. This included focusing on the family’s own definition of the current problem and the relevant history of the problem, then constructing a coherent story of the illness and its impact, thus recognising stressors and strengths. It was successful in improving health efficacy, communication towards mutual understanding and shared problem solving, as well as promoting better use of resources. Therefore, developing child resilience within the family could be explored further in future research, alongside developing measures to assess resilience and the effectiveness of an intervention.

In terms of addressing maternal depression to reduce child behavioural and emotional problems, the finding that maternal depression is a risk factor for child behavioural and emotional problems is consistent with previous research (e.g., Conners-Burrow, Swindle, McKelvey, & Bokony, 2015). It is also clear that mothers of children with IDD are more at risk for depression than mothers of typically developing children (e.g., Cheng, Palta, Poehlmann-Tynan, & Witt, 2015). It would therefore be beneficial to address these two aspects of maternal depression and child behavioural and emotional problems within a family of a child with IDD in future research. Schreibman (2000), for example, found that when psychological symptoms, such as depression, are present in parents, they are less likely to follow through on intervention procedures for their child's behavioural and emotional problems, which may be a reason why maternal depression is a risk factor for child behavioural and emotional problems. Interventions targeting reducing maternal depression would then also likely impact positively on child behavioural and emotional problems with possible implications for siblings and parent relationships also.

To conclude, considering this previous research and our findings that risk factors may come from within the family (e.g., the mother's depression and adverse life events), it is also of importance to consider parent-child relationships and a systemic family approach to interventions when looking at effectively reducing child behavioural and emotional problems.

Alternative findings

The selection of the proxy measure used in this study proved more difficult. Very few proxy measures have been developed which measured 'resilience' and also some overlap in consistency of items with the Resilience Scale chosen for mothers seemed logical. Therefore, it was decided to use the shortened version used in the Millennium Cohort Study (2012) as a subscale of their overall well-being measure, which was given to children without IDD. The wording was altered so that the measure could be then given to mothers to complete about their child.

It seems the proxy measure developed and chosen for this study does begin to capture some 'resilience' in children with IDD that is consistent with the hypothesis of how resilience might work in a compensatory model. In addition, Cronbach's alpha coefficient was also good for this measure in this study. Clearly, there is a possibility for a proxy resilience measure to be developed further. However, this proxy measure may also just be measuring elements of positivity or optimism in general well-being.

One of the potential limitations of this research was the use of an online survey to collect data. This was discussed during the ethics board meeting when gaining ethical approval for the online survey, and this issue was addressed by providing a hard copy of the survey to parents if requested, and also by the principal investigator (PhD Student, Elizabeth Halstead) attending many parent meetings to provide the hard copies to be completed at that time. However, it was noted the attraction to complete the survey in general might be from proactive, supported parents as they would be accessing the survey probably through a parent group or charity. This is an interesting discussion for the wider recruitment in IDD research. Frequently this is how recruitment occurs but arguably this may not reflect a true sample of parents of children with IDD. This sample was well educated and also likely interested and would know of the benefits of research. This is a tentative suggestion, as it cannot be confirmed; however, it may be worth exploring different ways to recruitment, for example approaching parents through GP surgeries. In studies two and three recruitment was conducted by flyers being advertised in NHS services and with parent groups, however, it is important to perhaps have the opportunity to encourage parents who would be less likely to pick up a flyer and complete the survey, to participate in research. During recruitment several parent groups were attended by the researcher to discuss the survey face to face; this also encouraged parents who would not have completed the survey when it was sent out via email, to participate in the research. Parents also said that they found completing this resilience measure difficult, and it did not necessarily reflect their child's resilience. It may have been easier to have asked practical questions about their child to establish if the child has a positive way of coping or a negative way of coping.

Chapter 5: Resilience in mothers of children with Autism Spectrum Disorder: Cross-sectional and longitudinal relationships.

Abstract

Behavioural symptoms of Autism Spectrum Disorder (ASD), and the severity of symptoms, have been explored in association with both negative and positive parental outcomes in both cross-sectional and longitudinal research. However, there is variability in the extent to which family members are affected by their child's ASD symptoms. In the present study we explored whether maternal resilience explains some of this variability and, specifically, whether resilience functions as a protective or compensatory factor. In addition, this study explored this association longitudinally and investigated whether resilience predicted later maternal well-being, when controlling for well-being at an earlier time point. Ninety-nine mothers of children aged between two and 13 years with ASD participated in an online survey at baseline and six months later. It was found that maternal resilience functioned as a compensatory factor, having a significant main effect relationship with depression. However, resilience was not found to predict maternal well-being outcomes over time. The severity of the child's current ASD symptoms was found to predict benefit finding in mothers over time. Building maternal resilience and providing support and intervention to improve child behavioural problems may result in improved well-being for mothers of children with ASD.

Key words: intellectual disability, developmental disability, autism, mothers, psychological well-being, resilience

Parenting a child with ASD is associated with a variety of parental positive and negative outcomes (see review by Hastings, 2008). Research has identified that parents of children with ASD experience higher stress levels than parents of typically developing children or children diagnosed with other IDDs, including Down's Syndrome, Cerebral Palsy, and Global Developmental Delay (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010; Eisenhower, Baker & Blacher, 2005; Estes et al., 2009, 2013; Hayes, & Watson, 2013; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Zablotsky, Bradshaw, & Stuart, 2013; Giovagnoli, 2015). Also, parents of children with ASD also experience more symptoms of depression and use of avoidance coping than parents of typically developing children (Wei et al., 2015).

The behavioural symptoms of ASD and the severity of symptoms have been explored in association with parental outcomes. It was noted by Smith et al. (2008) that the literature explores mostly child ASD symptoms, specifically, and parental outcomes (e.g., Eisenhower, Baker, & Blancher, 2005; Ello & Donovan, 2005; Lecavlier, Leone, & Wiltz, 2006). However, the question remains if it is primarily due to the child's ASD symptoms or child behavioural and emotional problems more generally (e.g., Hastings, Kovshoff, Ward et al. 2005; Herring et al., 2006). Again, variability is present in parents' mental health and well-being when raising a child with ASD; some parents' report significantly lower well-being and mental health problems than other parents, and some parents report positive outcomes (Benson, 2006; Benson & Karlof, 2009).

Giovagnoli (2015) found behavioural and emotional problems are strong predictors of parental stress. Firth and Dryer (2013) also found that children's behavioural and emotional problems affected overall levels of parental distress, such as stress, tension, anxiety, and depression. The severity of the child's ASD symptoms are also associated with parental stress and depression, suggesting that the severity of the child's ASD symptoms is positively related to the level of parental stress (e.g., Eisenhower, Baker, & Blacher, 2005; Hastings & Johnson, 2001; Baker-Ericzen et al., 2005; Hastings & Johnson, 2001; Hastings et al., 2005; Hill-Chapman et al., 2013; Osborne & Reed, 2009). In a longitudinal study, Benson (2010) found that the severity of a child's ASD symptoms predicted maternal anger. Other aspects of ASD symptomology have also been explored, such as the severity of social impairment, which was found to predict parenting stress (Firth & Dryer, 2013).

While negative parental outcomes are well established, positive parental outcomes are also associated with raising a child with ASD, such as personal growth, improved relationships with others, greater patience, and more empathy (Hastings & Taunt, 2002; Pakenham, Sofronoff, & Samios, 2005; Scorgie & Sobsey, 2000). Some parents report significantly lower well-being and mental health problems than other parents. The presence of positive outcomes reported in parents' mental health and well-being when raising a child with ASD supports this variation seen in maternal well-being (Benson, 2006; Benson & Karlof, 2009).

Parental resilience may account for some of the variation between the severity of child ASD symptomology and parental well-being. Resilience has been defined as "the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful" (Walsh 1998 p.263). Only a few studies have explored resilience in parents and caregivers of children with ASD. Ruiz-Robledillo et al. (2014) found resilience showed associations with overall general physical and psychological health of caregivers of children with ASD. Most research suggests that resilience is associated with mental health, such as anxiety, insomnia and depression in caregivers (Tang et al., 2013). The Resilience Scale for Adults (RSA: Friborg et al., 2006) has been used in a small population of parents of children with IDD, as part of a comparison between parents of children with Intellectual Disabilities (ID) and parents of children with Sanfilippo syndrome (a degenerative disorder with a progressive decline in children's intellectual and physical functioning) and it was found parents rated *social resources* as their highest protective factor, and *planned future* as their lowest protective factor (Grant et al., 2013). Resilience research to date in the IDD field is generally based on cross-sectional research, however Bayat (2007) suggests that resilience is a process that can only be shown over time, and suggested the need for longitudinal studies; however, only one longitudinal study with parents of children with IDD was found. This study was by Gertstein, Crnic, Blacher and Baker (2009), who conducted a longitudinal study exploring the trajectories of daily parenting stress in parents of young children with IDD. The study found factors such as psychological well-being, marital adjustment and positive parent-child relationships affected parenting stress differently in mothers and fathers, and it was therefore concluded parents affect each other's resilience. Therefore, this study will be the first to explore resilience in mothers of children with ASD longitudinally, as well as with cross-sectional data. First, this study will seek to replicate the previous cross-sectional findings from study two in a new USA sample of mothers of children with ASD compared to a UK sample of mothers of children with IDD, and with a different maternal resilience measure. This study seeks to determine whether the severity of the child's ASD symptoms is associated with positive and negative maternal well-being outcomes when resilience is a moderator, and child ASD symptoms are accounted for. Second, if resilience again functions as a compensatory factor to maternal well-being outcomes (as found in studies two and three of this thesis). Third, this study will explore further how resilience functions longitudinally, thus investigating whether maternal resilience predicts maternal well-being over time.

Method

Participants

The current sample was from a larger study of parents of children with ASD (*n* = 136). The participants were 99 mothers of children with ASD (84 male) aged between two and 13 years (*M* = 7.78, *SD* = 2.66). The mothers' ages ranged from 25 to 55 years (*M* = 40.00, *SD* = 6.16).

Table 5.1.

Mothers' Demographic Information

Variable		*n*	*Per cent*
Household income	$24,999 or less (low income)	10	10 %
	$25,000 and above (mean or high income)	90	90 %
Education level	High school (grades 10-12)	17	17 %
	Vocational education or some college classes	21	21 %
	College degree	41	41 %
	Post college professional degree (MA, PhD, MD, Law, other)	16	16 %
Employment Status	No paid employment	45	46 %
	Part time	20	20 %
	Full time	34	34 %
Ethnicity	White	86	87 %
	Hispanic or Latino	12	12 %
	Hispanic and/ or Latin American	10	10 %
	Black and/ or African American	2	2 %
	Native American or Aleutian Islander/ Eskimo	1	1 %
	Asian or Pacific Islander	1	1 %
	Other	1	1 %
Marital Status	Single/ separated/ widowed/ divorced	16	17 %
	Married	83	83 %

Measures

Nine measures plus a demographic questionnaire (see Appendix XXIV) were used in this analysis; all measures were completed by mothers of children with ASD.

Demographic Questionnaire. Demographic information was gathered using a questionnaire developed by the research team and included questions about the mother (see table 5.1. for details) and their child with ASD. Socio-Economic Position (SEP) has been associated with maternal well-being in several studies (e.g., Totsika et al., 2011), and so relevant data was gathered and combined several indicators into an index of deprivation. The first indicator was household income, the second was employment status, and the third was maternal educational level. Each indicator was scored dichotomously; educational level was scored 0 (*high school* *education or below*), or 1 (*vocational education, some college classes, college degree, post college professional degree*). Employment status was scored 0 (*no employment*) or 1 (*employment, full or part time*). Household income was scored as 0 (*low income, to $24,999*) or 1 (*income above $24, 999*). This is based on the U.S. Department of Health and Human Services, where the poverty guideline is less than $24,250 for an average of four persons in the household. Total SEP was calculated by summing the scores of these three indicators from the dichotomous coding, a high score indicated low socio economic position (see table 5.2.).

Table 5.2.

Total Deprivation Summed Score for Families

	n	*Per cent*
Low Deprivation (score of 3)	9	9 %
Score of 1	49	50 %
Score of 2	40	40 %
High Deprivation (score of 0)	1	1 %

Maternal Psychological Well-being

Positive and Negative Affect. The Positive and Negative Affect Schedule (PANAS: Watson, Clark & Tellegen, 1988, see Appendix XXV) was used to measure current maternal well-being. Respondents were asked to report their feelings in the present moment by responding to 20 items measuring positive mood (e.g., *inspired*) and negative mood (e.g., *distressed*). Participants responded to the questions based on their mood on that day using a seven-point scale ranging from 1 (*not at all*) to 7 (*extremely*). A total score was then calculated for positive mood by summing the scores on the ten positive items, and the same for the ten negative mood items. A high score is indicative of high levels of that emotion in the mother completing the measure. Possible scores ranged from ten to 70 for both the positive and negative subscales. Watson, Clark, & Tellegen (1988) reported high internal consistency, adequate test–retest reliability, and external validity with measures of distress and psychopathology. Cronbach’s alpha coefficients for the mothers in this study were .84 (Time 1) and .90 (Time 2) for positive affect and .87 (Time 1) and .87 (Time 2) for negative mood.

Depression. Maternal depressive symptoms were assessed using the Center for Epidemiological Studies Depression Inventory (CES-D: Devins et al., 1988; Radloff, 1977, see Appendix XXVI). The CES-D is a 20-item self-report questionnaire designed to assess depressive symptoms in adults. Participants are asked to indicate how frequently they have experienced various symptoms during the previous week, using a four-point scale 0 (*rarely or none of the time*) to 4 (*most or all of the time*). A high score is indicative of higher depression in mothers; to achieve this positively worded items are reverse coded. Previous studies have reported high internal consistency, adequate test-retest reliability, and good criterion and discriminant validity (Devins et al.,1988; Radloff, 1977). Cronbach’s alpha coefficients for the current study were .90 for Time 1 and .91 for Time 2.

Family Functioning. Family Functioning was assessed using the Family Adaptability and Cohesion Evaluation Scales IV (FACES: Olsen, 2011, see Appendix XXVII). The FACES includes six, seven-item subscales; Cohesion, Flexibility, Disengaged (family separateness), Enmeshed (family closeness), Rigid and Chaotic. Four of the subscales are the Unbalanced scales and example items for each include: Disengaged “Family members seem to avoid contact with each other when at home”; Enmeshed “Family members are too dependent on each other”; Rigid “Our family has a rule for every possible situation”; Chaotic “We never seem to get organised in our family”. Two of the subscales are Balanced scales and example items from each include: Cohesion “Family members consult other family members on personal decisions” and Flexibility “When problems arise, we compromise”. All items are answered using a five-point scale 1 (*does not describe our family*) to 5 (*very well* *describes our family*). Higher scores in each scale indicate a high level of the aspect of family functioning which the scale is measuring (e.g., family cohesion). The FACES IV scales have demonstrated adequate reliability and validity (Olsen, 2011). Cronbach's alpha coefficients for each scale were; Cohesion (.82 at T1 and T2), Flexibility (.75 at T1 and .80 at T2), Disengaged (.80 at T1 and .81 at T2), Enmeshed (.64 at T1 and .77 at T2), Rigid (.64 at T1 and .70 at T2), and Chaotic (.85 at T1 and .82 at T2).

Optimism. Maternal Optimism was measured using The Life Orientation Test-Revised (LOT-R: Scheier, Carver, & Bridges, 1994, Appendix XXVIII). The LOT-R was designed to measure generalized optimism and includes ten items asking mothers to indicate their agreement using a five-point scale 1 (*I disagree a lot*) to 5 (*I agree a lot*). Six of the ten items are included in the final score. Sample items include "In uncertain times, I usually expect the best" and "Overall, I expect more good things to happen to me than bad". A high total score indicates high optimism. Adequate internal consistency and validity has been established (Scheier et al., 1994). Cronbach's alpha coefficients in the current study were .84 for Time 1 and .79 for Time 2.

Anxiety. Maternal anxiety was assessed using the State-Trait Anxiety Inventory (STAI: Spielberger 1983; 2002). The STAI is a 40-item widely used self-report measure of anxiety, which measures state anxiety (e.g., current temporary experience of anxiety in specific situations) and trait anxiety (e.g., a general tendency to feel anxious across situations) using two subscales comprising 20 items each. Participants are asked to rate how much each item describes them (currently or in general) on a scale from 1 (*not at all/ almost never*) to 4 (*very much so/ almost always*). In this study the state anxiety subscale was used to measure current anxiety in mothers (see Appendix XXIX). In the STAI a total score is provided for state anxiety, the score ranges from 20 to 80, and a high score is indicative of higher levels of current anxiety. This measure has been used previously with parents of children with ASD and has demonstrated good internal consistency of.91 for the state scale (Reaven et al., 2015; Clifford & Minnes, 2013). The STAI also has good concurrent validity with other anxiety measures (Speilberger et al., 1983) and has shown good levels of inter-item reliability for the state subscale (ranging from .65 to .96) (Barnes et al., 2002). In this present study Cronbach's alpha coefficients for the state scale were .92 for Time 1 and Time 2.

Loneliness. Maternal loneliness was measured using the revised version of the UCLA Loneliness Scale (Peplau, & Cutrona, 1980, see Appendix XXX). The 20-item scale asks participants to describe their feelings of loneliness through non-lonely items (e.g., *I feel part of a group of friends* and *I lack companionship*). The items are rated on a four-point Likert scale ranging from 1 (*never*) to 4 (*always*). The scale has been shown to have good reliability (Russell, 1996). A higher score reflects a higher level of loneliness reported by the mother. Cronbach's alpha coefficients for this current study were .93 for Time 1 and Time 2.

Benefit Finding. Benefit finding was measured using the Post Traumatic Growth Inventory (PTGI: Tedeschi & Calhoun, 1996, see Appendix XXXI for example subscale). The PGTI is a 21-item measure used for assessing positive outcomes when "traumatic events" have been experienced (any life event which may have caused well-being to lesson). Five subscales are included in the scale; Relating to Others (seven items; *I have a greater sense of closeness with others*); New Possibilities (five items; e.g., *I am able to do better things with my life*); Personal Strength (four items; e.g., *I have a greater feeling of self-reliance*); Spiritual Change (two items; e.g., *I have a stronger religious faith*); Appreciation of Life (three items; e.g., *I can better appreciate each day*). Participants responded to each item using a five-point Likert scale ranging from 0 *(I did not experience this change as a result of the incident*) to 5 (*I experienced this change to a very great degree as a result of this incident).* In this study the "incident" is referring to having a child with ASD. The PGTI has good reliability and validity. The PGTI has been used previously with mothers of children with ASD. Cronbach's alpha coefficient for the full scale was .94, and Cronbach's alpha coefficients for the five subscales ranged from .77 to .90 (Zhang, Yan, Du, & Liu 2014). Cronbach's alpha coefficients for the full scale in this study were .89 for Time 1 and .89 for Time 2.

Maternal Moderator Variable

Resilience. Resilience was measured using the Ego-Resilience 89 Scale (ER-89: Block & Kremen, 1996, see Appendix XXXII) and is based on their experience with earlier resilience scales. The ER89 is a 14-item scale focusing on flexibility, curiosity, generosity and social skills. Sample items include "I quickly get over and recover from being startled" and "I am more curious than most people." Participants are asked to respond on a five-point response scale ranging from 1 (*does not apply at all)* to 4 (*applies very strongly)*. Cronbach's alpha coefficients for the current study were .71 for Time 1 and .77 for Time 2.

Maternal Exposure to "Risk"

Current Child ASD Symptoms. The severity of child's current ASD symptoms was measured using the parent report version of the Social Responsiveness Scale (SRS: Constantino, Przbeck, Friesen, & Todd, 2000, see Appendix XXXIII). The SRS is a 65-item scale measuring autistic traits, including social information processing "Concentrates too much on part of things rather than seeing the whole picture" [reverse coded], social use of language "Gets frustrated when trying to get ideas across in conversations", stereotypic/repetitive behaviours/preoccupations "Has repetitive odd behaviours, such as hand flapping or rocking", social awareness "Knows when he/she is too close to someone or invading someone's space", and the capacity for reciprocal social response "Is able to imitate others' actions". Responses to the questions are using a four-point Likert scale ranging from 1(*never true*) to 4 (*almost always true*). The responses are summed from the 65-items to produce a total score (index of autism symptom severity). A higher score indicates a higher level of severity of the child's current ASD symptoms. Prior psychometric studies on the SRS indicate good reliability and validity, with SRS scores being significantly correlated with symptom scores generated by the ADI-R (Constantino et al., 2003). Cronbach's alpha coefficients were .88 for Time 1 and .87 for Time 2.

Procedure

This study was a secondary data analysis, therefore ethical approval was gained in 2013 from the Institutional Review Board at Texas Christian University (see Appendix XXXIV) where the original recruitment was conducted. Participants were recruited through online resources throughout the United States (e.g., blogs, Facebook groups, online autism support groups) and through word of mouth. Mothers who expressed interest in the study were provided with further details about the study and were emailed a unique link to complete all of the questionnaires online using Qualtrics (private online research software; http://www.qualtrics.com/research-suite/). After clicking the link, participants first read and electronically signed the informed consent and then proceeded to complete questionnaires. Participants were given the option to leave questions blank; however, they were prompted to confirm that they wished to proceed after leaving an item blank. Upon completion of the survey, parents were mailed a $10 gift card for a national retailer. Approximately six months later, participants were contacted to complete the second part of the survey. Once again, they were emailed a unique link to the survey and completed the questionnaires online. After completion, parents were mailed another $10 gift card for a national retailer. Due to the nature of the recruitment methods, we are unable to determine the overall response rate for this survey.

Demographic Variables

The demographic variables presented in table 5.1. were recoded dichotomously: maternal employment was re-coded into two categories (no paid employment vs. employed), ethnicity was coded as white Hispanic or Latino versus all other categories, and education was coded into college level and above versus lower than college level. Other categories were dichotomously coded such as child gender (male vs. female).

Results

To assess maternal resilience in cross sectional and longitudinal data, multiple regression analyses were conducted for each of the eight psychological well-being measures (depression, family functioning (five subscales), optimism, positive and negative affect, anxiety, loneliness, benefit finding). Demographic variables that were statistically significant with outcome variables were selected to be included in each of the analyses from bivariate analyses (correlations or *t*-tests). Married mothers reported significantly higher scores on the FACES Rigid scale ($t(86) = -2.40$, $p = .018$). Mothers who had no additional children with ASD in the house had higher scores on the FACES cohesion scale ($t(89) = 2.15$, $p = .034$). Correlations showed that older mothers reported higher scores on the FACES chaotic scale ($r = .24$, $p = .024$). Therefore, age of mother, gender of child, marital status and having additional children with ASD in the house were all included as control variables in the analyses since they were associated at a bivariate level with at least one maternal outcome.

All of the continuous variables were examined for normality using Kolmogorov-Smirnov tests; this showed that all variables were normally distributed and suitable for parametric analysis. Multicollinearity issues between variables were checked using the Variance Inflation Factor (VIF) and the variables showed no multicollinearity problems (all values <10, average >1, tolerance > 0.1) (Bowerman & O’Connell, 1990; Myers, 1990).

Cross-sectional analyses

Cross-sectional analyses were conducted to establish whether maternal resilience functioned as a moderator between the severity of the child’s current ASD symptoms and maternal outcomes (see table 5.3.). Using Time 1 data, moderated multiple regression analyses for each of the eight selected maternal well-being outcome variables were conducted (depression, family functioning (five subscales), optimism, positive and negative affect, anxiety, loneliness, benefit finding). The key predictor entered in each analysis was the severity of the child's current ASD symptoms. Maternal resilience was entered in the analyses both as a main effect and as an interaction variable. Significant demographic variables were entered as control variables. The "PROCESS" custom dialogue box (Hayes, 2012) was installed into SPSS predictive analytics software for the moderated multiple regression analyses. Predictor variables were automatically mean-centred when using the PROCESS dialogue box (the variable mean is subtracted from every value of the variable).

Table 5.3.

Time 1 Cross Sectional Analysis of Maternal Well-being Outcomes

Time 1 Maternal well-being outcomes	Positive affect		Negative affect		Depression		Anxiety		Optimism		Benefit finding		Loneliness	
	R = .308		R = .249		R = .403		R = .387		R = .288		R = .234		R = .450	
	R^2 = .095		R^2 = .062		R^2 = .163		R^2 = .150		R^2 = .083		R^2 = .055		R^2 = .203	
	F = 1.259		F = .796		F = 2.330		F = 2.117		F = 1.089		F = .687		F = 3.012	
	n = 92		*n* = 92		*n* = 92		*n* = 92		*n*= 92		*n*= 91		*n* = 91	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional child with ASD	-1.396	.310	.829	.543	.780	.669	1.925	.340	-.431	.674	.134	.951	3.881	.058
Age of mother	.096	.475	.048	.717	.133	.456	-.081	.681	.096	.475	-.096	.659	.178	.380
Gender of child	3.106	.191	1.860	.428	1.749	.578	1.053	.761	.429	.808	3.805	.311	2.701	.438
Marital status	.495	.596	-.482	.602	-.785	.527	-.015	.991	-.271	.698	1.196	.425	-1.477	.290
Severity of ASD current symptoms	-.035	.238	.052	.081	.106	.008	.115	.009	-.035	.238	.069	.143	.124	.006
Maternal resilience	.175	.262	-.011	.945	-.467	.026	-.412	.073	.175	.262	.161	.524	-.434	.066
Severity of ASD current symptoms x maternal resilience	.005	.338	-.004	.527	.001	.922	.001	.860	.005	.338	-.002	.814	.011	.206

Time 1 Maternal well-being outcomes	Cohesion		Flexibility		Disengaged		Enmeshed		Rigid		Chaotic	
(continued)	R = .490		R = .389		R = .306		R = .309		R = .280		R = .343	
	R^2 = .240		R^2 = .151		R^2 = .094		R^2 = .095		R^2 = .078		R^2 = .118	
n = 88	F = 3.614		F = 2.039		F = 1.184		F = 1.205		F = .972		F = 1.525	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional child with ASD	-1.380	.133	-.275	.760	-.179	.839	-.517	.525	.299	.675	.821	.413
Age of mother	-.236	.014	-.036	.698	.117	.200	-.161	.056	-.036	.625	.250	.017
Maternal resilience	.370	.001	.300	.005	-.238	.023	.044	.641	.123	.142	-.127	.277
Gender of child	-1.964	.215	-2.976	.058	1.845	.228	-.292	.835	-1.359	.272	.368	.832
Marital status	-.250	.694	.721	.251	.056	.927	-.251	.658	-.283	.570	.157	.822
Severity of ASD current symptoms	-.003	.866	.019	.344	.012	.550	.028	.126	.026	.101	.033	.147

Severity of ASD current symptoms x maternal resilience	.001	.776	-.002	.693	.002	.665	-.002	.614	-.004	.190	-.002	.661

Note. Significant (p < .05) associations between variables are in boldface

In the cross-sectional analyses maternal resilience was not found as a significant interaction term in any of the models. However, maternal resilience had a significant independent effect on maternal depression, family balanced cohesion, flexibility, and disengaged subscales. The severity of the child's current ASD symptoms, as reported by the mother, was a significant independent predictor for the maternal outcomes anxiety and loneliness. Age of mother was the only demographic variable to be significantly associated with the FACES subscale balanced cohesion.

Longitudinal analyses

Consistent evidence has been found in previous studies (study two and three in this thesis) that resilience functions as a compensatory variable, and this present study also shows resilience is functioning as a compensatory variable. Therefore, to expand on these initial findings, longitudinal analyses were conducted to identify if maternal resilience at Time 1 predicted later maternal well-being at Time 2 (see Table 5.4.). This longitudinal analyses again used regression analyses for each of the eight selected maternal well-being outcome variables (depression, family functioning (five subscales), optimism, positive and negative affect, anxiety, loneliness, benefit finding). Time 2 well-being outcomes were entered as criterion variables in the regression analyses. The key predictor variables entered in each analysis were Time 1 maternal resilience, plus Time 1 the severity of child's current ASD symptoms, the Time 1 score for the criterion variables, and the four relevant demographic variables selected for the cross-sectional analyses.

This longitudinal multiple regression analyses showed that maternal resilience did not act as a significant predictor of maternal well-being outcomes at Time 2. The only variable to make an independent contribution to the prediction of later maternal well-being was the severity of the child's current ASD symptoms: mothers reported lower benefit finding scores at Time 2 when their child with ASD had more severe symptoms at Time 1.

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Table 5.4.

Longitudinal Analyses of Maternal Well-being Outcomes

Time 2 Maternal well-being outcomes	Positive affect R = .568 R^2 = .323 F = 4.217 *n* = 70		Negative affect R = .514 R^2 = .264 F = 3.177 *n* = 70		Depression R = .607 R^2 = .368 F = 5.164 *n* = 95		Anxiety R = .561 R^2 = .314 F = 4.063 *n* = 95		Optimism R = .687 R^2 = .472 F = 7.912 *n* = 95		Benefit finding R = .659 R^2 = .435 F = 6.703 *n* = 94		Loneliness R = .811 R^2 = .658 F = 16.513 *n* = 94	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional child with ASD	-.070	.521	-.015	.893	-.007	.944	.075	.495	.064	.295	-.063	.528	.013	.869
Age of mother	.112	.324	-.071	.551	.095	.391	-.075	.509	.035	.296	-.036	.731	.002	.984
Gender of child	.066	.561	-.009	.937	.033	.759	.047	.681	-.129	.964	.041	.690	-.077	.347
Marital status	.044	.692	.029	.801	-.007	.949	-.112	.314	.048	.361	-.085	.403	-.003	.965
Maternal resilience Time 1	-.040	.718	-.078	.493	-.150	.175	-.843	.554	.140	.651	.037	.715	-.078	.343
Severity of child ASD current symptoms Time 1	-.132	.224	.102	.370	.149	.175	.067	.402	-.148	.120	-.212	**.039**	.120	.162
Outcome Time 1	.523	**<.001**	.470	**<.001**	.484	**<.001**	.481	**<.001**	.600	**<.001**	.633	**<.001**	.743	**<.001**

Time 2 Maternal well-being outcomes continued	Cohesion R = .777 R^2 = .603 F = 12.587 *n* = 91		Flexibility R = .739 R^2 = .546 F = 9.956 *n* = 91		Disengaged R = .648 R^2 = .420 F = 5.999 *n* = 91		Enmeshment R = .692 R^2 = .479 F = 7.621 *n* = 91		Rigid R = .618 R^2 = .381 F = 5.110 *n* = 91		Chaotic R = .693 R^2 = .481 F = 7.672 *n* = 91	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Additional child with ASD	.064	.479	.038	.686	.122	.246	.038	.705	.195	.094	.057	.570
Age of mother	.035	.699	-.032	.738	.084	.444	.006	.955	-.219	.157	.079	.465
Gender of child	-.129	.158	-.021	.830	.049	.655	.025	.806	-.187	.307	.111	.286
Marital status	.048	.584	-.004	.964	-.166	.112	.001	.995	.193	.626	.135	.169
Maternal resilience Time 1	.140	.134	.135	.173	.519	.078	.025	.807	.034	.639	-.047	.643
Severity of child ASD current symptoms Time 1	.008	.922	.027	.772	-.075	.471	-.114	.266	.046	.672	-.053	.593
Outcome Time 1	.699	**<.001**	.684	**<.001**	.519	**<.001**	.719	**<.001**	.518	**<.001**	.656	**<.001**

Note. Significant (p < .05) associations between variables are in boldface, longitudinal results are shown after accounting the Time 1 score in each outcome

Discussion

The cross-sectional analyses were as hypothesised, and found maternal resilience had a significant independent effect on four maternal outcome variables including depression, the FACES scales of balanced subscales cohesion and flexibility, and the FACES unbalanced subscale disengaged; therefore, we found the strongest support for a compensatory model of resilience, as in chapter 3 (study 2). As discussed previously, the compensatory model is where risk factors have a direct main effect, reducing negative outcomes directly, thus overall the presence of resilience in a mother of a child with ASD has a positive impact on their well-being. This suggests that, overall, the presence of resilience in a mother has a positive impact on their well-being. The longitudinal analyses found maternal resilience did not act as a significant predictor of maternal well-being outcomes over time.

In the cross-sectional analysis the severity of the child's current ASD symptoms, as reported by the mother, had a significant independent effect on both anxiety and loneliness in mothers of children with ASD. This is consistent with previous research which found that severity of the child's ASD symptoms had a negative effect on maternal outcomes, such as anxiety, (e.g., Firth & Dryer, 2013). The longitudinal analyses showed high severity of the child's ASD symptoms predicted lower benefit-finding in mothers over time.

The longitudinal analyses results are not as hypothesised, as resilience did not predict maternal well-being outcome over time. Therefore, this contradicts previous researcher's theories about resilience predicting well-being over time (e.g., Bayat, 2007). When considering these results there are several study limitations and possible future research directions to be discussed. This longitudinal analysis was also able to test the challenge model, which is a theoretical perspective on resilience that suggests when exposed to low levels of risk, resilience builds over time (Fergus & Zimmerman, 2005; Brook, Whiteman, Gordon, & Cohen, 1986; 1989). This is based on the assumption that child ASD symptoms and thus child behavioural and emotional problems would act as a low level consistent “risk” in this theory. As this study found resilience did not predict maternal well-being over time, it is possible that on-going exposure to risk in these families may have increased their resilience over time and this may be reflected in the data from cross-sectional analyses- resilience functioning as a compensatory factor to improve maternal well-being. It is possible that in a sample of mothers of children with ASD, “low risk child behavioural and emotional problems”, such as the severity of the child’s ASD symptoms is actually “high risk child behavioural and emotional problems” when compared to families of children without ASD. It is known from previous literature (e.g., Emerson et al. 2011) child behavioural and emotional problems in families of children with IDD are high, and even higher than other families who have a child with ASD, therefore high risk in the current study might constitute “extremely high risk.” Therefore, theoretically families of children with ASD may have already built up significant resilience at a high or extremely high risk in response to their child’s behaviour, and this could be a possibility as to why the longitudinal analysis was not found to work in the expected way- resilience predicting well-being outcomes over time.

Mothers did provide all the data in this study which means there was a lack of source variance; however, this is common in IDD research due to recruitment approaches. Future research will need to incorporate independent or multiple informant approaches for key constructs to address source variance (e.g., child behavioural and emotional problems).

Another consideration for these unexpected longitudinal findings is the discussion of the selected resilience measure (as discussed previously in studies three and four). This current study is the first to use the ER-89 with mothers of children with ASD, and therefore this ER-89 measure, and the resilience measures currently available, may not be capturing resilience in these families. However, Cronbach’s alpha coefficients were good in the current study for the ER-89 (.71 for Time 1 and .77 for Time 2).This does give a clear direction for future research. Much more research is needed to clarify what these “resilience measures” are capturing. The attributes of “resilience” captured in the ER-89 suggests these do have an association with maternal outcomes, for example identifying one’s ability to “get over things quickly” suggests successful coping mechanisms. This is consistent with the findings in study two of this thesis, which also showed that the resilience measures being tested are capturing factors which are associated with maternal well-being outcomes. The resilience measure for this scored highly in a reliability and validity assessment (Windle, 2011). However, it is clear there are gaps to further develop resilience measures in future research, based on current definitions, or in particular with this population of children with ASD and their families given the specific challenges faced- such as high levels of child behavioural problems. Another consideration is the theory and discussion in literature of whether resilience can be captured in a measure, or if it is a process that unfolds over time. Social psychologists generally think of resilience as a trait-like phenomenon whereas developmental psychologist tend to think of resilience as something that develops over time (e.g., see Masten, Powell & Luthar, 2003; Masten & Obradović, 2006)

Another limitation to this study, and another possible explanation for the non-significant findings in the longitudinal analyses, is the time period between the two data points. The six-month time period between the two data points was not enough time for well-being outcomes to change. Previous research with families of children with ASD (e.g., Shattuck et al., 2007) conducted longitudinal analyses for a time period of four and a half years, to reflect the changes seen in child behavioural and emotional problems over adolescence. This study showed that over time as child behavioural and emotional problems decreased, maternal well-being improved. Therefore, future research should consider a longer time frame for follow up, to follow changes to child behavioural problems, and also to see if resilience has built in this time, and if these predict maternal well-being.

These findings may have some practical implications. The finding that maternal resilience is associated with maternal well-being may be used to inform clinical practice in improving well-being in mothers of children with ASD. In particular, it would be beneficial to directly try and build resilience in mothers to improve their well-being. One aspect that can currently be explored further is that it is important to examine attributes of “resilient mothers”, for example through the measure questions where mothers scored highly compared to other mothers, group comparisons can be made between different disabilities or with a group of mothers with typically developing children. This can also be explored further qualitatively to gain descriptive information on what mothers of children with IDD think makes them resilient. Several of the questions in the ER-89 could be linked to maternal well-being, for example self-esteem “I usually succeed in making a favourable impression”. Self-esteem has been linked in the general population to mental health problems. It has also been identified as a protective factor (Mann, Hosman, Schaalma & Vries, 2004).

Therefore, addressing specific questions in the resilience measures which are linked to previous research and intervention is a current practical implication for clinicians. Other well-being aspects such as self-efficacy in mothers has been shown as a protective factor, and to have a relationship with the severity of a child with ASD symptoms, in particular in mother child relationships (see Jones & Prinz, 2005 for a review). It is clear from this study that the severity of a child’s current ASD symptoms has an effect on well-being, in particular loneliness, and exploring aspects such as self-efficacy or self-esteem in parents may be important in these relationships. Exploration of these aspects and associations with resilience is needed to develop understanding of well-being in families of children with ASD.

Alternative findings

A second measure of resilience used with mothers of children with ASD was included in this study. As this study was a secondary data analysis, the measures were already selected before the data analysis for this paper began. However, upon discussing the reasoning behind the selection of the resilience measure, it was clear a similar thought process had occurred as with study two and three measure selections, looking at validity and length. The Ego-Resilience 89 scored highly in reliability and validity in past research, and was also of a reasonable length to be included within a survey.

Future research could explore resilience over a longer longitudinal time frame than was explored in this study. In study four the time frame was six months, and therefore there may not have been enough change in a mothers' life to show resilience is a predictor. It is possible the cross-sectional data is capturing resilience in relation to well-being outcomes at that one time, but this may be changeable over time, so the results may not be consistent in replicating cross-sectional studies. Arguably is "resilience" something you can really capture in a measure? Or is it a process that unfolds over time, if so, how is this followed within a research study.

Masten et al. (2004) found seven individuals made the change from a maladaptive coping style to a resilience coping style over the transition to adulthood in comparison to their peers. The factors that distinguished these individuals were "planfulness", future motivation, autonomy and adult support outside the family. Support is a known factor in improving well-being and it one element that may be linked to resilience which may be able to be measured over time by measuring perceived support and actual support of the individual. Therefore, these related factors could be looked at as a way of monitoring well-being over time. Studies show 'factors' of resilience, and what children and young people think makes them resilient and what adults think makes them resilient. If Rutter's (2012) description that resilience is reliant on environmental factors we may be able to measure resilience based on these changes in environmental factors over time. There is also the theory of steeling effects. Steeling effects is the exposure to stresses or adversities may either increase vulnerabilities through a sensitisation effect (Lyons et al. 2010). These theories require careful thought in planning future research.

Chapter 6: Overall Discussion

Parenting a child with IDD is a difficult but rewarding process, with much variation in parental well-being reported in research over the years. It is important to understand mechanisms that can influence and possibly improve these well-being outcomes in parents of children with IDD. This thesis has begun to explore the concept of resilience, as well as related factors, in an attempt to begin to understand whether resilience can work to improve overall maternal well-being. In this thesis resilience has begun to be explored in children with IDD through quantitative measures, which has only been explored in one paper previously (Ruiz-Robledillo et al., 2014). The findings in this thesis suggest that the protective measures are factors which have a relationship with well-being outcomes, as evidenced in all four studies. Studies two and four show maternal resilience had a significant main effect relationship- thus a compensatory effect- on the maternal well-being outcomes. Study three showed child resilience had a significant main effect- thus again a compensatory effect- on child behavioural and emotional problems. However, previous definitions of resilience suggest that resilience should work as a moderating factor in these relationships, but no evidence of this was found in these studies. Therefore, the questions remain- what exactly is resilience and can it be defined further? Can clear factors of resilience be identified to be useful in designing interventions to improve maternal well-being or child behavioural and emotional problems?

First in this thesis, the introduction is made of child behavioural and emotional problems, maternal well-being, and possible related factors which may work as a protective factor in this relationship. Chapter one identifies gaps in the literature, or where few studies are available. What is clear is that resilience is a highly subjective process, dependent on many factors, including experiences in life, personality characteristics, and social support. The definitions of resilience used in this literature varies and some definitions are from the 1980s (e.g. Rutter), therefore, there is a question of how the perception of resilience may have changed in time to the present day. This chapter also highlighted the way resilience is measured in current research is varied and inconsistent. This indicates two factors which would be useful to develop in future research, one is the concept of resilience, specifically in families of children with IDD, whose experiences vary from families of children without IDD, and secondly there is a need of consistently measuring what it is to be resilient.

Chapter two (study one) was a secondary data analyses which explored potential protective factors between child behavioural problems and maternal well-being. The data showed that perceived social support was a strong protective factor when child behavioural problems were high. It was also found that low levels of support were not as effective as high levels of support, as lower levels were associated with lower levels of life satisfaction and the positive affect of having a child with IDD, and higher levels of depression in mothers than high levels of support. These results showed the importance of mothers having good social support. These findings were also consistent with previous research (e.g. Smith, Greenberg, & Seltzer, 2012; Asberg et al., 2008; Glidden et al., 2006; Plant & Sanders, 2007). The main finding in this study was useful in clinical practice, as social support is important in maintaining healthy well-being in mothers of children with IDD.

Chapter three (study two) of this thesis began to explore resilience as a protective factor in mothers of children with IDD. This chapter also explored the theoretical perspectives of how resilience functions, as a protective factor, or as a compensatory factor. This chapter showed the strongest support for a compensatory model of resilience. However, we found that higher levels of resilience were associated with better maternal outcomes at low levels of child behavioural and emotional problems as opposed to high levels of child behavioural and emotional problems- the latter was expected. This was the first study to test resilience as a compensatory or protective factor in a moderator regression analysis in mothers of children with IDD and showed a need to develop the resilience literature further.

This study may have some practical implications. In particular, it would be beneficial to directly try and build resilience in mothers to improve their well-being and the aspects captured in the measure used (such as “I look for creative ways to alter difficult situations”) would be a good base for this. In clinical practice these thought process are often explored in Cognitive Behavioural Therapy and thus there is potential to develop a workshop, or an intervention to improve well-being by using the questions in the resilience measure to work from.

Chapter four (study three) was the first study to explore child resilience in children with IDD. This chapter showed that maternal depression and child resilience are both associated with child behavioural and emotional problems, and in addition maternal depression was found to have a positive relationship with child behavioural and emotional problems. Again this chapter found strong support for the compensatory model of resilience. It is suggested that future research could develop a proxy resilience measure, and also to develop the option for self-report. It would be very interesting to compare mother and child reports of the child’s resilience. This study also has clinical implications; for the aspects captured in the resilience measure to be considered when addressing child behavioural and emotional problems, and there is a question of can these be developed into an intervention with the child or wider family?

Chapter five (study four) was the final study in this thesis, which looked at resilience longitudinally. Again, resilience was found in mothers of children with ASD to act as a compensatory factor, thus supporting the findings in chapters three and four. However, maternal resilience did not predict maternal outcomes over time. It was found that the severity of child ASD symptoms did predict maternal well-being over time, which is consistent with previous research. This study was longitudinally over six months and thus arguably a longer time frame is needed to capture changes over time. Future research would be to explore this in a more complex manor, to capture life events, well-being, and child behaviour over time in the family to build a picture of what aspects of resilience predict well-being longitudinally. This study was also an opportunity to develop collaborations with international researchers and universities on a shared interest of resilience, which is both useful and interesting and gives context to resilience research outside of the UK. More research studies have been discussed and planned to develop the resilience field further with these international collaborations.

Future research

Developing a different resilience measure

While the research in this thesis makes several unique contributions to the literature surrounding children with IDD and their families, there are limitations identified.

The largest limitation, which is also interesting to explore, is the complex nature of resilience. This included a lack of an accepted definition of the concept, difficulty in measure selection, using measures not validated for this population, measures which are known to use different theoretical literature to measure the concept of ‘resilience’. However, the idea of overcoming adversity overlapped throughout these measures and did show to be associated with improving overall well-being in mothers of children with IDD.

As mentioned previously, all of the resilience measures were based on different perceptions of resilience and different literature, however the most common definition mentioned in the background literature to these measures was the Rutter definition of resilience, and therefore this seemed to provide a common theoretical background between measures. Despite this, the three measures had arguably little overlap. For example the four questions in the Resilience scale were: “I actively look for ways to replace losses I encounter in life”, “I believe that I can grow in positive ways by dealing with difficult situations”, “I look for creative ways to alter difficult situations”, “Regardless of what happens to me, I believe I can control my reaction to it". The questions in the proxy measure included "My child usually manages one way or another", "My child keeps interested in things", "My child feels their life has a sense of purpose", "My child finds life really worth living", "My child believes their life has meaning".

Table 6.1. presents the different resilience measures included in studies two, three and four. Potential overlaps have been highlighted; red shows questions which suggest an interest in things; green shows questions which relate to the control of emotions; and blue shows questions relating to reactions of situations. Interestingly there isn't an overlap between all three measures, showing that there is a lack of consistency in measures about what is actually being measured or the questions to measure resilience. It is clear there would be some use for establishing some consistency across resilience research, for example in the measures used in this population, and also the possible development or adaptation of a scale which addresses some of the specific factors faced by families of children with IDD.

Table 6.1.

Overlap Between Resilience Measures

Resilience Scale (used in study two)	Proxy measure (used in study three)	Ego Resiliency Scale (used in study four)
I actively look for ways to replace losses I encounter in life	My child usually manages one way or another	I am generous with my friends
I believe that I can grow in positive ways by dealing with difficult situations	My child keeps interested in things	I quickly get over and recover from being startled
I look for creative ways to alter difficult situations	My child feels their life has a sense of purpose	I enjoy dealing with new and unusual situations

Regardless of what happens to me, I believe I can control my reaction to it	My child finds life really worth living	I usually succeed in making a favourable impression on people
	My child believes their life has meaning	I enjoy trying new foods I have never tasted before
		I am regarded as a very energetic person
		I like different paths to familiar places
		I am more curious that most people
		Most of the people I meet are likeable
		I usually think carefully about something before acting
		I like to do new and different things
		My daily life is full of things that keep me interested
		I would be willing to describe myself as a ‘pretty strong personality’
		I get over my anger at someone reasonably quick

Bringing together the literature bases and knowledge of protective factors and successful coping mechanisms may provide an accurate measure of resilience. It is important that a resilience measure is first of all contextual to the risk/ stressor being experienced. For example, within a school, having a disability, experiencing bereavement; but each of these have common factors that could be brought together to give an individual a “high score” which we would hypothesise gives the tools to be “resilient”. Previously identified individual protective factors that are promoting positive outcomes against the effects of adversity include; self-esteem (Murry et al. 2001; Edari & McManus, 1998; Stewart et al. 1997), positive self-concept (Edari & McManus, 1998; Kitano & Lewis, Wand et al. 1997; Waxman et al. 2003; Werner, 2000); positive ethnic or racial identify (Samaan, 2000, Gonzales & Kim, 1997, Wallace, 1999); religious beliefs (Meschke & Patterson, 2003; Wener, 2000); positive orientation to a person’s environment (Edari & McManus, 1998); high educational expectations (Nettle & Pleck, 1996; Waxman et al. 2003); strong achievement motivation (Wang et al. 2003; Werner, 2000); optimism (Stewart et al. 1997); internal locus of control (Edari & McManus, 1998; Stewart et al. 1997; Werner, 2000); self-efficacy (Murry et al. 2001; Coleman & Karraker, 1998); easy-going temperament (Edari & McManus 1998; Stewart et al. 1997).

Previously identified skills as protective factors that are promoting positive outcomes against the effects of adversity include: general and social competence (Edari & McMans 1998; Meschke & Patterson, 2003), social skills (Edari & McManus, 1998; Wang et al, 1997, 1999), intelligence and academic skills (Edari & McManus, 1998; Stewart et al. 1997; Werner, 2000), Cognitive skills (Stewart et al. 1997, Werner, 2000), problem solving skills (Southwich et al. 2005, Stewart et al. 1997). It should be noted that intelligence could also be a vulnerability factor (Kitano & Lewis, 2005).

Family factors have also been identified as protective in the face of adversity; parent-child relationships affect adjustment (Stewart et al. 1997, Wang et al. 1999), a warm, cohesive, supportive family environment with strong communication (Gonzales & Kim, 1997, Taylor & Wang, 2000). Social support networks are a clear protective factor (e.g. Murry et al. 2000; Gorman-Smith & Tolan, 2003). These have also been shown to affect well-being positively providing emotional support and caring (Samaaan, 2000, Wang et al. 1999) and a sense of belonging (Edari & McManus, 1998).

For young people the school environment is key in protecting children (Lynch, 2003; Meschke & Patterson, 2003), this includes positive classroom practices and high teacher expectations (Taylor & Wang, 2000), a positive school environment, such as participation and positive social interactions among peers and teachers (Meschke & Patterson, 2003; Stewart et al. 1997; Wang et al. 1997).

All of these factors could be developed into a modular type measure dependent on the context of the risk and also the developmental age of the individual. This would also identify gaps for practitioners to focus on when providing help and guidance to an individual. When exploring further the possibility of developing future measures, it would be useful to use a qualitative research approach to look at more meaning and detail into resilience, and what resilience means to that person and if they rate themselves as resilient. Several protective factor measures were used in this thesis which would provide a starting point for this measure design, including Optimism (LOT-R: Scheier, Carver, & Bridges, 1994), positive affect (PANAS: Watson, Clarke, & Tellegen, 1988), self-leadership (The brief 20-item Self Leadership Scale; SLS: Steinhardt, Dolbier, Mallon, & Adams, 2003). Symptomatology was also assessed using the Center for Epidemiologic Studies Depression Index (CES-D: Radloff, 1997), negative affect scale (PANAS), perceived stress scale (PSS: Cohen, 1988), and symptoms of illness (Symptoms Checklist: Bartone et al., 1989).

Further research

There are several studies which have shown the importance of family in supporting resilience. Bayat (2007) identified the need to pull resources together and being connected as a family as two necessary factors for resilience. In additional 62% of families defined themselves as becoming closer as a result of having a child with a disability, and 63% of data contained the family becoming more compassionate, less selfish, and more mindful of individual differences. As well as finding healthier perspectives on life. It was also identified that families did not always find it easy to unite and work together. However, often families reported that ultimately having a child with disabilities has made them stronger (e.g. "*Autism has made us stronger and more cohesive, my children are very protective of their sister".)* Svetaz (2000) found that adolescents with learning disabilities were as likely to report that they feel connected to their families as the comparison group. However, they were less likely to report that they engaged in activities with their parents.

When looking at the wider literature to explore potential resilience interventions that may be suitable to be adapted for use with parents. One intervention fits with much of the discussion in this thesis. The resilience intervention included four two hour classroom sessions with university students to learn how to manage change and difficult situations more effectively (Steinhardt & Dolbier, 2008). The intervention included sessions on transforming stress into resilience; four typical responses to stress were discussed, including give up, put up, bounce up, and step up. Activities were conducted within the sessions to reinforce these decisions. Two coping mechanisms were discussed in the sessions, problem based and emotion focused coping, this was the focus of session one. It has been established previously in this thesis that problem based coping is more effective. Session two focused on taking responsibility, owning one's power to choose and create. Examples of denial, blaming, and making excuses were given. A diagram was presented for each case with a line, the aim was to get above the line, and participants engaged in a five-step process to help move above the line, this was also linked with self-esteem (a factor discussed previously as being related to resilience). Session three focused on empowering interpretation and this used the ABCDE thinking model by Albert Ellis (Ellis, 2001). A is for activating the event or stressor, B is for belief and represents the disempowering interpretations, C is for consequence, D for disputing the disempowering beliefs, and E for the amount of energy one has available. This model has been adapted and used with adults with ID successfully in the context of cognitive behavioural therapy (Oathamshaw & Haddock, 2006) and with parents of children with ID (Jones & Passey, 2004). Session four of the intervention was about self –leadership and creating meaningful connections. This theme of creating meaningful connections is apparent in the resilience ID literature. Participants were taught that experiencing self-leadership is essential to taking responsibility, focusing on empowering interpretations. A number of outcome measures were used including the Connor-Davidson Resilience Scale (CD-RISC: Connor & Davidson, 2003), the Dispositional Resilience Scale (Bartone, Ursano, Wright & Ingraham, 1989), and the Brief Coping Orientations to problems experienced Scale (Brief COPE: Carver, 1997).

An ideal study for future research would be to engage parents of children with ID into workshops or an online system that worked through ways to improve aspects that they felt they needed help with or to improve on. Modules might include social skills, positive thinking, self-efficacy, optimism, and positive parent-child relationships. Parents can then engage in the module at a time in their life when they feel they need it, so this provides a very flexible, fluid approach to resilience and it changing over time. Parents could do each section as many times as necessary over time and this design would provide ongoing support to parents. In addition to widen the intervention, an online workshop could be designed to be available to parents to increase the number of participants, and provide the flexibility needed for families who may not be able to travel to attend workshops. This could run alongside face to face workshops. In addition, these groups would provide a meeting point for families of children with IDD, which is known to be beneficial.

Practical implications

Our findings may have some practical implications. In particular, it would be beneficial to directly try and monitor perceived social support in mothers of children with IDD, and to encourage mothers to find support in local support groups provided by charities or other forms of support, to improve their well-being. Secondly, practical coping and social support could be explored further in terms of an intervention to improve well-being; however literature is very minimal when exploring interventions in parents of children with IDD so this would have to be developed.

However, interventions to directly improve child behavioural and emotional problems in children with IDD have been identified, such as providing materials of information, workbooks and videotapes for parents, and therapist instructions, which have been shown to reduce parental stress, and parents reported high levels of satisfaction (Hudson et al., 2003). A meta-analysis showed that a number of interventions have been successful in improving positivity, and therefore well-being (Sin & Lyubomirsky, 2009). Several positive psychology interventions were found to be effective in improving well-being, such as a person identifying their strengths and using their signature strengths in new ways (Seligman, Steen, Park, & Peterson, 2005); cognitive strategies- e.g. replaying positive experiences and self-monitoring well-being (Fava, Rafanelli, Cazzaro, Conti, & Grandi, 1998); and practicing emotional skills such as mindfulness and acceptance (BÉdard et al., 2003; Grossman, Tiefenthaler-Gilmer, Raysz, & Kesper, 2007). It may be that the previous research into what we suspect to be aspects of resilience, such as positivity, may help form a resilience intervention, which would also help develop a clear concept of resilience. Exploration of these types of interventions which focus on aspects of resilience for families of children with IDD is needed in future research.

The idea of resilience may still be unclear; however, knowledge of these protective factors/ coping mechanisms would enable practitioners to be alerted to vulnerable individuals in their service. Practically taking this research forward a package of interventions would work in terms of addressing specific risk areas. Inclusive school approaches have been shows to be beneficial (Kitano & Lewis, 2005; Maddox & Prinz, 2003, Wang et al. 1997) as well as skills related programs (Nettle & Pleck, 1996; Pincus & Friedman, 2004). A short intervention on building social support and social networks (Berkman, 1995; Taylor et al. 2002) as well as family focused interventions (Berkman 1995; Stewart et al. 1997) would be a good starting point for practice.

Dissemination

All four empirical chapters in this thesis are intended to be published in peer reviewed journal articles. Throughout the time researching in this PhD conferences have been attended to present posters and presentations. I was awarded the dissertation travel award for the Gatlinburg Conference 2016 for study two. See Appendix XXXV for a list of publications I contributed to during my PhD.

Conclusions

To conclude, this thesis demonstrated the relationship between child behavioural problems and maternal well-being, in addition to exploring additional factors such as resilience which may influence this relationship. This thesis has provided a unique contribution to the field of resilience in IDD research and has provided some evidence that resilience works as a compensatory factor in improving maternal well-being. What we do know from this thesis is that using the three resilience measures tested, resilience does not function in the expected way, as a moderating variable. This could be because of the concept of resilience, or the measures used to measure it. This discussion explores future research and interventions, which include many directions and therefore not all have been discussed in great detail, however this discussion does show the need and scope for future research in this resilience area and also how the research in this thesis can be used to inform these potential future interventions and measures.

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Appendix I

Demographic questionnaire

The following questions ask for background information about you and your child with special needs. Please tick the appropriate boxes or write in the space provided.

1) **What is your relationship to looking after your child?**

Primary Carer ☐ Secondary Carer ☐

2) **Are you male or female?**

Male ☐ Female ☐

3) **What is your age in years on your last birthday?……………………..**

4) **What is your current marital status?**

Married ☐ Living together ☐ Divorced ☐

5) **In total how many people currently live in your house?**

Adults……………… Children……………………..

6) **Please tick the boxes next to all of the educational qualifications that you hold**

No qualifications ☐ GCSE ☐ HNC ☐

A levels ☐ University Degree ☐ Post graduate ☐

7) **Are you currently employed?**

Yes ☐ No ☐

8) **If so, do you work full time or part time?**

Full time ☐ Part time ☐

9) **What is your relationship to your child with special needs (e.g., mother, father, adoptive mother/father, foster mother/father)?**

....

10) How old is your child with special needs? ………..years………..months.

11) Is your child male or female? Male ☐ Female ☐

12) Which school does your child attend? ……………………………………………..

13) Do you have respite available to you for your child with special needs?

Yes ☐ No ☐

14) If yes, do you use this available respite?

Yes ☐ No ☐

15) Please tick the boxes below to indicate any diagnosis/ conditions that apply to your child with special needs?

Learning Disability (“Intellectual Disability)………………………….. ☐

Autism……………………………………………………………..... ☐

Aspergers………………………………………………………….. ☐

Down’s Syndrome………………………………………………… ☐

Cerebral Palsy…………………………………………………….. ☐

ADHD……………………………………………………………. ☐

Other diagnosis (please specify)………………………………………

16) Does your child with special needs have a sensory impairment which interferes with his/her day to day life?

No Sensory problems …………………………………………….. ☐

If so, what is your child’s impairment?

Visual impairment……………………………………………….. ☐

Hearing impairment………………………………………………. ☐

17) **Does your child with special needs currently suffer from epileptic fits?**

Yes ☐ No ☐

18) **Does your child with special needs have problems with mobility, that means it is difficult for them to move around independently (e.g., wheelchair user)**

Yes ☐ No ☐

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

Yes ☐ No ☐

If yes, please specify……………………………………………………………………….

20) **Does your child with special needs live with you?**

☐ Lives with respondent

☐ Lives with other parent

☐ Stays some time with other

☐ Stays some time with respondent

☐ Residential home

☐ Residential home with spends holidays with respondent

Appendix II

The Hospital Anxiety and Depression Scale (HADS)

Appendix III

The Satisfaction with Life Short Scale

Below are five statements that you may agree or disagree with. Using the 1-7 scale below indicate your agree with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7- Strongly agree
- 6- Agree
- 5- Slightly agree
- 4- Neither agree nor disagree
- 3- Slightly disagree
- 2- Disagree
- Strongly disagree

1. _____ In most ways my life is close to ideal.
2. _____ The conditions of my life are excellent.
3. _____ I am satisfied with my life.
4. _____ So far I have gotten the important things I want in life.
5. _____ If I could live my life over, I would change almost nothing.

Appendix IV

The Positive and Negative Affect Schedule (PANAS)

This scale consists of a number of words that describe different feelings and emotions. Read each item and then click on the response on the dropdown list next to the word and select one of the responses. **Indicate to what extent you feel this way right now, that is, at the present moment.**

	Very slight of not at all	**A little**	**Moderate**	**Quite a bit**	**Extremely**
1. Interested	1	2	3	4	5
2. Excited	1	2	3	4	5
3. Strong	1	2	3	4	5
4. Enthusiastic	1	2	3	4	5
5. Proud	1	2	3	4	5
6. Alert	1	2	3	4	5
7. Inspired	1	2	3	4	5
8. Determined	1	2	3	4	5
9. Attentive	1	2	3	4	5
10. Active	1	2	3	4	5

Appendix V

The Short Support Functions Scale

Name____ Date____________

Listed below are 12 different types of assistance which people sometimes find helpful. This questionnaire asks you to indicate how much you need help in these areas. Please *circle* the response that best describes your needs. Please answer all the questions.

To what extent do you have or feed a need for any of the following types of help or assistance:		Never	Once in a While	Sometimes	Often	Quite Often
1.	Someone to talk to about things that worry you	1	2	3	4	5
2.	Someone to help take care of your child	1	2	3	4	5
3.	Someone to talk to when you have questions about raising your child	1	2	3	4	5
4.	Someone who loans you money when you need it	1	2	3	4	5
5.	Someone to encourage of keep you going when things seem hard	1	2	3	4	5
6.	Someone who accepts your child regardless of how (s)he acts	1	2	3	4	5
7.	Someone to help with household chores	1	2	3	4	5
8.	Someone to relax or joke with	1	2	3	4	5
9.	Someone to do things with your child	1	2	3	4	5
10.	Someone to provide your child transportation	1	2	3	4	5
11.	Someone to hassle with agencies or individuals when you can’t	1	2	3	4	5
12.	Someone who tells you about series for your child or family	1	2	3	4	5

Appendix VI

The Shortened Ways of Coping Questionnaire

We would like to know how you cope with everyday experiences. Obviously there are many different ways of coping but we are interested in the way that you have been dealing with your child with special needs. Each item below says something about a particular way of coping and we are interested in to what extent you have been doing this, to cope with stressful situations. Do not answer on the basis of whether it seems to be working or not, just whether you are doing it or not.

		Not used	Used Somewhat	Used Quite a Bit	Used a Great Deal
1.	I daydream or imagine a better time or place than the one I am in	1	2	3	4
2.	I draw on my past experiences	1	2	3	4
3.	I think up a couple of different solutions to problems	1	2	3	4
4.	I wish that I could change how I feel	1	2	3	4
5.	I try to come out of experiences better than when I went in	1	2	3	4
6.	I wish I could change what has happened	1	2	3	4
7.	I try to analyse the situation in order to understand it better	1	2	3	4
8.	I usually know what has to be done, so I keep up my efforts to make things work	1	2	3	4
9.	I take it out on other people	1	2	3	4
10.	I avoid being with people in general	1	2	3	4
11.	I have fantasies or wishes about how things might turn out	1	2	3	4
12.	I stand my group and fight for what I want	1	2	3	4
13.	I wish that the situation would go away or somehow be over with	1	2	3	4
14.	I make a plan of action and follow it	1	2	3	4

Appendix VII

The Positive Contributions Scale from the Kansas Inventory of Parental Perceptions (KIPP)

MY CHILD_____________IS:

The blank space after the word "child" is there to remind you to think only of your child with special needs when you answer each statement.

Reach each statement and circle the one response that best described how much you agree or disagree with each statement. The answers and their meanings are:

1= STRONGLY DISAGREE

2=DISAGREE

3= AGREE

4= STRONGLY AGREE

Part A

MY CHILD______IS:

1.	The reason I attend religious services more frequently	1	2	3	4
2.	Why I met some of my best friends	1	2	3	4
3.	The reason my life has better structure	1	2	3	4
4.	Why I am a more responsible person	1	2	3	4
5.	The reason I've learned to control my temper	1	2	3	4
6.	Responsible for my learning patience	1	2	3	4
7.	Responsible for my increased awareness of people with special needs	1	2	3	4
8.	Fun to be around	1	2	3	4
9.	The reason I am more realistic about my job	1	2	3	4
10.	Responsible for my being more aware and concerned for the future of mankind	1	2	3	4
11.	Kind and loving	1	2	3	4

12.	Helpful to other family members, which saves time and energy for me	1	2	3	4
13.	A source of pride because of his/her artistic accomplishments	1	2	3	4

Part B

I CONSIDER MY CHILD______TO BE:

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

Part C

THE PRESENCE OF MY CHILD______:

26.	Is an inspiration to improve my job skills	1	2	3	4
27.	Helps me understand people who are different	1	2	3	4
28.	Is a source of pride because of his/her athletic achievements	1	2	3	4
29.	Cheers me up	1	2	3	4
30.	Confirms my faith in God	1	2	3	4

31.	Gives a new perspective to my job	1	2	3	4
32.	Renews my interest in participating in different activities	1	2	3	4
33.	Is very uplifting	1	2	3	4
34.	Is a reminder that all children, including those with special needs, need to be loved	1	2	3	4
35.	Is a reminder that everyone has a purpose in life	1	2	3	4
36.	Makes us more in charge of ourselves as a family	1	2	3	4
37.	Helps me take things as they come	1	2	3	4

Part D

BECAUSE OF MY CHILD______:

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

Appendix VIII

The Reiss Scales for Children's Dual Diagnosis (Mental Retardations and Psychopathology)

INSTRUCTIONS

The test presents a list a maladaptive behaviours that could create problems in the lives of children with mental retardation. Each item on the list is defined. A few examples are given for each item to help you understand the meaning of the definition.

Your task is to read each item and tell us if you think that the item is **currently NO PROBLEM,** a **PROBLEM,** or a **MAJOR PROBLEM** in the child's life. Please keep in mind that we do not want to know simply if the behaviour occurs; what we would like is your opinion if the problem occurs with sufficient frequency with sufficient intensity, or under sufficiently strange or inappropriate circumstances, so that the behaviour category is a problem of a major problem in the child's life.

RATING SCALE

No Problem. Use this rating if any of the following are true:

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

Problem. Use this rating if one of more of the following are true:

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

Major Problem. Use this rating if one of more of the following are true:

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

RESPOND BY CIRCLING DESIRED ALTERNATIVE

1. **AFRAID OF STRANGERS** Becomes fearful in the presence of adult strangers. *Examples: resists going near an unfamiliar adult even when encouraged to do so under appropriate circumstances, cried when meeting an adult for the first time, cried in the crowd.*

   No Problem Problem Major Problem

2. **ANGRY** Frequently feels hostile or mad. *Examples: gets mad easily, argues a lot, interrupts others when ignored, expresses anger in inappropriate ways.*

   No Problem Problem Major Problem

3. **ANXIOUS** Appears nervous or tense. *Examples: nervous, overreacts to unexpected sounds or events, vigilant, worries.*
   No Problem Problem Major Problem

4. **AVOIDS BY ILLNESS** Fakes sickness, disability, or pain in order to avoid something he/she does not want to do. *Examples: says he/she has a stomach ache in order to avoid going to school, says he/she has a headache in order to avoid cleaning up room.*

   No Problem Problem Major Problem

5. **AVOIDS PEERS** Dislikes interacting with other children. *Examples: prefers to play alone, avoids groups, parallel play only, pushes/hits others when approached.*

   No Problem Problem Major Problem

6. **BIZARRE IDEAS** Expresses strange ideas. *Examples: says that he/she is a sailor, says that he/she should collect as many rocks as possible.*

   No Problem Problem Major Problem

7. **BLANK STARES** Appears expressionless and emotionless. *Examples: sometimes appears to be in a trance, gazes off into space.*

   No Problem Problem Major Problem

8. **BODILY COMPLAINTS** Complains about aches and pains. *Examples: headaches, stomach aches, dizziness, constipation, diarrhoea, unexplained recurrent pains.*

   No Problem Problem Major Problem

9. **BONDING PROBLEM** Child or infant has not formed normal emotional attachments with parents/caretakers. *Examples: does not seek closeness if caretaker enters room, does not calm when held by parents, does not respond to affection from parents/ caretakers.*

No Problem Problem Major Problem

10. **BULLIES OTHERS** Controls others with threats, verbal abuse, or actual physical attack. *Examples: intimidates smaller or weaker children, bosses around smaller or weaker children.*

No Problem Problem Major Problem

11. **CHANGES IN SLEEP BEHAVIOUR** A change in usual sleep habits. *Examples: recent trouble falling asleep, wakes up in the middle of night, has trouble waking in mornings.*

No Problem Problem Major Problem

12. **COMMUNCIATION PROBLEM** Marked difficulty in communicating with others. *Examples: makes up and uses own words for things, no mode of communication, abnormal gestures, marked speech problem, echolalia, stuttering.*

No Problem Problem Major Problem

13. **CONFUSING SPEECH** Poorly related or bizarre ideas or thoughts. *Examples: speech makes no sense, thinking is hard to follow, expresses strange ideas, thoughts jump from one topic to another.*

No Problem Problem Major Problem

14. **CRYING SPELLS** Periodic bouts of sobbing. *Examples: easily moved to tears, cried more often than most children, cried for no apparent reason.*

No Problem Problem Major Problem

15. **DESTRUCTIVE** Deliberately damages property. *Examples: breaks windows, deliberately destroys furniture, throws objects, turns over furniture.*

No Problem Problem Major Problem

16. **DISOBEDIENT** Does not follow rules or directions given by people in authority. *Examples: does not listen to teacher, does not follow rules of group home/ residence, does not follow simple requests.*

No Problem Problem Major Problem

17. **DISTRACTED** Attention to a task is easily interrupted by extraneous or irrelevant stimuli. *Examples: short attention span, has trouble concentrating.*

No Problem Problem Major Problem

18. **ENURESIS/ENCOPRESIS** A child beyond the age of toilet training with inadequate bladder or bowel control. *Examples: bed wetting, urinating on the floor, defecating in pyjamas or pants.*

No Problem Problem Major Problem

19. **EXCESSIVE NEED FOR REASSURANCE** Frequently needs to be told that things are okay. *Examples: excessive need to be told that he/she is loved or liked, excessive need to be told that he/she is doing a good job, repeatedly needs to be told the time of a scheduled event or reassured that it will occur.*

No Problem Problem Major Problem

20. **EXCESSIVE SENSITIVITY TO CRITICISM** Excessive or inappropriate reactions to criticism. *Examples: reacts to failure by crying, quits easily, becomes angry when criticized, can't handle criticism.*

No Problem Problem Major Problem

21. **FEARFUL** Afraid of many objects or situations. *Examples: afraid to go places, afraid to try new activities, afraid of many different things.*

No Problem Problem Major Problem

22. **FEELS UNLOVED** Has perceptions that parents or significant others do not love or care about him/her. *Examples: says that parents/ caretakers do not love him/her, says that nobody cares about him/her, says that parents/ caretakers love others (e.g., brothers or sisters) more.*

No Problem Problem Major Problem

23. **GAZE AVOIDANCE** Actively avoids eye contact. *Examples: infrequent eye contact with others, becomes upset when face-to-face contact is forced.*

No Problem Problem Major Problem

24. **HALLUCINATIONS** Experiences things that are not really there. *Examples: hears voices, hears sounds, has visions, feels strange bodily sensations.*

No Problem Problem Major Problem

25. **HEADACHES** Complains about aches and pains in the head. *Examples: says head hurts, has migraine headaches, has tension headaches.*

No Problem Problem Major Problem

26. **IMPATIENT** Needs/ demands must be met immediately. *Examples: demanding, can't wait his/her turn, easily frustrated.*

No Problem Problem Major Problem

27. **IMPULSIVE** Reacts quickly without firs thinking about the likely consequences. *Examples: makes decisions quickly, quick-tempered.*

No Problem Problem Major Problem

28. **INATTENTIVE** Pays little attention to people or to events around him/her. *Examples: pays little attention when spoken to, seems "spaced out"*

No Problem Problem Major Problem

29. **INVOLUNTARY MOTOR MOVEMENTS** Repetitive movements beyond the control of the person. *Examples: excessive blinking, strange motor movements, frequent shrugs, hand flapping.*

No Problem Problem Major Problem

30. **IRRITABLE** Easily annoyed or provoked. *Examples: easily frustrated, becomes angry over minor annoyances, easily offended, feelings are hurt easily.*

No Problem Problem Major Problem

31. **ISOLATED** Spends a lot of time alone. *Examples: has no friends, plays alone, is ignored or avoided by other children.*

No Problem Problem Major Problem

32. **LACKS ENJOYMENT** Does not seem to enjoy things anymore. *Examples: has no fun, does not want to play anymore, does not want to do much of anything.*

No Problem Problem Major Problem

33. **LIES** Habitually says things that he/she knows are false or misleading. *Examples: lies about getting into fights, fabricates incredible tales, lies about being late.*

No Problem Problem Major Problem

34. **NEGATIVE SELF-IMAGE** Dislikes self. *Examples: says he/she is study, says he/she is a bad person, says he/she is ugly.*

No Problem Problem Major Problem

35. **OBESE** Excessively overweight. *Examples: perceived by others as being fat, eats too much.*

No Problem Problem Major Problem

36. **OBJECT ATTACHMENT** Strong and persistent attachments to a particular object. *Examples: often wants to hold a particular ball, searches for missing objects, likes to carry around a key chain and get upset when the key chain cannot be found.*

No Problem Problem Major Problem

37. **OVERACTIVE** Excessive movement to the point where the person has difficulty staying still. *Examples: appears to be in constant motion, excessive physical movement, pacing, constant changing activity.*

No Problem Problem Major Problem

38. **PESSIMISTIC** Has a negative view of the future. *Examples: negative outlook, lacks hope, expects the worse, negative thinking.*

No Problem Problem Major Problem

39. **PHYSICALLY AGGRESSIVE** Physically attacks others. *Examples: fights, spits on others, hits others.*

No Problem Problem Major Problem

40. **PICA** Tendency to eat nonedible objects. *Examples: eats dirt, eats paint chips, eats paper, drinks cleaner solution.*

No Problem Problem Major Problem

41. **REBELLIOUS** Defies authority and/or resists control from adults. *Examples: defiant, refuses to co-operate with adults, hostile towards authority figures.*

No Problem Problem Major Problem

42. **RUNS AWAY** Leaves without permission and without informing other people *Examples: runs away from home, runs away from residential facility, runs away from school.*

No Problem Problem Major Problem

43. **SAD** Displays frequent or excessive feelings of unhappiness. *Examples: often gives appearance of unhappy child, has bouts of crying, rarely smiles.*

No Problem Problem Major Problem

44. **SEEKS MEDICAL CARE** Frequently asks for or seeks out medical attention. *Examples: asks for medicine, often needs medical care for one thing after another.*

No Problem Problem Major Problem

45. **SELF-INJURY** Repeatedly injuries body of purpose. *Examples: bites arm, hits self repeatedly, bangs head repeatedly.*

No Problem Problem Major Problem

46. **SELF-STIMULATORY BEHAVIOUR** Repetitive movements that are performed frequently and appear to be non-functional. *Examples: body-rocking, object-twirling, head-rocking.*

No Problem Problem Major Problem

47. **SEPARATION ANXIETY** Afraid of being away from parent/caretaker. *Examples: cries or becomes upset when mother/caretaker leaves the room, cried when mother/caretaker leaves child at school.*

No Problem Problem Major Problem

48. **SETS FIRES** Deliberately starts fires. *Examples: sets fire to room, sets fires in school.*

No Problem Problem Major Problem

49. **SEXUAL PROBLEM** Repeatedly performs sexual behaviours that are socially disapproved. *Examples: sexual expression at inappropriate times or places, masturbates in public.*

    No Problem Problem Major Problem

50. **SHY** Uncomfortable in the presence of other people. *Examples: dislikes being the center of attention, bashful, ill at ease in groups, dislikes meeting new people.*

    No Problem Problem Major Problem

51. **SOCIAL INADEQUACIES** Has difficulty relating to peers in appropriate or satisfying ways. *Examples: has no friends, tends to be disliked, insensitive to the feelings of other people.*

    No Problem Problem Major Problem

52. **STEALS** Takes property that belongs to others. *Examples: takes classsmate's possessions, takes money from others.*

    No Problem Problem Major Problem

53. **STOMACHACHES** Complains about headaches. *Examples: says stomach is upset, feels nauseous, complains of gassy stomach.*

    No Problem Problem Major Problem

54. **STRANGE BEHAVIOUR** Engages in behaviour that impresses many observers as unusual, peculiar, strange, or bizarre. *Examples: hoards food in pockets or under bed, usually wears several layers of clothes regardless of the weather, always mutters things to self.*

    No Problem Problem Major Problem

55. **SUICIDAL STATEMENTS** Thinks about, attempts, or threatens to kill himself/herself. *Examples: says that he/she would like to die, intentionally cuts or hurts self, tries to get run over by cars.*

    No Problem Problem Major Problem

56. **TEMPER TANTRUMS** Angry outbursts when frustrated or disappointed. *Examples: shouts and yells when not given in to, has outbursts when asked to do something he/she does not want to do.*

No Problem Problem Major Problem

57. UNCOMPLETED ACTIVITIES Marked tendency not to finish things. *Examples: usually does not finish tasks, does form one uncompleted activity to another.*

No Problem Problem Major Problem

58. UNUSUAL VOCALIZATIONS Makes strange or unusual sounds. *Examples: grunts, barking noises, whispered words, sudden anger or swear words when not obviously angry.*

No Problem Problem Major Problem

59. VERBALLY ABUSIVE Threatens or insults other people. *Examples: taunts, insults, threatens others, makes fun of other people, yells or shouts at others.*

No Problem Problem Major Problem

60. WITHDRAWN Avoids personal contact with other people. *Examples: excessively shy, doesn't participate in group activities, prefers to be alone, socially isolated.*

No Problem Problem Major Problem

Appendix IX

Participant number	Question Number	Measure	Subscale	Replaced With	Notes
1	48	KIPP	Learning	3.1	
2	48	KIPP	Learning	3.4	
8	1	Support	12 item scale	2.67	
8	4	Support	12 item scale	2.67	
10	33	KIPP	Happiness	3	
14	16	KIPP	Learning	2.4	
14	48	KIPP	Learning	2.4	
15	13	REISS	Psychosis	0.4	
15	24	REISS	Significant behaviour	1.02	(Significant behaviour missing values were averaged over all remaining items in the measure as cannot be averaged as a subscale (as directed from Reiss manual,1990)
15	37	REISS	Attention	0.4	
16	28	REISS	Withdrawn	0.4	
17	6	REISS	Psychosis	Excluded	In the REISS scale participant 17 was excluded as REISS manual (1990) suggests if participant is missing 2 or more items from one subscale the average scores cannot be computed for the missing data. Each
17	8	REISS	Somatoform behaviour	Excluded	
17	10	REISS	Conduct disorder	Excluded	

17	12	REISS	Psychosis	Excluded	subscale includes 5 items.
17	13	REISS	Psychosis	Excluded	
17	24	REISS	Significant behaviour	Excluded	*Reiss, S. & Valenti-Hein, D. (1990) Reiss Scales for Children's Dual Diagnosis: Test Manual, 2nd Ed.*
17	25	REISS	Somatoform behaviour	Excluded	
17	27	REISS	Anger/self-control	Excluded	
17	33	REISS	Significant behaviour	Excluded	
17	34	REISS	Poor self esteem	Excluded	
17	35	REISS	Significant behaviour	Excluded	
17	38	REISS	Depression	Excluded	
17	43	REISS	Depression	Excluded	
17	44	REISS	Somatoform behaviour	Excluded	
17	9	KIPP	Career job growth	0.75	
17	9	Coping	Wishful thinking	1.6	
22	16	REISS	Attention	Excluded	In the REISS scale participant 22 was excluded as REISS manual (1990) suggests if participant is missing 2 or more items from one subscale the average scores cannot be computed for the missing data. Each subscale includes 5 items.
22	24	REISS	Significant behaviour	Excluded	
22	43	REISS	Depression	Excluded	
22	51	REISS	Depression	Excluded	

22	57	REISS	Attention	Excluded	
25	12	REISS	Psychosis	0.2	
25	28	REISS	Withdrawn	0.2	
25	29	REISS	Significant behaviour	0.43	
28	16	KIPP	Learning	2.3	
31	9	KIPP	Career/job growth	Excluded	In the KIPP participant 31 was excluded as all items on the career subscale were missing
31	19	KIPP	Career/job growth	Excluded	
31	26	KIPP	Career/job growth	Excluded	
31	31	KIPP	Career/job growth	Excluded	
32	9	KIPP	Career/job growth	Excluded	In the KIPP participant 32 was excluded as all items on the career subscale were missing
32	19	KIPP	Career/job growth	Excluded	
32	26	KIPP	Career/job growth	Excluded	
32	31	KIPP	Career/job growth	Excluded	
35	No items completed	Support	12 item scale	Excluded	In the support scale participant 35 was excluded as all items were missing
37	No items completed	Support	12 item scale	Excluded	In the support scale participant 37 was excluded as all items were missing
39	No items completed	Support	12 item scale	Excluded	In the support and KIPP scales participant 39 was

					excluded as all items were missing
42	No items completed	KIPP Support	50 item scale 12 item scale	Excluded	In the support and KIPP scales participant 42 was excluded as all items were missing
43	48	KIPP	Learning	2.7	
44	19	KIPP	Career/job growth	1.5	
45	6	RESS	Psychosis	0.4	
48	No items completed	KIPP	50 item scale	Excluded	In the KIPP scale participant 48 was excluded as all items were missing
53	48	KIPP	Learning	2.7	
56	13	REISS	Psychosis	0.2	
57	No items completed	Support	12 item scale	Excluded	In the support scale participant 57 was excluded as all items were missing
61	6	REISS	Psychosis	Excluded	In the REISS participant 61 was excluded as REISS manual (1990) suggests if participant is missing 2 or more items from one subscale the average scores cannot be computed for the missing data.
61	7	REISS	Psychosis	Excluded	
61	8	REISS	Somatoform behaviour	Excluded	
61	9	REISS	Autism/pervasive	Excluded	
61	10	REISS	Conduct disorder	Excluded	
61	11	REISS	Depression	Excluded	

61	12	REISS	Psychosis	Excluded	
61	13	REISS	Psychosis	Excluded	
61	14	REISS	Significant behaviour	Excluded	
61	15	REISS	Conduct disorder	Excluded	
61	16	REISS	Attention deficit	Excluded	
61	17	REISS	Attention deficit	Excluded	
61	18	REISS	Significant behaviour	Excluded	
61	19	REISS	Poor self esteem	Excluded	
65	9	Support	12 item scale	Excluded	In the support scale participant 65 was excluded as 4 of 12 items were missing and this was deemed too many to replace with an average.
65	10	Support	12 item scale	Excluded	
65	11	Support	12 item scale	Excluded	
65	12	Support	12 item scale	Excluded	
68	2	Life satisfaction	5 item scale	2.6	
71	3	KIPP	Personal growth	2.6	
73	48	KIPP	Learning	2.9	
75	11	REISS	Depression	0.2	
75	11	KIPP	Happiness	1.14	

75	13	KIPP	Pride	3.4	
75	48	KIPP	Learning	3	
76	48	KIPP	Learning	3	
78	48	KIPP	Learning	3.4	
80	4	HADS	Depression	1.3	
80	59	REISS	Significant behaviour	0.45	
80	3	Coping	Practical coping	Excluded	In the coping scale participant 80 was excluded as 12 of the 14 items were missing.
80	4	Coping	Wishful thinking	Excluded	
80	5	Coping	Practical coping	Excluded	
80	6	Coping	Wishful thinking	Excluded	
80	7	Coping	Practical coping	Excluded	
80	8	Coping	Practical coping	Excluded	
80	9	Coping	Wishful thinking	Excluded	
80	10	Coping	Wishful thinking	Excluded	
80	11	Coping	Wishful thinking	Excluded	
80	12	Coping	Practical coping	Excluded	
80	13	Coping	Wishful thinking	Excluded	

80	14	Coping	Practical coping	Excluded	
82	11	KIPP	Happiness	1.14	
82	13	KIPP	Pride	3.4	
83	58	REISS	Autism/pervasive	0	
84	20	REISS	Self esteem	0	
84	10	Support	12 item scale	2.75	
88	3	Support	12 item scale	3.25	
90	No items completed	Support	12 item scale	Excluded	In the support scale, participant 90 was excluded as no items were completed.
95	7	REISS	Psychosis	0.2	
95	16	REISS	Attention	0.2	
100	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 100 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		

104	11	HADS	Anxiety	1.29	
106	7	REISS	Psychosis	1.4	
108	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 108 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
109	48	KIPP	Learning	2.6	
109	2	Coping	Practical coping	Excluded	In the coping scale participant 109 was excluded as 13 out of 14 items were missing.
109	3	Coping	Practical coping	Excluded	
109	4	Coping	Wishful thinking	Excluded	
109	5	Coping	Practical coping	Excluded	
109	6	Coping	Wishful thinking	Excluded	
109	7	Coping	Practical coping	Excluded	
109	8	Coping	Practical coping	Excluded	

109	9	Coping	Wishful thinking	Excluded	
109	10	Coping	Wishful thinking	Excluded	
109	11	Coping	Wishful thinking	Excluded	
109	12	Coping	Practical coping	Excluded	
109	13	Coping	Wishful thinking	Excluded	
109	14	Coping	Practical coping	Excluded	
110	18	REISS	Significant behaviour	0.2	
111	27	REISS	Anger/ self-control	0.4	
113	13	REISS	Psychosis	0.4	
113	9	KIPP	Career/Job growth	Excluded	In the KIPP scale participant 113 was excluded as 3 of the 4 items in the subscale career were missing and therefore and average could not be calculated to fill in the missing values.
113	19	KIPP	Career/Job growth	Excluded	
113	31	KIPP	Career/Job growth	Excluded	
114	48	REISS	Significant behaviour	0.18	
115	44	KIPP	Strength and family closeness	2.1	
115	4	Coping	Wishful thinking	1.28	
115	13	Coping	Wishful thinking	1.28	
116	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and

		KIPP	50 item scale		REISS scales participant 116 was excluded as all items were missing in these scales.
		Support	12 item scale		
		Coping	14 item scale		
		Life Satisfaction	5 item scale		
		HADS	14 item scale		
117	No Items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 117 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
119	48	KIPP	Learning	3	
120	56	REISS	Anger/Self control	1.2	
120	57	REISS	Attention	0.4	
121	6	KIPP	Personal growth	2	

122	48	KIPP	Learning	2.4	
124	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 124 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
128	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 128 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
129	48	KIPP	Learning	3.1	
131	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 131 was excluded as all items

		KIPP Support Coping Life satisfaction HADS	50 item scale 12 item scale 14 item scale 5 item scale 14 item scale		were missing in these scales.
132	19	KIPP	Career	2.3	
133	No items completed	KIPP Support Coping Life satisfaction HADS	50 item scale 12 item scale 14 item scale 5 item scale 14 item scale		In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 133 was excluded as all items were missing in these scales.
134	2	REISS	Anger/ Self-control	0.4	
134	14	KIPP	Social network	1.6	
137	18	KIPP	Personal growth	2.8	
138	No items completed	REISS	60 item scale		In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 138 was excluded as all items

		KIPP	50 item scale		were missing in these scales.
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
139	5	KIPP	Personal growth	2.6	
42	10	Coping		1.42	
144	32	KIPP	Social network	0.8	
144	33	KIPP	Happiness	3.4	
144	48	KIPP	Learning	1.7	
145	19	KIPP	Career/job growth	Excluded	In the KIPP scale participant 145 was excluded as 3 of the 4 items in the subscale career were missing and therefore and average could not be calculated to fill in the missing values.
145	26	KIPP	Career/job growth	Excluded	
145	31	KIPP	Career/job growth	Excluded	
147	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 147 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		

		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
151	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 151 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		
152	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 152 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS			

			14 item scale		
153	No items completed	REISS	60 item scale	Excluded	In the support, coping, life satisfaction, HADS, KIPP and REISS scales participant 153 was excluded as all items were missing in these scales.
		KIPP	50 item scale		
		Support	12 item scale		
		Coping	14 item scale		
		Life satisfaction	5 item scale		
		HADS	14 item scale		

Appendix X

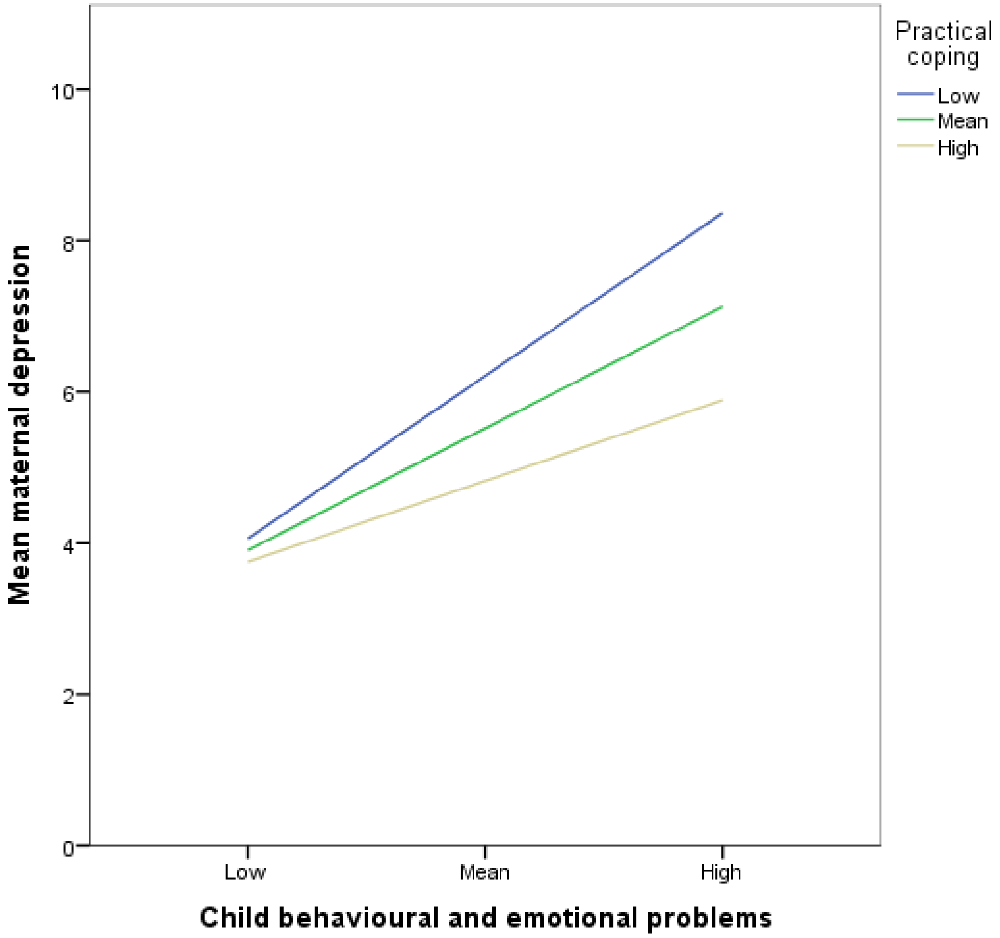


Figure 2.4. Shows the plot for maternal depression as the outcome variable. There was a positive relationship between child behavioural and emotional problems and positive maternal depression at all three levels of practical coping (low, *p*<.001, mid *p*<.001, high, *p* = .005). Thus the nature of the interaction effect was unclear. From the plot itself, it is clear that higher levels of practical coping were associated with lower levels of depression when child behavioural and emotional problems were at high levels. Depression had an almost significant relationship as an independent predictor to coping levels (*p*= .58).

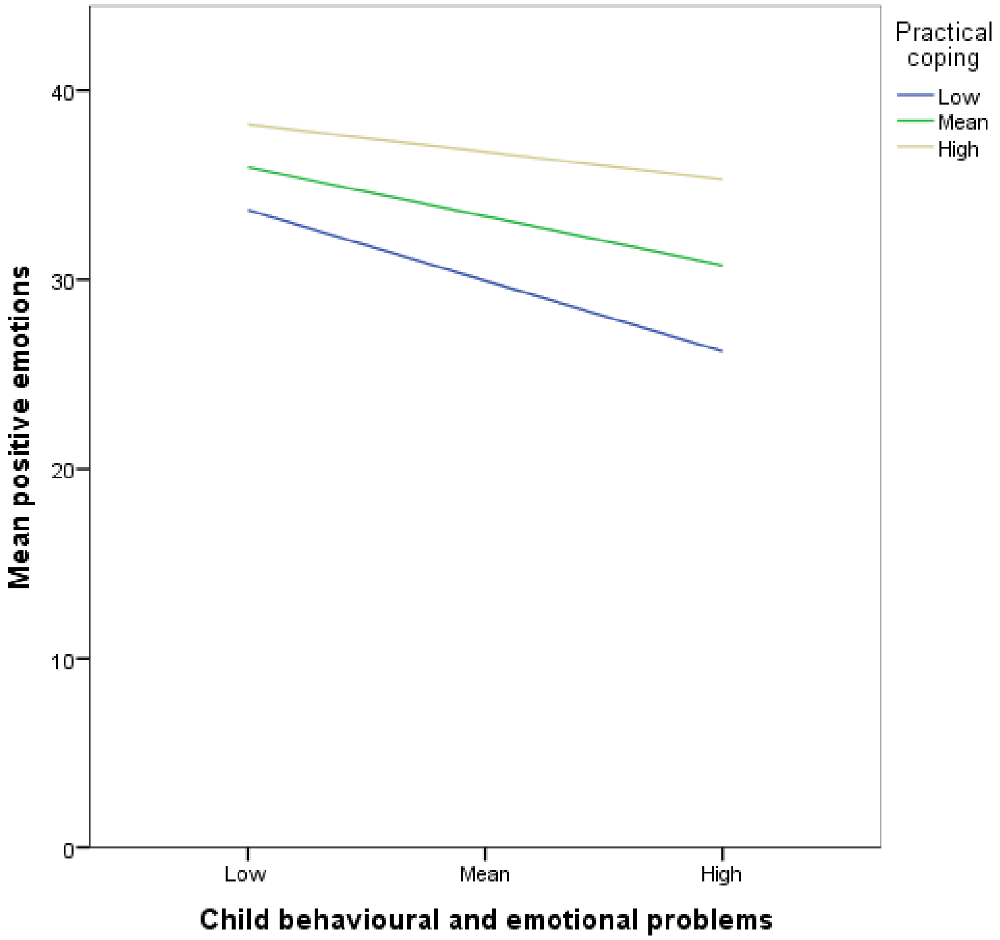


Figure 2.5.. Shows the plot for positive affect as the outcome variable. There was a negative relationship between child behavioural and emotional problems and positive affect at mid and low (*ps*<.001) levels of practical coping, but not when practical coping was high (*p* = .081). This suggested that the lower levels of practical coping were associated with positive affect and had a different impact on positive affect to when practical coping is high. However, higher levels of practical coping were associated with less of decrease in positive affect, and this occurred when child behavioural and emotional problems were at high levels.

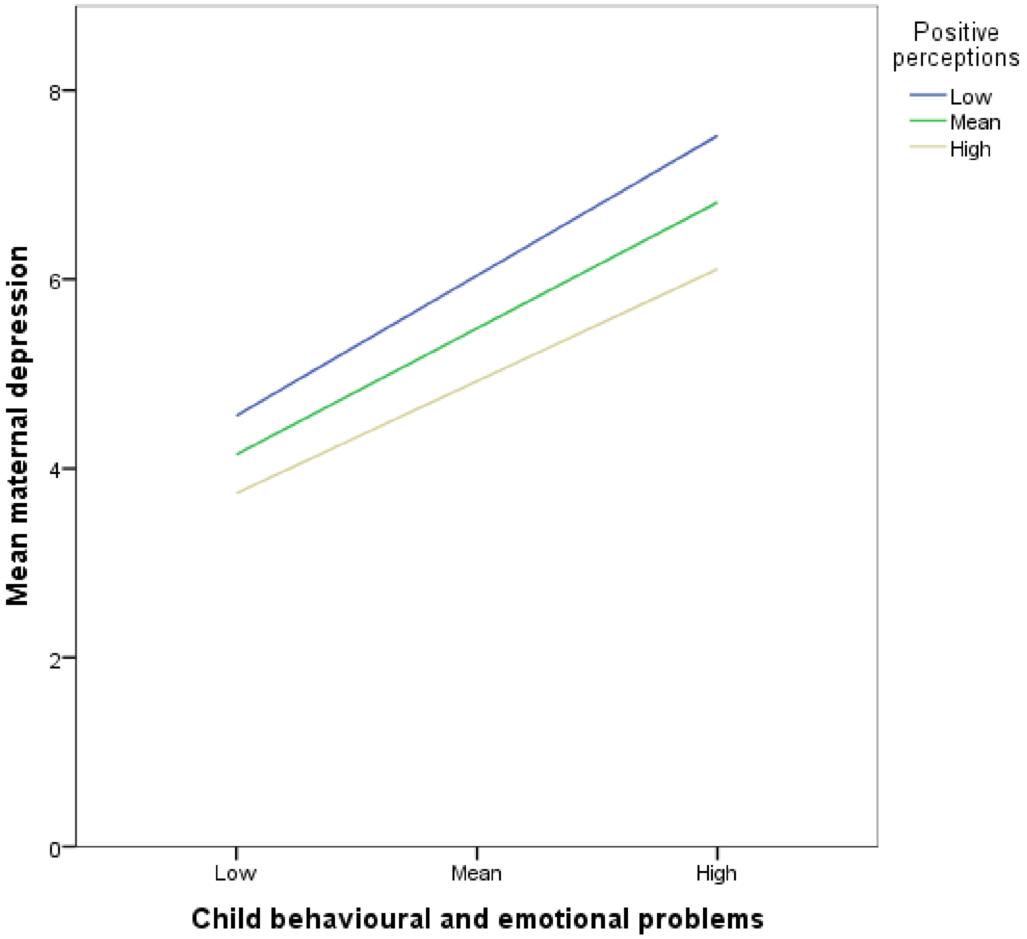


Figure 2.6. Shows the plot for maternal depression as the outcome variable. There was a positive relationship between child behavioural and emotional problems and positive maternal depression at all three levels of positive perceptions (low, p<.001, mid p<.001, high, p = .017). Thus the nature of the interaction effect was unclear. From the plot itself, it is clear that higher levels of positive perceptions were associated with lower levels of depression when child behavioural and emotional problems were at high levels.

Appendix XI

Questions about you and your family

The following questions ask for background information about you, your family, and your child with developmental disabilities. Please tick the appropriate response or write in the spaces provided.

Please complete the following questions about **<u>your child with developmental disabilities (e.g. learning disabilities (LD) and/ or Autism Spectrum Disorder (ASD))</u>**

If you have more than one child with developmental disabilities, please complete this questionnaire about your ***eldest*** *child who is under the age of 15 years old.*

1. How old is your child? __________ Years ____________ Months

2. Is your child male or female? Male ☐ Female ☐

3. What is the primary diagnosis of your child? (e.g. Learning disabilities, Down syndrome)

………

4. Does your child have any additional/secondary diagnoses? (e.g. ASD)

………………………………………………………………………………………

……………………………………………………………………………………...

5. Was your child's disability acquired? ☐ Or from birth? ☐

6a	Is your child able to walk by him/ herself?	Not at all	☐	Not up stairs	☐	Upstairs and Elsewhere	☐
6b	Is your child able to walk with help?	Not at all	☐	Not up stairs	☐	Upstairs and Elsewhere	☐
7.	Does your child feed him/herself?	Not at all	☐	With help	☐	Without help	☐
8.	Does your child wash him/herself?	Not at all	☐	With help	☐	Without help	☐
9.	Does your child dress him/herself?	Not at all	☐	With help	☐	Without help	☐

Please tick the most appropriate description that refers to your child's sensory abilities

10.	Hearing	Deaf or almost	☐	Hearing Impaired	☐	Normal hearing	☐
11.	Speech	Never a word	☐	Odd words only	☐		
		Sentences and normal speech	☐	Can talk but doesn't	☐		

12. Does your child have any health conditions? e.g. epilepsy, gastrointestinal problems

……………………………………………………………………………………………………..

13. Does your child with developmental disabilities normally live with you?

Yes ☐ No ☐

Please complete the following questions about you.

14. What is your relationship to your child……………………………………….
(e.g., mother, father, step mother/ father, adoptive parent)

15. Are you the primary caregiver for your child? (i.e. look after them the majority of the time) Yes ☐ No ☐

16. Please give your age in years …………………….

17. *Recent data from research with families of children with special needs has shown community settings and resources are important in understanding family member's views and experiences. With this in mind, could you please write down your full postcode below*

Current post code:________________________________

18. To which of the following ethnic groups do you consider yourself to belong? Please tick the appropriate box.

White – British	☐	Any other Asian Background, please specify………………	☐
White – Irish	☐	Black/Black British – Caribbean	☐
White-Welsh	☐	Any other Black Background, please specify………………	☐
Any other White Background, please specify……………….	☐	Mixed – White and Asian	☐
White and Black Caribbean	☐	Asian/Asian British – Indian	☐
Mixed – White and Black African	☐	Asian/Asian British – Bangladeshi	☐
Any other Mixed Background	☐	Black/Black British – African	☐
Asian/Asian British – Pakistani	☐		

19. What is your current marital status?

Married and currently living with spouse, or currently living with partner ☐

Divorced/Separated/Single/widowed and NOT currently living with a partner ☐

20. Please tick the highest level of your educational qualifications.

No formal educational qualifications ☐

Fewer than 5 GCSE's or O Level's, NVQ 1, or BTECH First Diploma ☐

5 or more GCSE's or O Level's, NVQ 2, or equivalent ☐

3 or more 'A' Levels, NVQ 3, BTECH National, or equivalent ☐

Polytechnic/University degree, NVQ 4, or equivalent ☐

Masters/ Doctoral degree, NVQ 5, or equivalent ☐

21. What is your current employment status? Unemployed ☐ Self Employed ☐
Part-time ☐ Full-time ☐

Appendix XII

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

1. Caring for ___________ puts a strain on me TRUE FALSE

2. Other member of the family have to do without things because of _____________ TRUE FALSE

3. Our family's social life has suffered because of caregiving responsibilities and financial stress TRUE FALSE

4. I can go to visit friends whenever I want TRUE FALSE

5. There are many places where we can enjoy ourselves as a family when ______________ comes along. TRUE FALSE

6. Members of our family get to do the same kind of things other families do. TRUE FALSE

7. The constant demands for care for ____________ limit growth and development of someone else in our family. TRUE FALSE

Appendix XIII

Having a child with developmental disabilities

The following statements focus on **your own and your family's experiences** of having a child with developmental disabilities. Please respond to all questions by ticking an answer that best describes how you feel.

	Strongly Agree	**Agree**	**Not Sure**	**Disagree**	**Strongly Disagree**
1. Since having this child I feel I have grown as a person.	☐	☐	☐	☐	☐
2. Having this child has helped me to learn new things / skills.	☐	☐	☐	☐	☐
3. Raising this child helps put life into perspective.	☐	☐	☐	☐	☐
4. Since having this child, my family has become closer to one another.	☐	☐	☐	☐	☐
5. Since having this child, my family has become more tolerant and accepting.	☐	☐	☐	☐	☐
6. Since having this child I have become more determined to face up to challenges.	☐	☐	☐	☐	☐
7. Since having this child I have a greater understanding of other people.	☐	☐	☐	☐	☐

Appendix XIV

Family relationships

Appendix XV

Your attitude towards life

Consider how well the following statements describe **<u>your behaviour and actions</u>** on a scale from 1 to 5. Please circle the number that best reflects your behaviour.

		Does not describe me at all				**Describes me very well**
1.	I actively look for ways to replace the loses I encounter in life	1	2	3	4	5
2.	I believe that I can grow in positive ways by dealing with difficult situations	1	2	3	4	5
3.	I look for creative ways to alter difficult situations	1	2	3	4	5
4.	Regardless of what happens to me, I believe I can control my reaction to it	1	2	3	4	5

Appendix XVI

Strengths and Difficulties Questionnaire

Appendix XVII

Ethics Application Approved

REPLYREPLY ALLFORWARD
Mark as unread

Bangor Research Applications [redacted]
Tue 01/07/2014 15:42
Inbox
To:
Elizabeth Jane Halstead;

Action Items

Dear Elizabeth,

2014-13046-A11442 Amendment to Resilience and life in families of children and young people with intellectual and developmental disabilities

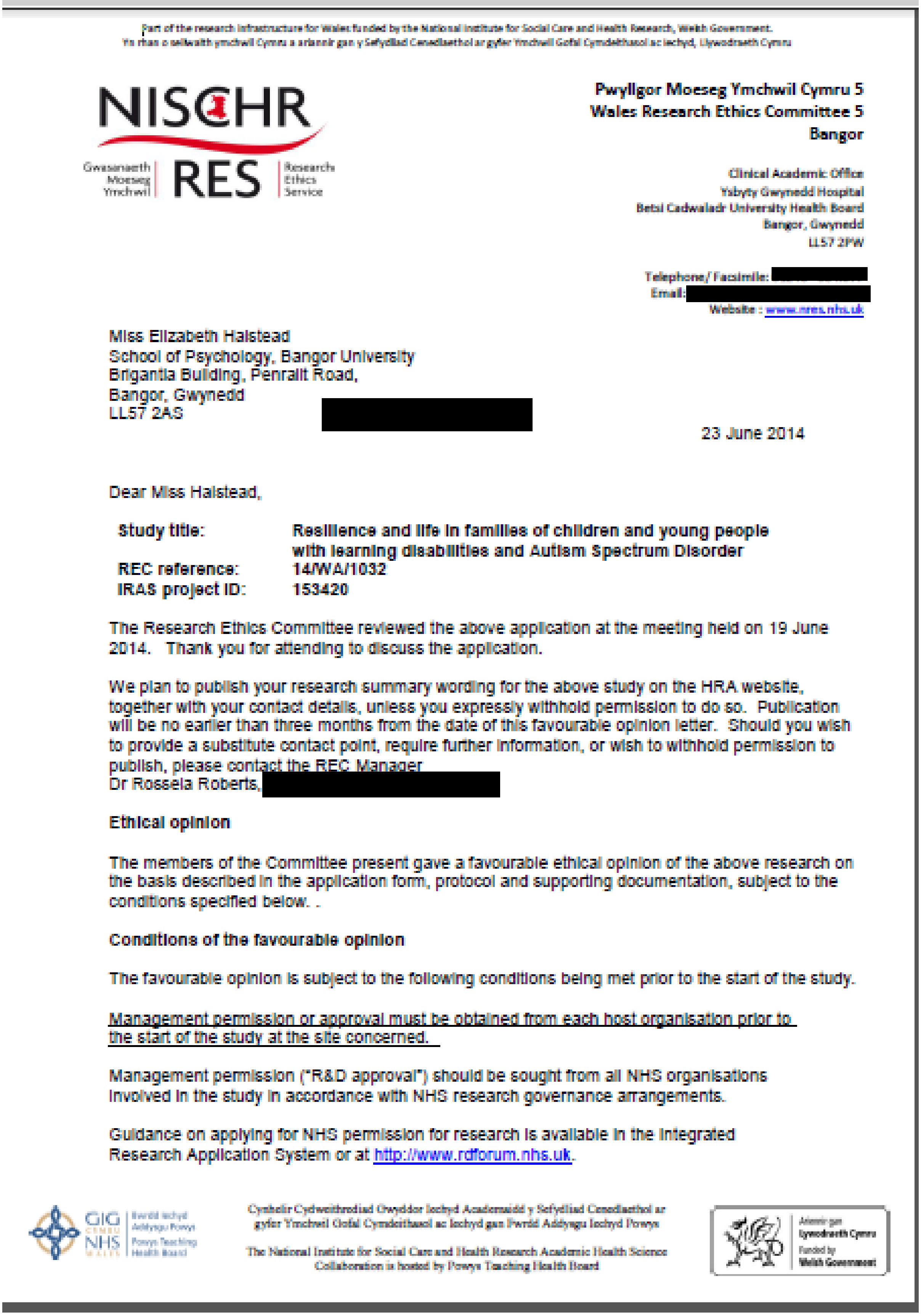
Your research proposal number 2014-13046-A11442 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.
.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.



Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR
Gwasanaeth Moeseg Ymchwil | RES | Research Ethics Service

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: [redacted]
Email: [redacted]
Website : www.nres.nhs.uk

Miss Elizabeth Halstead
School of Psychology, Bangor University
Brigantia Building, Penrallt Road,
Bangor, Gwynedd
LL57 2AS [redacted]

23 June 2014

Dear Miss Halstead,

Study title:	**Resilience and life in families of children and young people with learning disabilities and Autism Spectrum Disorder**
REC reference:	**14/WA/1032**
IRAS project ID:	**153420**

The Research Ethics Committee reviewed the above application at the meeting held on 19 June 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager
Dr Rossela Roberts, [redacted]

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

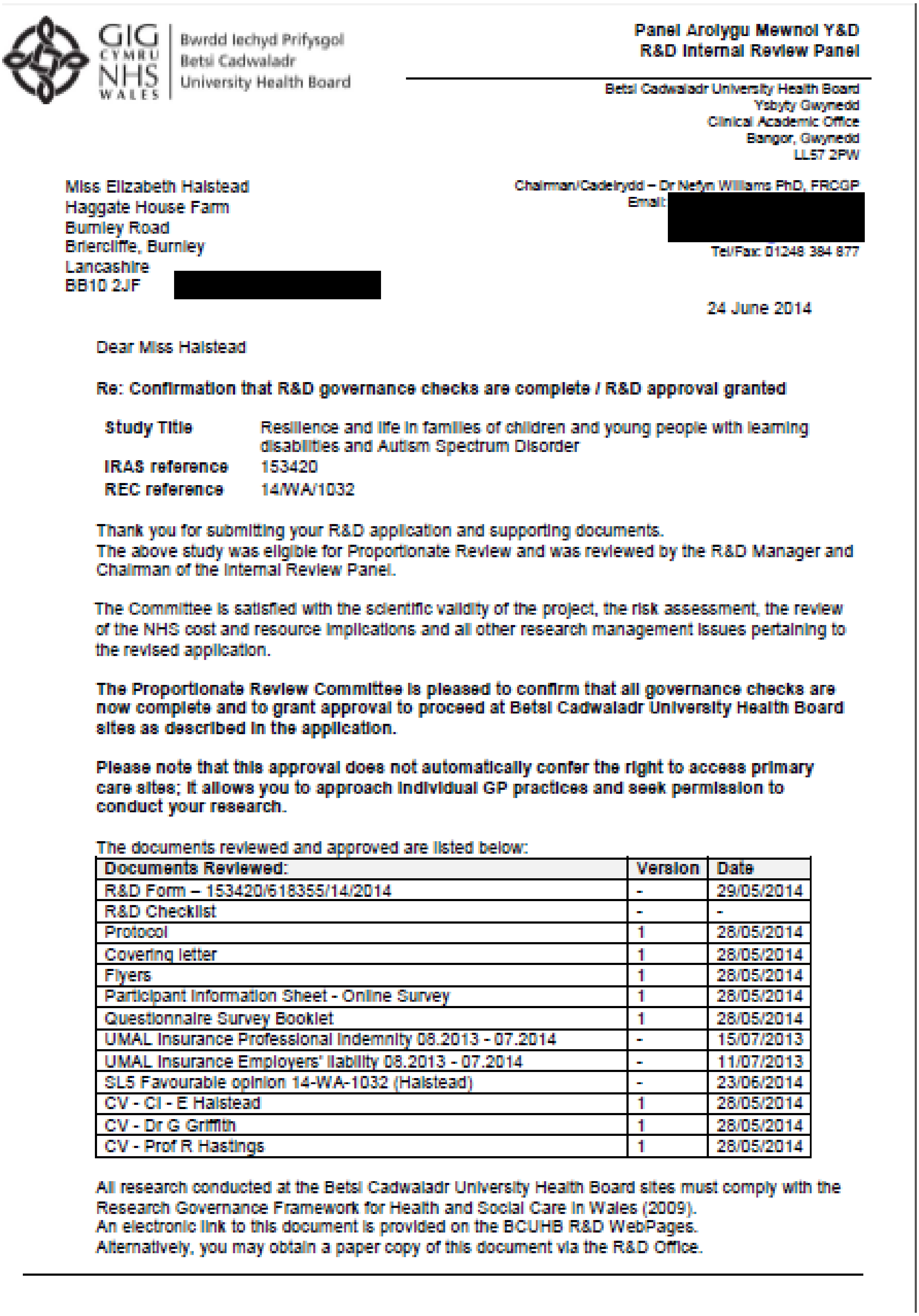
Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

GIG CYMRU NHS WALES | Bwrdd Iechyd Addysgu Powys | Powys Teaching Health Board

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

Ariennir gan Llywodraeth Cymru
Funded by Welsh Government



GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D
R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: [redacted]
Tel/Fax: 01248 384 877

Miss Elizabeth Halstead
Haggate House Farm
Burnley Road
Briercliffe, Burnley
Lancashire
BB10 2JF [redacted]

24 June 2014

Dear Miss Halstead

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	Resilience and life in families of children and young people with learning disabilities and Autism Spectrum Disorder
IRAS reference	153420
REC reference	14/WA/1032

Thank you for submitting your R&D application and supporting documents.
The above study was eligible for Proportionate Review and was reviewed by the R&D Manager and Chairman of the Internal Review Panel.

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Proportionate Review Committee is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

Please note that this approval does not automatically confer the right to access primary care sites; it allows you to approach individual GP practices and seek permission to conduct your research.

The documents reviewed and approved are listed below:

Documents Reviewed:	**Version**	**Date**
R&D Form – 153420/618355/14/2014	-	29/05/2014
R&D Checklist	-	-
Protocol	1	28/05/2014
Covering letter	1	28/05/2014
Flyers	1	28/05/2014
Participant Information Sheet - Online Survey	1	28/05/2014
Questionnaire Survey Booklet	1	28/05/2014
UMAL Insurance Professional Indemnity 08.2013 - 07.2014	-	15/07/2013
UMAL Insurance Employers' liability 08.2013 - 07.2014	-	11/07/2013
SL5 Favourable opinion 14-WA-1032 (Halstead)	-	23/06/2014
CV - CI - E Halstead	1	28/05/2014
CV - Dr G Griffith	1	28/05/2014
CV - Prof R Hastings	1	28/05/2014

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009).
An electronic link to this document is provided on the BCUHB R&D WebPages.
Alternatively, you may obtain a paper copy of this document via the R&D Office.

Appendix XVIII

Are you a parent of a child with developmental disabilities?

ReAL

Research with families of children with developmental disabilities

If you participate in the ReAL survey you can enter into a prize draw to win one of five £20 high street vouchers

Find our survey online at
bangor.onlinesurveys.ac.uk/therealproject

Want to have your say? We are looking for parents of children with developmental disabilities. If your child is aged between 5 and 15 years old and has a developmental disability we are asking you to complete a national online survey, which will help us better understand experiences of a family with a child with developmental disabilities (e.g. learning disabilities and Autism Spectrum Disorder).

"I found filling out the survey easy because I related to the questions, and as I was reflecting on my experience I felt positive about my parenting"

Mum of 15 year old boy with ASD

Why is my say important? Each experience of parenting is unique, and that is why it is important for us to know about yours. Knowing more about the well-being of parents will enable us to help other families.

PRIFYSGOL BANGOR UNIVERSITY

To take part in the survey please log onto
bangor.onlinesurveys.ac.uk/therealproject
Find us on Facebook www.facebook.com/TheReALP
And twitter @The_ReALProject

Ydych chi'n rhiant I blentyn ag anableddau datblygiadol?

ReAL

Research with families of children with developmental disabilities

If you participate in the ReAL survey you can enter into a prize draw to win one of five £20 high street vouchers

Gellwch weld ein holiadur ar-lein yn
bangor.onlinesurveys.ac.uk/therealproject

Ydych chi eisiau cael dweud eich dweud? ydyn ni'n chwilio am rieni plant gydag anableddau datblygiadol. Os yw eich plentyn rhwng 5 a 15 oed, a chydag anabledd datblygiadol, rydyn ni'n gofyn i chi lenwi holiadur ar-lein cenedlaethol, a fydd yn ein helpu i ddeall yn well brofiadau teulu gyda phlentyn sydd ag anableddau datblygiadol (e.e. anableddau dysgu ac Anhwylder Sbectrwm Awtistaidd).

"Roeddwn i'n gweld bod llenwi'r holiadur yn hawdd, oherwydd fy mod yn uniaethu â'r cwestiynau, a gan fy mod yn adfyfyrio ar fy mhrofiad, roeddwn i'n teimlo'n gadarnhaol ynghylch fy sgiliau magu plant"
Mam bachgen 15 oed gydag Anhwylder Sbectrwm Awtistaidd

Pam mae fy marn yn bwysig? Mae profiad pawb o fagu plant yn unigryw, a dyna pam ei bod yn bwysig ein bod yn gwybod am eich profiad chi. Bydd gwybod mwy am les rhieni yn ein galluogi i helpu teuluoedd eraill.

PRIFYSGOL
BANGOR
UNIVERSITY

Os oes gennych unrhyw gwestiynau, anfonwch e-bost at Liz Halstead ar [redacted]

Mae'r astudiaeth yn cael ei chyllido gan Brifysgol Bangor, a daw i ben 30.05.2015.

Appendix IX

National ReAL Project

For **parents** of children with developmental disabilities

Funded by Bangor University

Research with families of children with developmental disabilities

Invitation to participate

Dear Parent,

We would like to invite you to participate in a national survey exploring **well-being in parents** of children with developmental disabilities. If your child is aged between 5 and 15 years old, and has a developmental disability, we would like you to participate in our survey.

Each experience of parenting a child is unique and that is why it is important for us to know about yours. Knowing more about family experiences and parental well-being will enable us to better understand families with children with developmental disabilities and help to inform interventions that help families.

The survey is available online, to enter go to
bangor.onlinesurveys.ac.uk/therealproject

As a small thank you for your time you can enter into a prize draw to win one of five £20 high street vouchers.

"I found filling out the survey easy because I related to the questions, and as I was reflecting on my experience I felt positive about my parenting"

Mum of 15 year old boy with ASD

For more **information** please contact Liz Halstead on [redacted]
or find us on Facebook at www.facebook.com/TheReALP and twitter @The_ReALProject
Alternatively see the attached information sheets.

National ReAL Survey

For **parents** of children with developmental disabilities

Funded by Bangor University

Research with families of children with developmental disabilities

To take part in the survey please log onto
bangor.onlinesurveys.ac.uk/therealproject

This national ReAL survey is to find out about the well-being of parents of children with developmental disabilities. If you are a parent, and would like to complete the survey, as a small thank you for your time you can enter into a prize draw to win one of five £20 high street vouchers.

Who can participate?

We are looking for parents of children with a developmental disability. If your child is aged between 5 and 15 years old, and has a developmental disability, you can participate. Developmental disabilities include children with learning disabilities or Autism Spectrum Disorder, including Asperger syndrome.

What are you asking me to do?

If you would like to participate in the national ReAL survey, all you need to do is go to
bangor.onlinesurveys.ac.uk/therealproject
and follow the instructions, which will guide you through the survey questions. Or you can order a paper copy from us if you prefer.

The survey can be found online at bangor.onlinesurveys.ac.uk/therealproject

If you require a paper copy of the survey to be returned in a freepost envelope, please email Liz Halstead at [redacted] (please specify if you require larger text)
The organisation that passed on this information on to you may also have copies.

What is the research about?

The results of the survey will improve our understanding of the well-being and experiences of parents and their children with developmental disabilities. We hope by gaining a better understanding of what contributes to the well-being of parents with a child with developmental disabilities, this will help to develop ways in which other families can be supported in future.

Do I have to take part?

Your participation is completely voluntary.

Research with families of children with developmental disabilities

What if I decide I don't want to continue filling out certain questions or the survey once I have started?

We ask that you complete the survey, if you can. Of course, you may decide to withdraw from the survey at any point. Also, man questions will have a 'prefer not to answer' option if you do not wish to answer that particular question. You can also choose simply not to answer a question, if answering it makes you feel uncomfortable.

What happens to my answers if I decide I don't want to complete the survey?

If you are completing the online survey, the answers automatically save each time you click continue, if you are happy for us to use the answers you have completed so far then do you not need to do anymore. If you want all your answers to be withdrawn from the study please email [redacted] with the date that you began the survey and your child's age and gender. We will then be in touch requesting a unique identifiable question so your answers can be excluded from the data set. If you are completing the survey by paper copy, then you can decide whether you wish to post your completed answers to us in the freepost envelope provided.

Can I start the online survey and return to it later?

Yes, each time you click 'continue' the survey automatically saves. There is a 'Finish Later' button at the bottom of each page which allows you to return to the online survey later, you can either bookmark the page or be sent a unique URL to take you straight back to the last question you completed. Please keep a note of the URL as there is no record kept by either the survey system or ourselves.

Will my information be confidential?

All data collected will remain anonymous and will be kept in a database that is only accessible to those working on the project. If published, the information will be presented without any reference to identifying information. This study has been reviewed and approved by the School of Psychology and NHS Ethics committee.

What will happen to the results of the research study?

We hope that this study will contribute to understanding more about parents of children with developmental disabilities. The results of the study will be distributed in a scientific journal and presented in conferences as well as distributed to charities and other interested organisations.

How long will the survey take me to complete?

We estimate the survey will take around 20 minutes to complete.

Research with families of children with developmental disabilities

Is the survey easy to complete?

Yes, all the questions are multiple choice or just require very short answers.

What are the possible benefits of taking part?

While you may not directly benefit by participating in this study, we hope that the information you give us will help inform interventions that could help other parents and young people in future.

What are the possible disadvantages or risks of taking part?

We do not foresee any disadvantages or risks by taking part in this survey.

How do I enter the prize draw?

Once you have completed the survey, an option will appear for you to enter your email address. If you wish to receive a short summary of results once the study has finished, or **enter into the prize draw to win one of five £20 High Street Vouchers,** please enter your email address and tick the appropriate boxes asking you what you would like your email to be used for. Your email address will be stored on a confidential mailing list separate to your data set and therefore your email will not be identified as part of any data collected. We will not share you email address with any other researchers and you will not receive anything other than the results of the study or information about winning a voucher through this email.

What if something goes wrong or I want to complain?

In the unlikely circumstance you wish to complain please contact:

Mr Hefin Francis
School Manager
School of Psychology
Adeilad Brigantia, Penrallt Road
Gwynedd. LL57 2AS

Tel: [redacted]
Fax: [redacted]
Email: [redacted]

I have read the above and I am happy to participate, what do I do now?

Great, follow the link to the online survey bangor.onlinesurveys.ac.uk/therealproject

You can either click on it or copy and paste it into your browser.

You can obtain a paper copy survey pack from the organisation that provided you with this information or email [redacted]. .

Thank you very much for taking this time to read this information.

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BANGOR
UNIVERSITY

Project ReAL Cenedlaethol

Ar gyfer rhieni plant gydag anableddau datblygiadol
Ariennir gan Brifysgol Bangor

Research with families of children with developmental disabilities

Gwahoddiad i gymryd rhan

Annwyl Riant,

Hoffem eich gwahodd i gymryd rhan mewn holiadur cenedlaethol sy'n edrych ar les mewn rhieni plant sydd ag anableddau datblygiadol. Os yw eich plentyn rhwng 5 a 15 oed, a chydag anabledd datblygiadol, hoffem i chi lenwi ein holiadur.

Mae profiad pawb o fagu plant yn unigryw, a dyna pam ei bod yn bwysig ein bod yn gwybod am eich profiad chi. Bydd gwybod mwy am brofiadau rhieni a'u lles yn ein galluogi i ddeall yn well deuluoedd eraill â phlant sydd ag anableddau datblygiadol, a helpu i ddylanwadu ar ymyriadau sy'n helpu teuluoedd.

Mae'r holiadur ar gael ar-lein, ewch i
bangor.onlinesurveys.ac.uk/therealproject

I ddiolch i chi am eich amser, gellwch fod â chyfle i ennill un o bum taleb siopau'r stryd fawr, gwerth £20.

"Roeddwn i'n gweld bod llenwi'r holiadur yn hawdd, oherwydd fy mod yn uniaethu â'r cwestiynau, a gan fy mod yn adfyfyrio ar fy mhrofiad, roeddwn i'n teimlo'n gadarnhaol ynghylch fy sgiliau magu plant"

Mam bachgen 15 oed gydag Anhwylder Sbectrwm Awtistaidd

Am fwy o wybodaeth, cysylltwch â Liz Halstead ar [redacted],
neu gellwch gael hyd i ni ar Facebook yn www.facebook.com/TheReALP a twitter @The_ReALProject
Gellwch hefyd ddarllen y taflenni gwybodaeth sydd ynghlwm.

Research with families of children with developmental disabilities

Holiadur ReAL Cenedlaethol

Ar gyfer rhieni plant gydag anableddau datblygiadol

Ariennir gan Brifysgol Bangor

I gymryd rhan yn yr holiadur, logiwch i mewn i
bangor.onlinesurveys.ac.uk/therealproject

Pwrpas yr holiadur ReAL cenedlaethol hwn yw dod i wybod am les rhieni plant gydag anableddau datblygiadol. Os ydych chi'n rhiant, ac yr hoffech lenwi'r holiadur, i ddiolch i chi am eich amser, gellwch fod â chyfle i ennill un o bum taleb siopau'r stryd fawr, gwerth £20.

Pwy all gymryd rhan?

Rydyn ni'n chwilio am rieni plant sydd ag anabledd datblygiadol. Os yw eich plentyn rhwng 5 a 15 oed, a chydag anabledd datblygiadol, gellwch gymryd rhan. Mae anableddau datblygiadol yn cynnwys plant gydag anableddau dysgu neu Anhwylder Sbectrwm Awtistaidd, yn cynnwys syndrom Asperger.

Beth ydych chi'n gofyn i mi ei wneud?

Os hoffech gymryd rhan yn yr arolwg ReAL cenedlaethol, y cyfan sy'n rhaid i chi ei wneud yw mynd i
bangor.onlinesurveys.ac.uk/therealproject
a dilynwch y cyfarwyddiadau, a fydd yn eich arwain drwy gwestiynau'r holiadur. Neu gellwch archebu copi papur gennym ni, pe bai'n well gennych.

Gellwch weld yr holiadur ar-lein yn bangor.onlinesurveys.ac.uk/therealproject

Os oes arnoch angen copi papur o'r holiadur i'w ddychwelyd mewn amlen radbost, e-bostiwch Liz Halstead ar [redacted] (dywedwch os oes arnoch angen testun mwy)
Efallai y bydd gan y sefydliad a drosglwyddodd y wybodaeth hon i chi gopïau hefyd.

Ynglŷn â beth y mae'r ymchwil?

Bydd canlyniadau'r holiadur yn gwella'n dealltwriaeth o les a phrofiadau rhieni a'u plant gydag anableddau datblygiadol. Drwy gael gwell dealltwriaeth am yr hyn sy'n cyfrannu at les rhieni plant gydag anableddau datblygiadol, gobeithiwn y bydd hyn yn ein helpu i ddatblygu ffyrdd y gellir cefnogi teuluoedd eraill yn y dyfodol.

A oes rhaid imi gymryd rhan?

Eich dewis chi yw cymryd rhan ai peidio.

Research with families of children with developmental disabilities

Beth os ydw i'n penderfynu nad ydw i eisiau parhau i ateb cwestiynau penodol, neu'r holiadur, ar ôl i mi ddechrau?

Rydym yn gofyn i chi lenwi'r holiadur, os gellwch. Wrth gwrs, gellwch dynnu'n ôl o'r holiadur ar unrhyw adeg.
Bydd gan lawer o gwestiynau opsiwn 'mae'n well gennyf beidio ag ateb' hefyd os nad ydych yn dymuno ateb y cwestiwn penodol hwnnw.
Gellwch hefyd ddewis peidio ag ateb cwestiwn, os bydd ei ateb yn gwneud i chi deimlo'n anghyfforddus.

Beth fydd yn digwydd i'm hatebion os ydw i'n penderfynu nad ydw i eisiau gorffen yr holiadur?
Os ydych chi'n llenwi'r holiadur ar-lein, bydd yr atebion yn cael eu cadw'n awtomatig bob amser yr ydych chi'n clicio 'parhau', os ydych chi'n hapus i ni ddefnyddio'r atebion rydych chi wedi'u rhoi hyd yma, yna nid oes arnoch chi angen gwneud unrhyw beth arall. Os ydych chi am i'ch holl atebion gael eu tynnu'n ôl o'r astudiaeth, e-bostiwch [redacted] gyda'r dyddiad y gwnaethoch chi ddechrau'r holiadur, ac oedran a gender eich plentyn. Byddwn yn cysylltu â chi wedyn i ofyn am gwestiwn unigryw fel y gellir eithrio'ch atebion o'r set data. Os ydych chi'n llenwi'r holiadur drwy gopi papur, yna gellwch benderfynu a ydych yn dymuno postio'ch atebion atom ni yn yr amlen radbost a ddarperir.

Alla'i ddechrau'r holiadur ar-lein, a dychwelyd ato'n ddiweddarach?
Gellwch. Bob amser rydych chi'n clicio 'parhau', mae'r holiadur yn cael ei gadw'n awtomatig. Ceir botwm 'Gorffen Wedyn' ar waelod pob tudalen sy'n eich galluogi i ddychwelyd at yr holiadur ar-lein yn ddiweddarach. Gellwch naill ai fewnosod nod tudalen, neu dderbyn URL unigryw i fynd â chi'n syth yn ôl i'r cwestiwn diwethaf y bu i chi ei ateb. Gwnewch nodyn o'r URL gan nad ydym ni na system yr holiadur yn cadw unrhyw gofnod ohono.

Fydd fy ngwybodaeth yn gyfrinachol?
Bydd yr holl wybodaeth a gesglir yn parhau'n ddienw ac yn cael ei chadw mewn cronfa ddata sydd i'w gweld gan y rhai sy'n gweithio ar y project yn unig. Os caiff ei chyhoeddi, bydd y wybodaeth yn cael ei chyflwyno heb unrhyw gyfeiriad at wybodaeth lle gellir adnabod rhywun. Mae'r astudiaeth hon wedi ei hadolygu ac wedi cael cymeradwyaeth Pwyllgor Moeseg yr Ysgol Seicoleg a'r Gwasanaeth Iechyd Gwladol.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?
Gobeithiwn y bydd yr astudiaeth hon yn cyfrannu at ddeall mwy am rieni plant gydag anableddau datblygiadol. Bydd canlyniadau'r astudiaeth yn cael eu dosbarthu mewn cyfnodolyn gwyddonol, a'u cyflwyno mewn cynadleddau, yn ogystal â'u dosbarthu i elusennau a sefydliadau eraill sydd â diddordeb.

Pa mor hir fydd yr holiadur yn ei gymryd i mi ei lenwi?
Rydym yn amcangyfrif y bydd yr holiadur yn cymryd tua 20 munud i'w lenwi.

Research with families of children with developmental disabilities

Ydi'r holiadur yn hawdd ei lenwi?
Ydi - mae pob cwestiwn yn un amlddewis, neu'n gofyn am ateb byr yn unig.

Beth yw’r manteision posib o gymryd rhan?
Efallai a fyddwch yn manteisio'n uniongyrchol o gymryd rhan yn yr astudiaeth hon, ond gobeithiwn y bydd y wybodaeth a roddwch i ni yn ein helpu i ddylanwadu ar ymyriadau a allai helpu rhieni a phobl ifanc eraill yn y dyfodol.

Beth yw’r anfanteision neu’r risgiau posibl wrth gymryd rhan?
Nid ydym yn rhagweld unrhyw anfanteision na risgiau o ganlyniad i gymryd rhan yn yr astudiaeth.

Sut ydw i’n cael cyfle i ennill taleb £20?
Ar ôl chi lenwi'r holiadur, bydd dewis yn ymddangos i chi nodi'ch cyfeiriad e-bost. Os ydych chi'n dymuno derbyn crynodeb byr o ganlyniadau ar ôl i'r astudiaeth orffen, **neu fod â chyfle i ennill un o bum taleb siopau'r stryd fawr, gwerth £20,** nodwch eich cyfeiriad e-bost a thiciwch y bocsys perthnasol yn gofyn i chi ar gyfer beth yr hoffech chi i'ch e-bost gael ei ddefnyddio. Cedwir eich cyfeiriad e-bost ar restr bostio gyfrinachol ar wahân i'ch set data, ac felly ni chysylltir ef â’ch atebion i’r holiadur. Ni fyddwn yn rhannu'ch cyfeiriad e-bost gydag unrhyw ymchwilwyr eraill, ac ni fyddwch yn derbyn unrhyw beth ar wahân i ganlyniadau'r astudiaeth neu wybodaeth am ennill taleb drwy'r e-bost hwn.

Beth os aiff rhywbeth o’i le, neu fy mod am gwyno?
Os byddwch yn dymuno cwyno, cysylltwch â:

Mr Hefin Francis
Rheolwr yr Ysgol
Ysgol Seicoleg
Adeilad Brigantia, Ffordd Penrallt
Gwynedd. LL57 2AS

Ffôn: [redacted]
Ffacs: [redacted]
E-bost: [redacted]

Rydw i wedi darllen yr uchod, ac yn hapus i gymryd rhan. Beth yw'r cam nesaf?
Gwych, dilynwch y cyswllt i'r holiadur ar-lein yn
bangor.onlinesurveys.ac.uk/therealproject

Gellwch naill glicio arno, neu ei gopïo a'i bastio i'ch porwr.

Gellwch gael pecyn holiadur papur gan y sefydliad a roddodd y wybodaeth hon i chi, neu drwy e-bostio [redacted]

Diolch yn fawr iawn i chi am gymryd yr amser i ddarllen y wybodaeth hon.

Appendix XX

31/01/2015

[redacted]

[redacted]

To [redacted]

Thank you kindly for agreeing to pass on the study information to parents at your school. I have enclosed 34 leaflets and information sheets (32 and a couple spare).

For more information or if you wish to contact me regarding anything, please phone Liz Halstead on [redacted]/ email [redacted]

Kind Regards,

Liz Halstead

The ReAL Project Team

Liz Halstead, The ReAL Project, School of Psychology, Bangor University,
Brigantia Building, Bangor University, Bangor, Gwynedd, Wales, UK LL57 2AS

11/03/2015

[redacted]

To [redacted],

Please find enclosed information for a study being conducted through Bangor University for parents of children with learning disabilities and or Autism Spectrum Disorder. If you could help by distributing the flyers to parents of children or by displaying them in your service I would be very grateful.

This study has been approved by all relevant NHS ethics committees and the School of Psychology ethics at Bangor University.

For more information please phone Liz Halstead on [redacted]/ email [redacted]

Kind Regards,

The ReAL Project Team

Liz Halstead, The ReAL Project, School of Psychology, Bangor University,
Brigantia Building, Bangor University, Bangor, Gwynedd, Wales, UK LL57 2AS

PRIFYSGOL BANGOR UNIVERSITY 1884

Appendix XXI

Consent form

Research with families of children with developmental disabilities

Please <u>initial</u> the boxes if you agree to the following:

I confirm I have read and understood the information sheets about this survey ☐

I confirm I have received enough information about the study and have had the opportunity to ask any questions I may have about this survey ☐

I understand my data will be kept anonymous under the data protection Act, 1998 ☐

I understand my participation in this study is voluntary and that I may withdraw and at any point without reason or consequence ☐

I confirm I am willing to take part in this survey ☐

Please sign below

Name (printed) ____

Signature ____

Date ____

Thank you, please turn over to begin the survey

Appendix XXII

Your child's attitude towards life

The next few sentences are about **your child with developmental disabilities** and their attitude towards life with a disability. Please say how much you agree with each sentence by ticking the appropriate box for each statement.

	Strongly Agree	**Agree**	**Not Sure**	**Disagree**	**Strongly Disagree**
1. My child usually manages one way or another	☐	☐	☐	☐	☐
2. My child keeps interested in things	☐	☐	☐	☐	☐
3. My child feels their life has a sense of purpose	☐	☐	☐	☐	☐
4. My child finds life really worth living	☐	☐	☐	☐	☐
5. My child believes their life has meaning	☐	☐	☐	☐	☐

Adapted based on Wagnild and Young's resilience scale

Appendix XXIII

Family Life Events

The following questions are about your family and their life experiences. Please answer all questions honestly and as best you can. You may find some of the questions a little sensitive. **All questions refer to experiences in the <u>past 12 months</u>.** When referring to spouse/ partner, this could mean a current partner who lives in your house with your child with developmental disabilities or the other parent of your child with developmental disabilities

1.	Has your child moved house in the last 12 months?	Yes ☐	No ☐
2.	Has your child been in hospital in the past 12 months for a short time for a health problem?	Yes ☐	No ☐
3.	Have you or your spouse/ partner been in hospital or in ill health (e.g. bedridden for a week, multiple hospital visits) in the past 12 months?	Yes ☐	No ☐
4.	Have you and your spouse/ partner permanently separated or divorced in the past 12 months?	Yes ☐	No ☐
5.	Have any of your child’s grandparents passed away in the past 12 months?	Yes ☐	No ☐
6.	Has your child changed school in the past 12 months?	Yes ☐	No ☐
7.	During the past 12 months has your child ever been off school for a continuous period of 2 weeks or more, other than for school holidays?	Yes ☐	No ☐

8. Please outline any other significant life event that has occurred within the family over the past 12 months

____

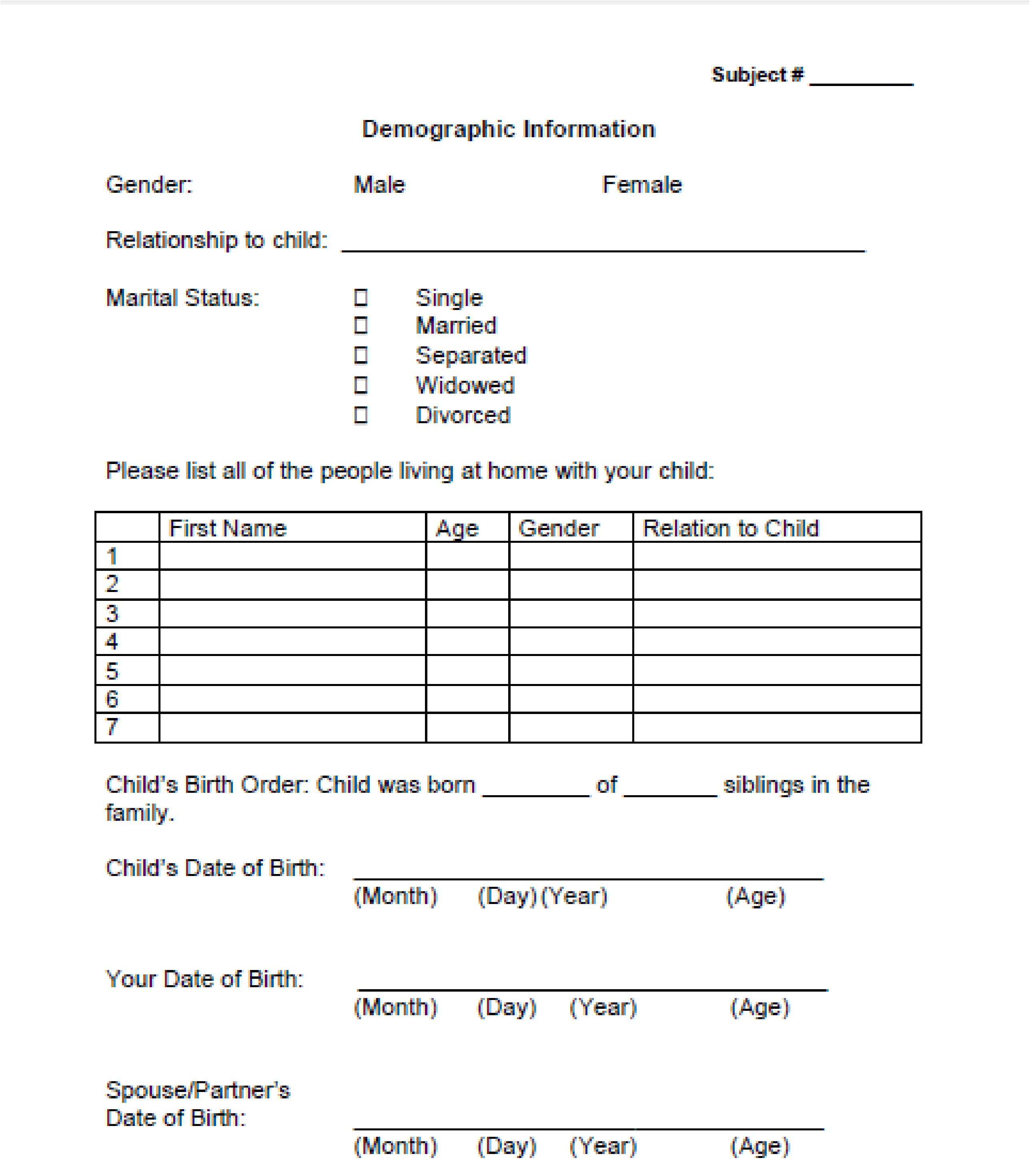
____

____

____

Questions adapted from MSC (2012)

Appendix XXIV



Subject # ________

Demographic Information

Gender: Male Female

Relationship to child: ______________________________

Marital Status:
☐ Single
☐ Married
☐ Separated
☐ Widowed
☐ Divorced

Please list all of the people living at home with your child:

	First Name	Age	Gender	Relation to Child
1				
2				
3				
4				
5				
6				
7				

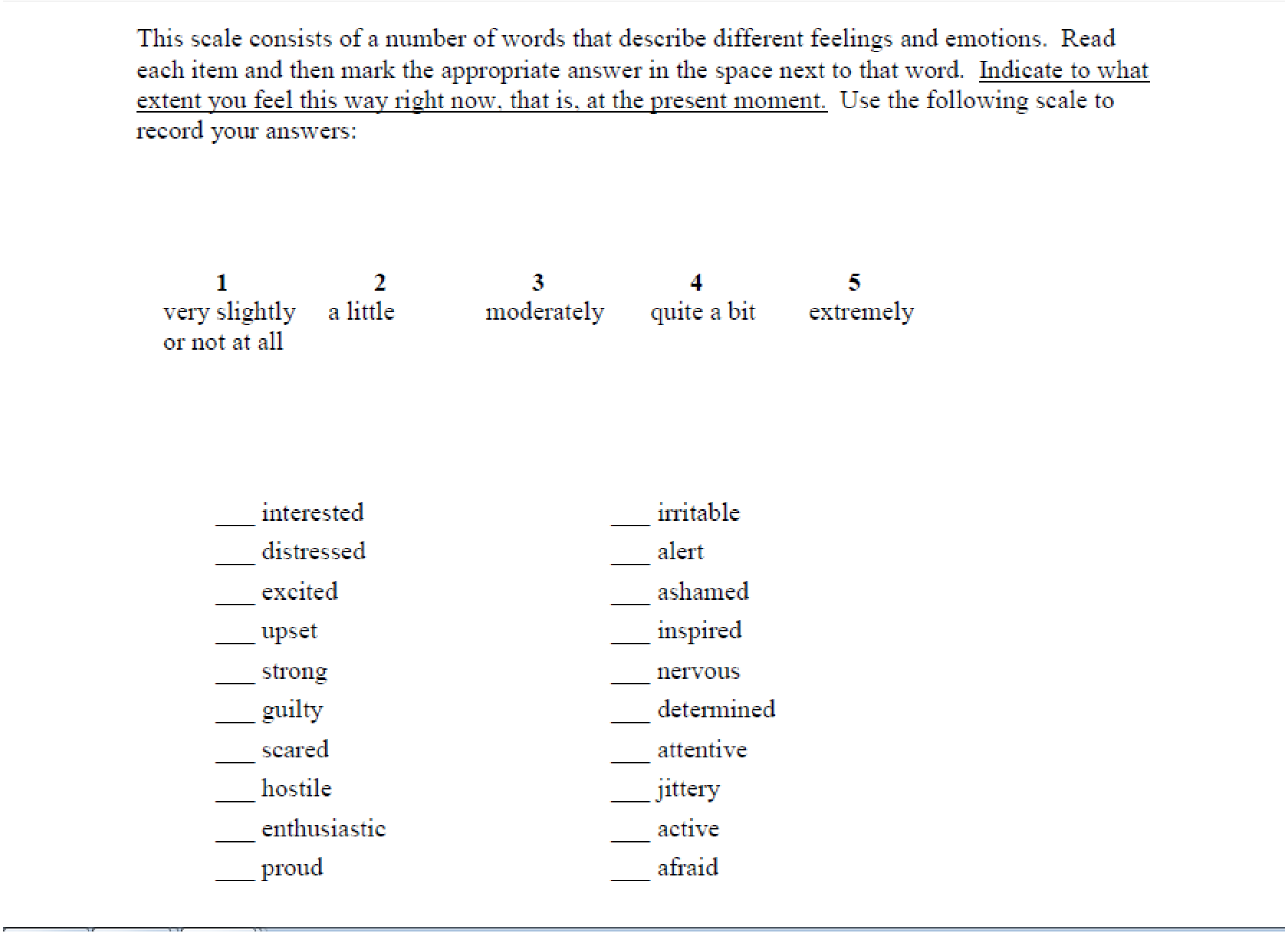
Child's Birth Order: Child was born ________ of _______ siblings in the family.

Child's Date of Birth: ______________________________
(Month) (Day) (Year) (Age)

Your Date of Birth: ______________________________
(Month) (Day) (Year) (Age)

Spouse/Partner's Date of Birth: ______________________________
(Month) (Day) (Year) (Age)

Appendix XXV



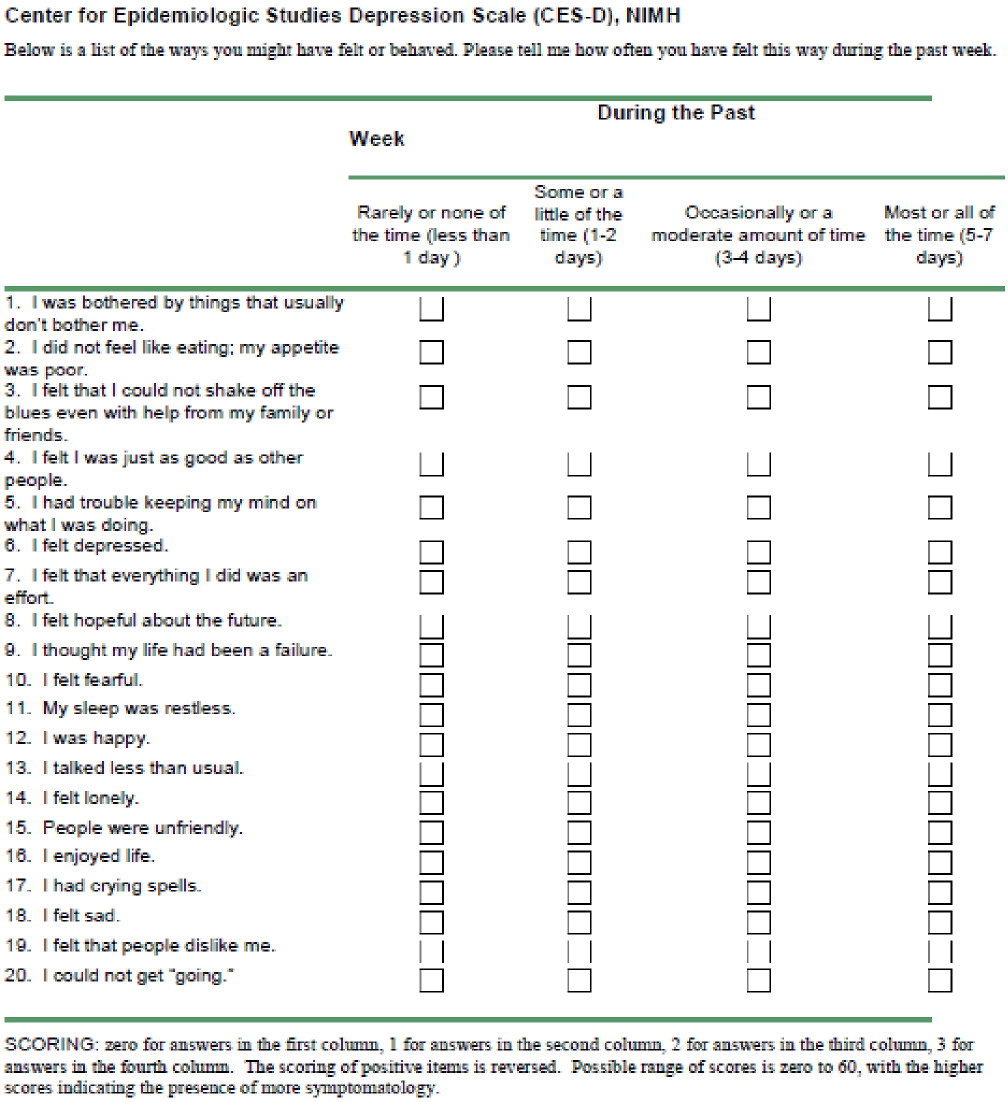
This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you feel this way right now, that is, at the present moment. Use the following scale to record your answers:

1	2	3	4	5
very slightly or not at all	a little	moderately	quite a bit	extremely

___ interested
___ distressed
___ excited
___ upset
___ strong
___ guilty
___ scared
___ hostile
___ enthusiastic
___ proud

___ irritable
___ alert
___ ashamed
___ inspired
___ nervous
___ determined
___ attentive
___ jittery
___ active
___ afraid

Appendix XXVI



Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	During the Past Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	☐	☐	☐	☐
2. I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
3. I felt that I could not shake off the blues even with help from my family or friends.	☐	☐	☐	☐
4. I felt I was just as good as other people.	☐	☐	☐	☐
5. I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
6. I felt depressed.	☐	☐	☐	☐
7. I felt that everything I did was an effort.	☐	☐	☐	☐
8. I felt hopeful about the future.	☐	☐	☐	☐
9. I thought my life had been a failure.	☐	☐	☐	☐
10. I felt fearful.	☐	☐	☐	☐
11. My sleep was restless.	☐	☐	☐	☐
12. I was happy.	☐	☐	☐	☐
13. I talked less than usual.	☐	☐	☐	☐
14. I felt lonely.	☐	☐	☐	☐
15. People were unfriendly.	☐	☐	☐	☐
16. I enjoyed life.	☐	☐	☐	☐
17. I had crying spells.	☐	☐	☐	☐
18. I felt sad.	☐	☐	☐	☐
19. I felt that people dislike me.	☐	☐	☐	☐
20. I could not get "going."	☐	☐	☐	☐

SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.

Appendix XXVII

FACES IV

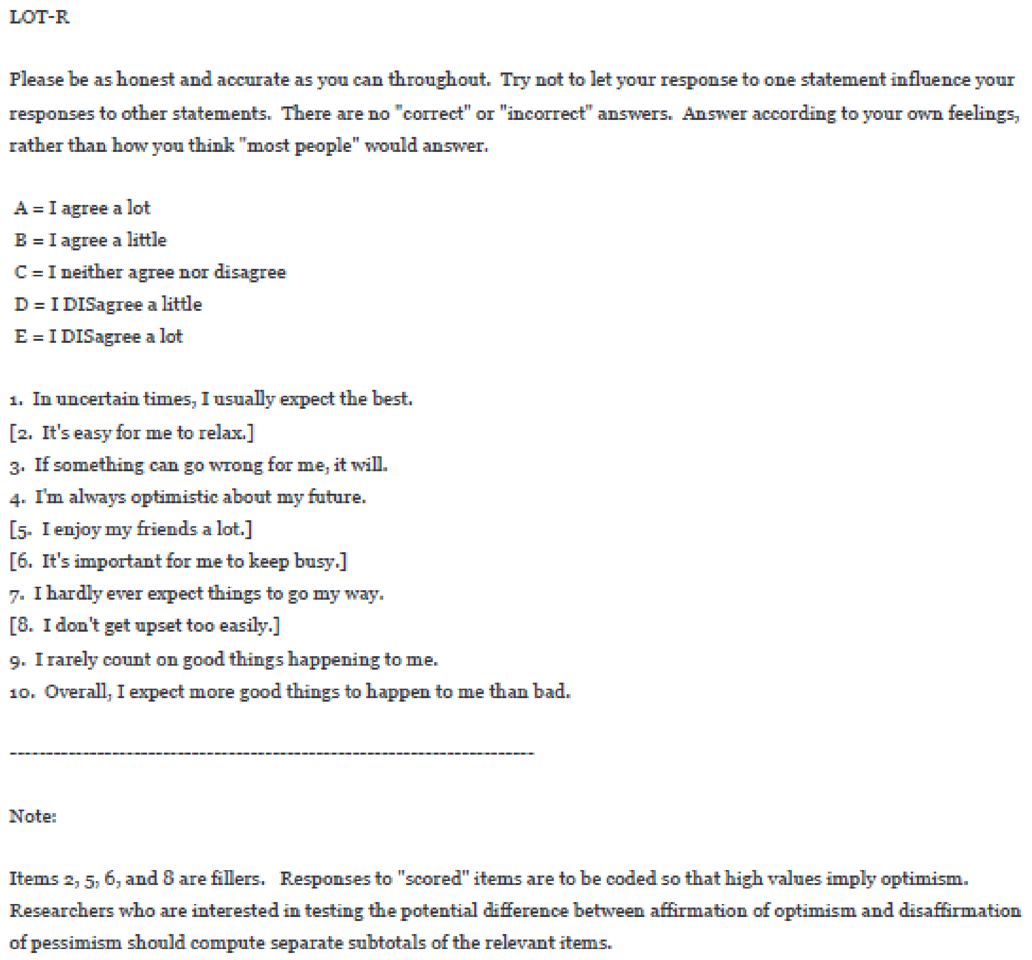
Mark the number for each statement that best describes your family.

1 Does not describe our family at all	2 Slightly describes our family	3 Somewhat describes our family	4 Generally describes our family	5 Very well describes our family

Family members are involved in each others lives.	①	②	③	④	⑤
Our family tries new ways of dealing with problems.	①	②	③	④	⑤
We get along better with people outside our family than inside.	①	②	③	④	⑤
We spend too much time together.	①	②	③	④	⑤
There are strict consequences for breaking the rules in our family.	①	②	③	④	⑤
We never seem to get organized in our family.	①	②	③	④	⑤
Family members feel very close to each other.	①	②	③	④	⑤
The parents check with the children before making important decisions.	①	②	③	④	⑤
Family members seem to avoid contact with each other when at home.	①	②	③	④	⑤
Family members feel pressured to spend most free time together.	①	②	③	④	⑤
There are severe consequences when a family member does something wrong.	①	②	③	④	⑤
We need more rules in our family.	①	②	③	④	⑤
Family members are supportive of each other during difficult times.	①	②	③	④	⑤
Children have a say in their discipline.	①	②	③	④	⑤
Family members feel closer to people outside the family than to other family members.	①	②	③	④	⑤
Family members are too dependent on each other.	①	②	③	④	⑤
This family has a rule for almost every possible situation.	①	②	③	④	⑤
Things do not get done in our family.	①	②	③	④	⑤
Family members consult other family members on personal decisions.	①	②	③	④	⑤
In solving problems, the children’s suggestions are followed.	①	②	③	④	⑤
Family members are on their own when there is a problem to be solved.	①	②	③	④	⑤
Family members have little need for friends outside the family.	①	②	③	④	⑤
It is difficult to get a rule changed in our family.	①	②	③	④	⑤
It is unclear who is responsible for things (chores, activities) in our family.	①	②	③	④	⑤

Family members like to spend some of their free time with each other.	①	②	③	④	⑤
	1 Does not describes describe our family	**2 Slightly describes our family**	**3 Somewhat describes our family**	**4 Generally describes our family**	**5 Very well our family**
We shift household responsibilities from person to person.	①	②	③	④	⑤
This family doesn’t do things together.	①	②	③	④	⑤
We feel too connected to each other.	①	②	③	④	⑤
Once a task is assigned to a member, there is little chance of changing it.	①	②	③	④	⑤
There is no leadership in this family.	①	②	③	④	⑤
Although family members have individual interests, they still participate in family activities.	①	②	③	④	⑤
Family members make the rules together.	①	②	③	④	⑤
Family members rarely depend on each other.	①	②	③	④	⑤
We resent family members doing things outside the family.	①	②	③	④	⑤
It is important to follow the rules in our family.	①	②	③	④	⑤
No one in this family seems to be able to keep track of what their duties are.	①	②	③	④	⑤
This family has a good balance of separateness and closeness.	①	②	③	④	⑤
When problems arise, we compromise.	①	②	③	④	⑤
Family members know very little about the friends of other family members.	①	②	③	④	⑤
Family members feel guilty if they want to spend time away from the family.	①	②	③	④	⑤
Family members feel they have to go along with what the family decides to do.	①	②	③	④	⑤
It is hard to know who the leader is in this family.	①	②	③	④	⑤

Appendix XXVIII



LOT-R

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

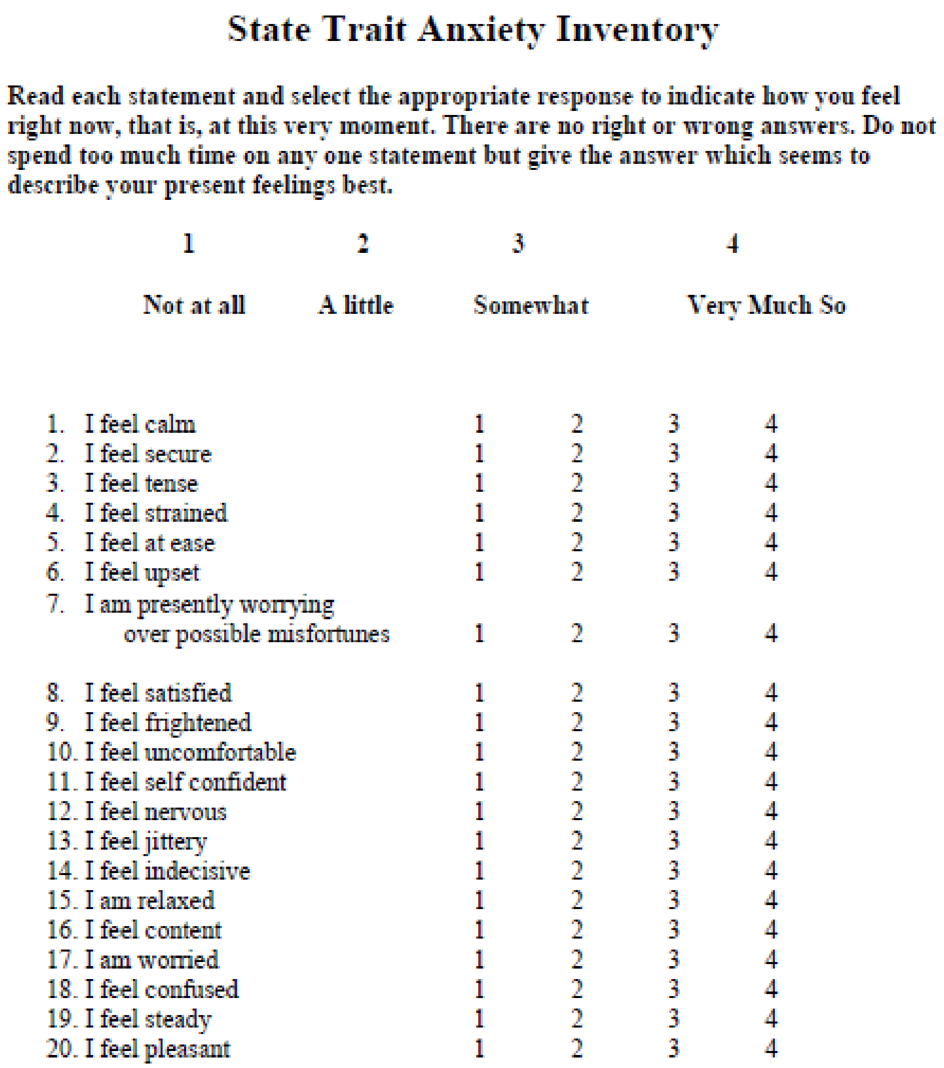
A = I agree a lot
B = I agree a little
C = I neither agree nor disagree
D = I DISagree a little
E = I DISagree a lot

1. In uncertain times, I usually expect the best.
[2. It's easy for me to relax.]
3. If something can go wrong for me, it will.
4. I'm always optimistic about my future.
[5. I enjoy my friends a lot.]
[6. It's important for me to keep busy.]
7. I hardly ever expect things to go my way.
[8. I don't get upset too easily.]
9. I rarely count on good things happening to me.
10. Overall, I expect more good things to happen to me than bad.

Note:

Items 2, 5, 6, and 8 are fillers. Responses to "scored" items are to be coded so that high values imply optimism. Researchers who are interested in testing the potential difference between affirmation of optimism and disaffirmation of pessimism should compute separate subtotals of the relevant items.

Appendix XXIX



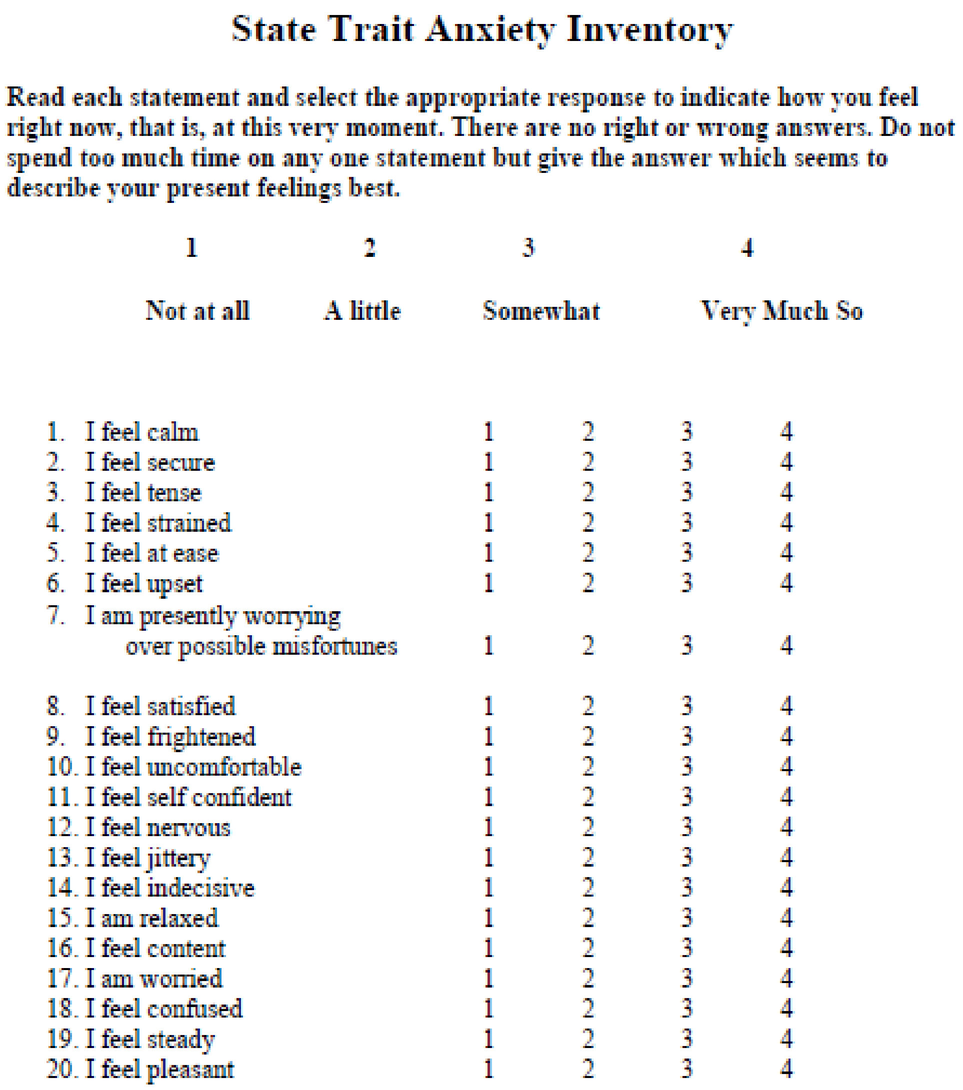
State Trait Anxiety Inventory

Read each statement and select the appropriate response to indicate how you feel right now, that is, at this very moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

1	2	3	4
Not at all	A little	Somewhat	Very Much So

1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I feel tense	1	2	3	4
4. I feel strained	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel uncomfortable	1	2	3	4
11. I feel self confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I feel jittery	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel confused	1	2	3	4
19. I feel steady	1	2	3	4
20. I feel pleasant	1	2	3	4

Appendix XXX



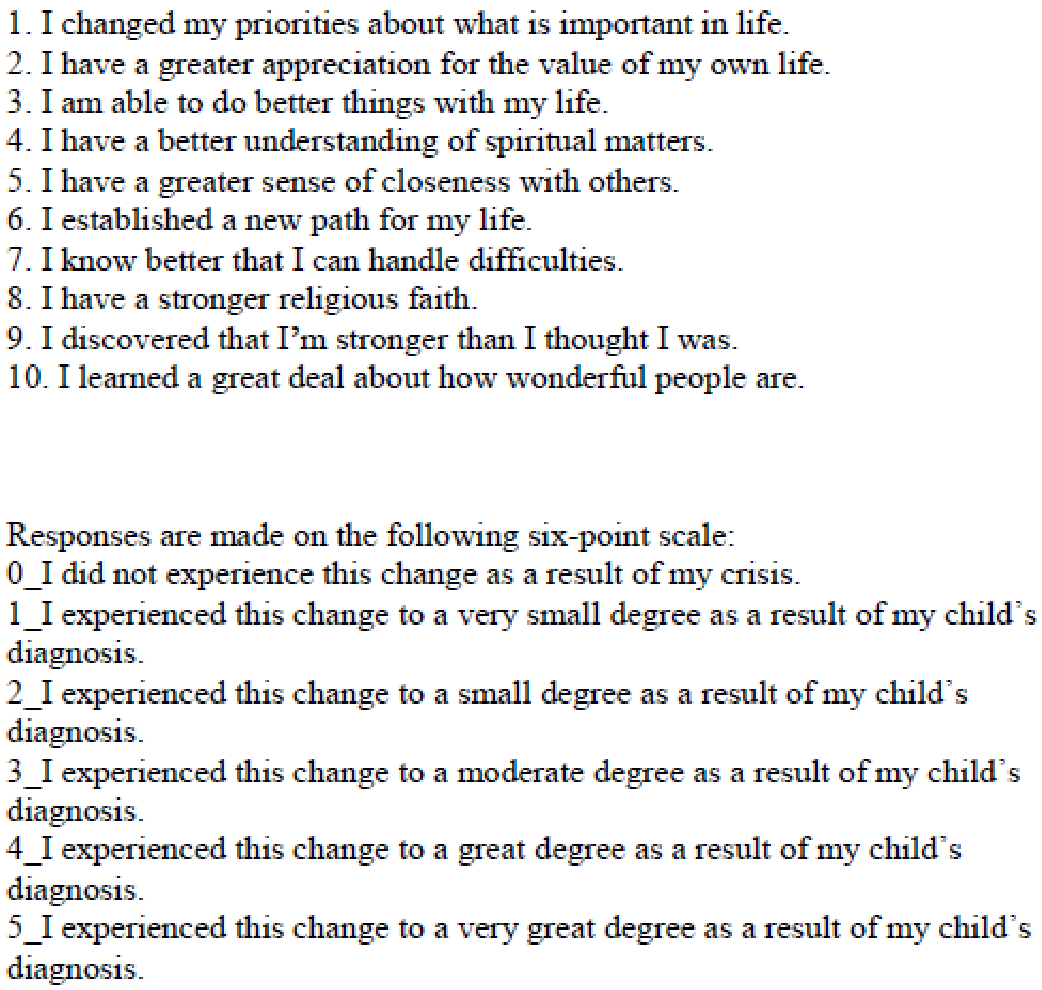
State Trait Anxiety Inventory

Read each statement and select the appropriate response to indicate how you feel right now, that is, at this very moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

1	**2**	**3**	**4**
Not at all	**A little**	**Somewhat**	**Very Much So**

1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I feel tense	1	2	3	4
4. I feel strained	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel uncomfortable	1	2	3	4
11. I feel self confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I feel jittery	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel confused	1	2	3	4
19. I feel steady	1	2	3	4
20. I feel pleasant	1	2	3	4

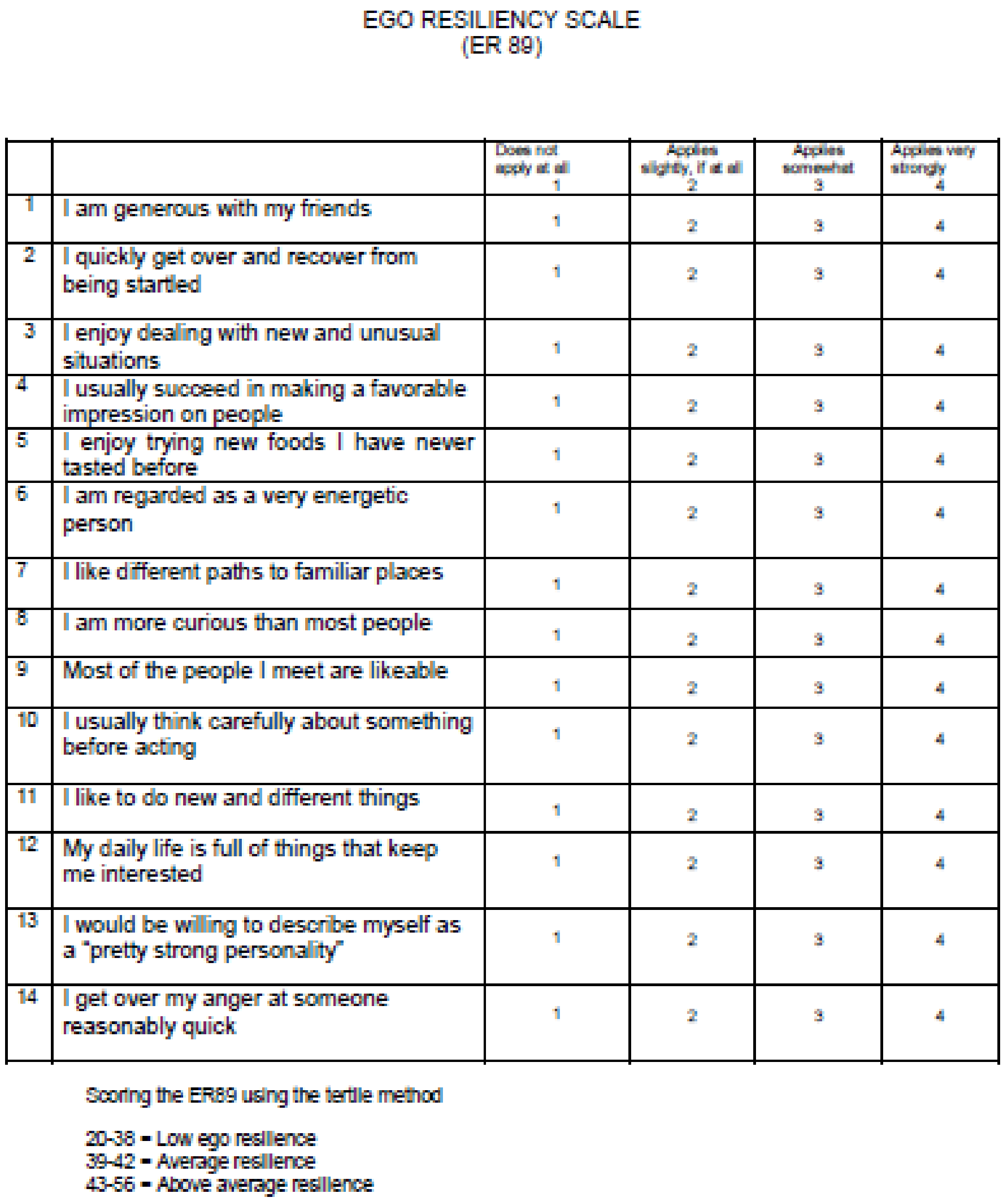
Appendix XXXI



1. I changed my priorities about what is important in life.
2. I have a greater appreciation for the value of my own life.
3. I am able to do better things with my life.
4. I have a better understanding of spiritual matters.
5. I have a greater sense of closeness with others.
6. I established a new path for my life.
7. I know better that I can handle difficulties.
8. I have a stronger religious faith.
9. I discovered that I'm stronger than I thought I was.
10. I learned a great deal about how wonderful people are.

Responses are made on the following six-point scale:
0_I did not experience this change as a result of my crisis.
1_I experienced this change to a very small degree as a result of my child's diagnosis.
2_I experienced this change to a small degree as a result of my child's diagnosis.
3_I experienced this change to a moderate degree as a result of my child's diagnosis.
4_I experienced this change to a great degree as a result of my child's diagnosis.
5_I experienced this change to a very great degree as a result of my child's diagnosis.

Appendix XXXII



EGO RESILIENCY SCALE
(ER 89)

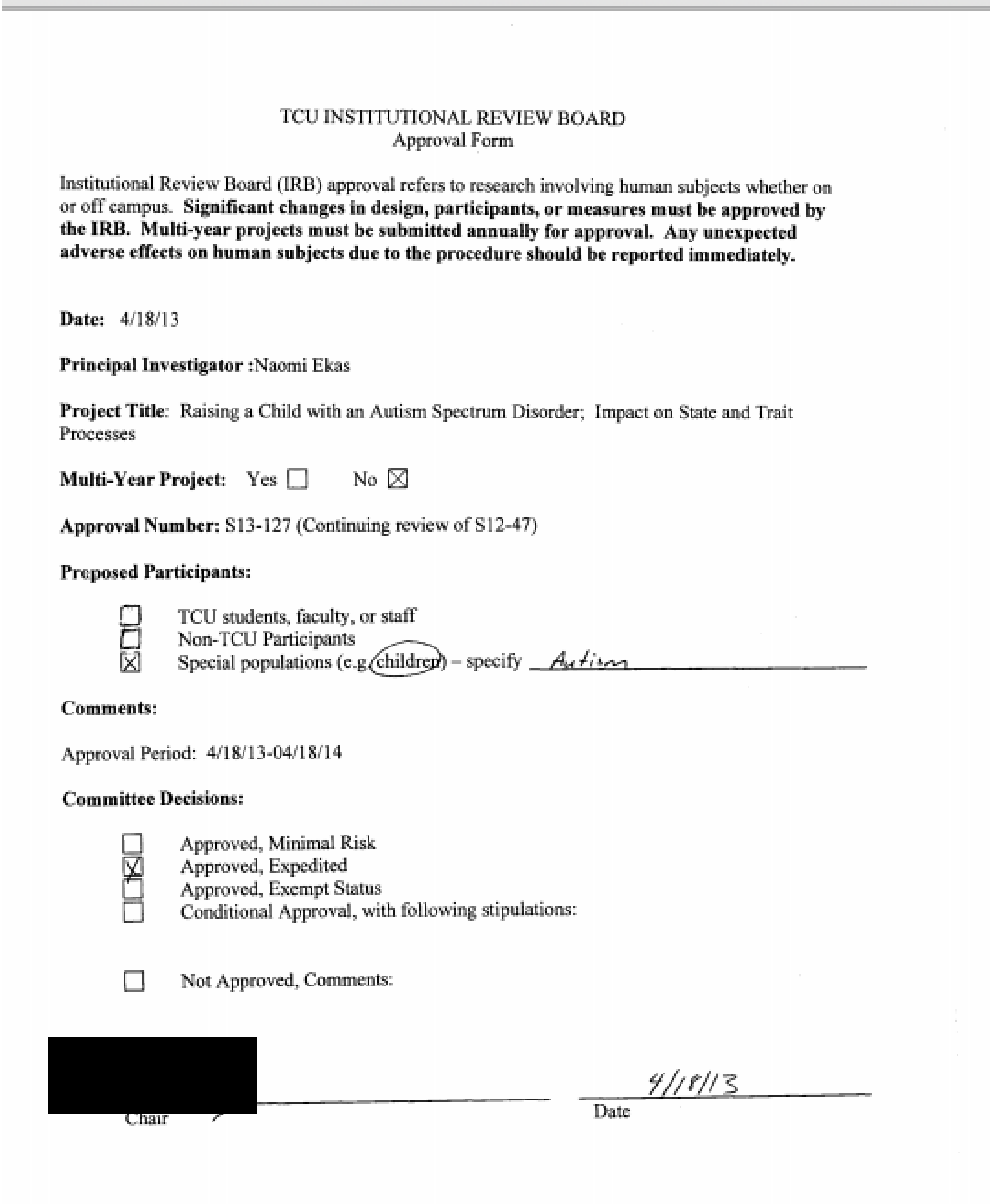
		Does not apply at all 1	Applies slightly, if at all 2	Applies somewhat 3	Applies very strongly 4
1	I am generous with my friends	1	2	3	4
2	I quickly get over and recover from being startled	1	2	3	4
3	I enjoy dealing with new and unusual situations	1	2	3	4
4	I usually succeed in making a favorable impression on people	1	2	3	4
5	I enjoy trying new foods I have never tasted before	1	2	3	4
6	I am regarded as a very energetic person	1	2	3	4
7	I like different paths to familiar places	1	2	3	4
8	I am more curious than most people	1	2	3	4
9	Most of the people I meet are likeable	1	2	3	4
10	I usually think carefully about something before acting	1	2	3	4
11	I like to do new and different things	1	2	3	4
12	My daily life is full of things that keep me interested	1	2	3	4
13	I would be willing to describe myself as a "pretty strong personality"	1	2	3	4
14	I get over my anger at someone reasonably quick	1	2	3	4

Scoring the ER89 using the tertile method

20-38 = Low ego resilience
39-42 = Average resilience
43-56 = Above average resilience

Appendix XXXIII

Appendix XXXIV



TCU INSTITUTIONAL REVIEW BOARD
Approval Form

Institutional Review Board (IRB) approval refers to research involving human subjects whether on or off campus. **Significant changes in design, participants, or measures must be approved by the IRB. Multi-year projects must be submitted annually for approval. Any unexpected adverse effects on human subjects due to the procedure should be reported immediately.**

Date: 4/18/13

Principal Investigator : Naomi Ekas

Project Title: Raising a Child with an Autism Spectrum Disorder; Impact on State and Trait Processes

Multi-Year Project: Yes ☐ No ☒

Approval Number: S13-127 (Continuing review of S12-47)

Proposed Participants:

☐ TCU students, faculty, or staff
☐ Non-TCU Participants
☒ Special populations (e.g. [✓ children]) – specify Autism

Comments:

Approval Period: 4/18/13-04/18/14

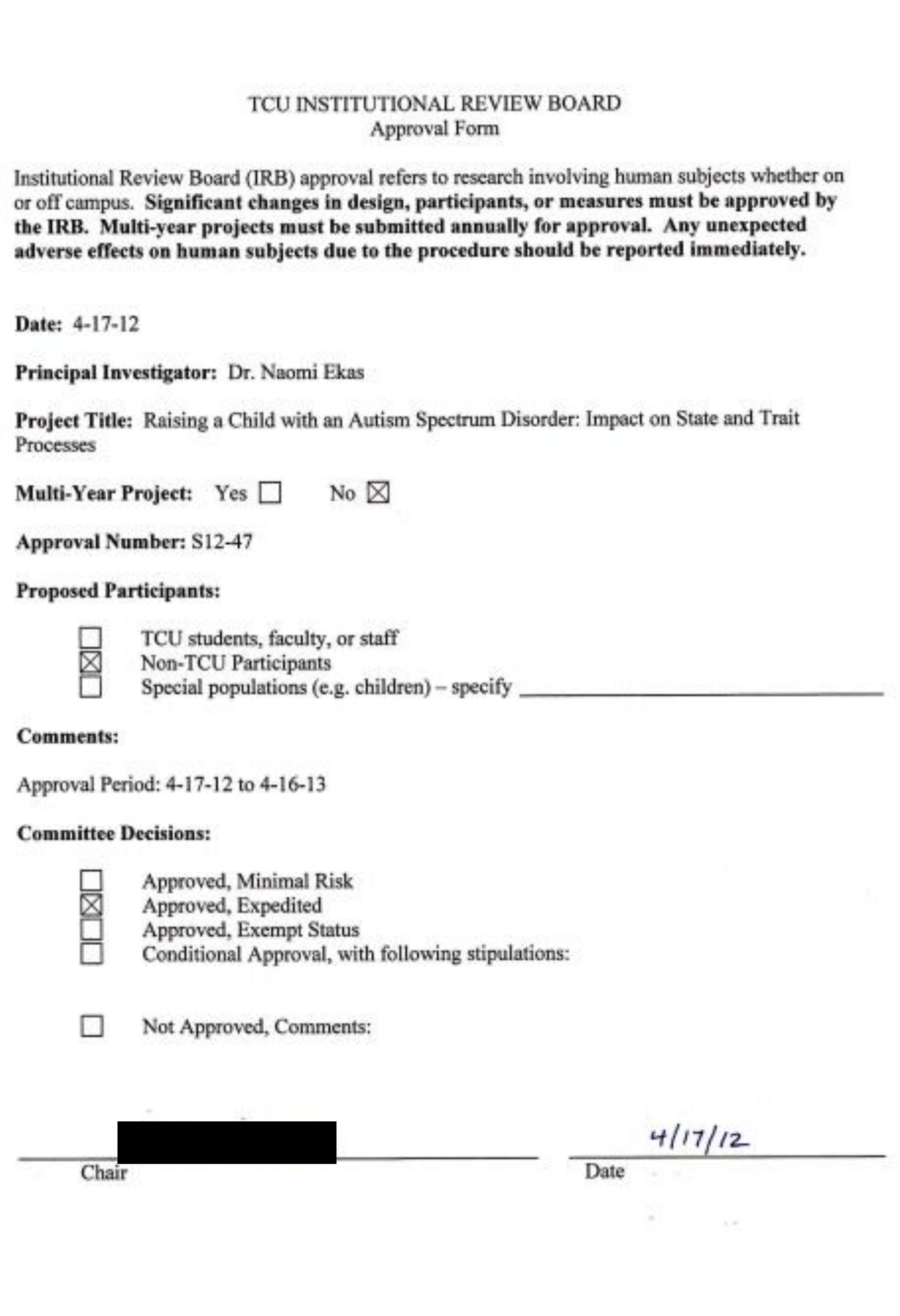
Committee Decisions:

☐ Approved, Minimal Risk
☑ Approved, Expedited
☐ Approved, Exempt Status
☐ Conditional Approval, with following stipulations:

☐ Not Approved, Comments:

[redacted]
Chair

4/18/13
Date



TCU INSTITUTIONAL REVIEW BOARD
Approval Form

Institutional Review Board (IRB) approval refers to research involving human subjects whether on or off campus. **Significant changes in design, participants, or measures must be approved by the IRB. Multi-year projects must be submitted annually for approval. Any unexpected adverse effects on human subjects due to the procedure should be reported immediately.**

Date: 4-17-12

Principal Investigator: Dr. Naomi Ekas

Project Title: Raising a Child with an Autism Spectrum Disorder: Impact on State and Trait Processes

Multi-Year Project: Yes ☐ No ☒

Approval Number: S12-47

Proposed Participants:

☐ TCU students, faculty, or staff
☒ Non-TCU Participants
☐ Special populations (e.g. children) – specify ____________________

Comments:

Approval Period: 4-17-12 to 4-16-13

Committee Decisions:

☐ Approved, Minimal Risk
☒ Approved, Expedited
☐ Approved, Exempt Status
☐ Conditional Approval, with following stipulations:

☐ Not Approved, Comments:

[redacted]
Chair

4/17/12
Date

Appendix XXXV

Turley R, Weightman A, **Halstead E**, Morgan H**,** Morgan F, Noyes J, Brophy S, Kipping R,Whitehead S. NICE Guidance title: Managing overweight and obesity among children and young people: lifestyle weight management services. Review 2: The barriers and facilitators to implementing lifestyle weight management programmes for children and young people. 2013

Turley R, Morgan H, Noyes J, Weightman A, Morgan F, Whitehead S, **Halstead E**. NICE Guidance title: Tobacco: harm-reduction approaches to smoking. Short title: Tobacco: harm reduction. Review 4: Barriers and facilitators to implementing smoking cessation and tobacco harm reduction approaches; including user and provider perspectives . 2012.

Parahoo K, McDonough S, McCaughan E, Noyes J, Semple C, **Halstead EJ**, Neuberger MM, Dahm P. Psychosocial interventions for men with prostate cancer. Cochrane Database of Systematic Reviews 2013, Issue 12. Art. No.: CD008529. DOI: 10.1002/14651858.CD008529.pub3.

Parahoo, K., McDonough, S., McCaughan, E., Noyes, J., Semple, C., Halstead, E. J., ... & Dahm, P. (2015). Psychosocial interventions for men with prostate cancer: a Cochrane systematic review. *BJU international*,*116*(2), 174-183.

Appendix XXXVI

Resilience in Children and Young People with Disabilities:

Systematic Review with embedded primary research.

PROTOCOL

Elizabeth Halstead

Introduction

As research into resilience is continually increasing, policy makers and practitioners are showing an increasing interest in the concept of resilience, and its influence on quality of life (Windle, 2010). However there is little evidence to suggest any focus on children with disabilities receiving any resilience promotion or guidance. Some children with disabilities suffer additional adversity such as abuse (NSPCC, 2002), this can include bullying in school and abuse at home. The strategic government policy has focused in recent years on safeguarding children from abuse, and assessing the risk and resilience factors in children based on theory by Daniel, Wassell and Gilligan (1999).

As children with disabilities are considered more vulnerable in *Gordon, R. et al, (2000) The Child's World Training & Development Pack, NSPCC*, and also at a higher risk of adversity including their disability itself and abuse from others, it is important to review existing literature on the concept of resilience and look at proposed and current Health, Education and Social care policies in the UK. The policies often focus on assessment of children for risk and resilience factors, therefore it is important to look at the measures used to measure resilience and look at their adaptability for children with disabilities as currently there is no assessment of resilience specifically for children with disabilities. Many of the Health and Social care programmes: such as Aiming High for Disabled children, from the previous government have been archived and therefore it is an ideal time to review the policies related to resilience in children with disabilities.

The Review

Aim

The aim of this systematic review is to conceptualise resilience in relation to children with disabilities. The systematic review will consider national policies, interventions and measures, to aid the understanding of the concept of resilience, and address the following questions:

Stream 1

1a. How does mixed method evidence conceptualise resilience?

   i) Research into the concept of resilience and what it is to be resilient.
   ii) Charities working with children and their view on resilience.

Stream 2

2a. What do the policies say about resilience and children with disabilities?

2b. How does this relate to the conceptualisation of resilience?

2c How does this relate to the programme theory underpinning the policy?

Stream 3

3a. What tools are being used to measure resilience?

3b. What concept of resilience is underpinning the tools (including domains of resilience)?

3c. What are the psychometric properties of the measures found not stated in the review (Windle, Noyes, 2010)?

Stream 4

4a. What interventions have been developed and tested to promote resilience for children with disabilities?

4b. What concept of resilience has been used in these interventions?

4c. What is the programme theory underpinning these interventions?

Post review question:

1. The views of children and young people with disabilities, along with others around them on resilience and what it means to them.

Design

A mixed method systematic review design will be used to address each aspect of the review. This will be based on the Evidence for Policy and Practice Information and Co-ordinating (EPPI) Centre (institute of Education, London) and the EPPI Centre Guidance by Oliver et al. (2005). The evidence will be in four streams; policy, conceptualisation, interventions and measures. Once the evidence for the systematic review has been collated, a focus group and individual interviews will be conducted with children with disabilities to establish their conceptualisation of resilience (ethical approval will be gained for this).

Review Streams and questions

Stream 1. General literature	Stream 2. Policies	Stream 3. Measures	Stream 4. Interventions
1. How does mixed method evidence conceptualise resilience?	1. What do the policies say about resilience and children with disabilities? 2. How does this relate to the conceptualisation of resilience? 3. How does this relate to the programme theory underpinning the policy?	1. What tools are being used to measure resilience? 2. What concept of resilience is underpinning the tools? 3. What are the psychometric properties of the measures found?	1. What interventions have been developed and tested to promote resilience for children with disabilities? 2. What concept of resilience has been used in these interventions? 3. What is the programme theory underpinning these interventions?

Quality Screening Exercise

Systematic and extensive searches of CINAHL (1980 to 2011), MEDLINE (CSA EARLIEST to 2011), psychINFO (CSA earliest to 2011), ASSIA (Earliest to 2012), Ovid Nursing Full Text Plus (1995 to 2012), Cochrane Library, Web of Knowledge, Google/Google scholar, websites, references from journals.	Searches of policy documents, best guidance documents and websites using PDF searches of previously agreed search terminology.	Systematic and extensive searches of CINAHL (1980 to 2011), MEDLINE (CSA EARLIEST to 2011), psychINFO (CSA earliest to 2011), ASSIA (Earliest to 2012), Ovid Nursing Full Text Plus (1995 to 2012), Cochrane Library, Web of Knowledge, Google/Google scholar, websites, references from journals.	Systematic and extensive searches of CINAHL (1980 to 2011), MEDLINE (CSA EARLIEST to 2011), psychINFO (CSA earliest to 2011), ASSIA (Earliest to 2012), Ovid Nursing Full Text Plus (1995 to 2012), Cochrane Library, Web of Knowledge, Google/Google scholar, websites, references from journals.

In depth appraisal (CASP) – *Excluding policy/ conceptualisation documents*

Documents/journals or websites which include evidence to conceptualise resilience in relation to children with disabilities	Policy documents which include information of resilience in relation to children with disabilities	An assessment of the psychometric features of measures not included in (Windle, Bennet, Noyes, 2011) and a description of previous measures used for measuring resilience in children.	Quantitative/ Qualitative and mixed method studies which are an intervention to promote resilience for children with disabilities.

Mixed method synthesis

Synthesis 1	Synthesis 2	Synthesis 3	Synthesis 4
1. Quality assessment	1. Data extraction	1. Quality assessment	1. Quality assessment
2. Data extraction	2. Findings	2. Data extraction	2. Data extraction
3. Findings		3. Findings	3. Findings

1. Does the concept of resilience in the literature match the definitions and programme theory of resilience upon which policies are based?

2 Does the concept of resilience in the literature match the definitions and programme theory behind the interventions that promote resilience, if they are using a concept (considering the domains of resilience)?

3. Does the concept of resilience in the literature match the definitions and theory behind the measures if they are using a concept of resilience (considering the domains of resilience)?

Primary Research – focus group, small group or individual interviews (as appropriate) with children and young people with disabilities to establish:.

1. **What are** the views of children and young people with disabilities on resilience and what does resilience mean to them?

Overarching Synthesis of findings to answer each review question and aim:

Post review Primary Research – focus group, small group or individual interviews (as appropriate) with children and young people with disabilities to establish:

1. To what extent do children and young people's views and meanings of resilience collected in primary research map onto current concepts and definitions in the literature?
2. What are the views of children and young people with disabilities on current resilience promoting interventions, and do their views and experiences match with the programme theory and logic of interventions reported in the literature?
3. If designing a new resilience promoting intervention for children and young people with disabilities - what do children and young people think would work and what would the intervention look like?

Search Methodology

A systematic review addressing Stream 1, 3 and 4 described above will be conducted. A wide range of databases and websites will be searched systematically and will identify relevant studies which have been made available in English and published between 1980 and May 2012.

Electronic sources; databases and websites

The following sources will be searched:

Databases:

ASSIA (Applied Social Science Index and Abstract)

CINAHL (Cumulative Index of Nursing and Allied Health Literature)

Cochrane Central Register of Controlled Trials

Cochrane Database of Systematic Reviews

EMBASE

Medline

Ovid Nursing Full Text Plus

PsycINFO

Websites:

NSPCC

The Resilience Project

Additional Searches

Following the searches of the databases and websites, reference lists of the included studies will be read through for identification of any other studies, and citation tracking will be conducted in Web of Knowledge. The journals that contain the greatest number of papers which have met the inclusion criteria will be searched through from January 2011 to identify any additional papers. In order to identify any unpublished work or research in progress, the first author of included studies will be contacted if it has been published since 2005.

The following websites will be searched as a rapid review for policy documents for stream 2; these will include any documents which are relevant in the UK:

Health, Education and Social Care local and national policies

An outline search strategy has been developed through Medline via Ovid as a strategy to identify research on children and young people, who have a mental or physical disability, and which incorporates the concept of resilience in some aspect. This search strategy has been tested against 10 papers known to the author, and will be tested against a further 15 to ensure sensitivity. Then it will be used in all other sources detailed above.

The Search Strategy has been developed to cover the three topics, children, disability and resilience. The search included key word searching, and the use of medical subject (MeSH) headings has been used, however this has been restricted, allowing for more specific searching in the title and abstract.

MeSH headings were explored, to develop a list of words associated with children up to 25 years. This was then combined with terminology of disabilities, and then of resilience. The three concepts are then ‘and’d together.

This search resulted in 6113 hits in Medline. In order to reduce ‘noise’ the searches were merged with adj in order to gain results which were relevant to children with disabilities, instead of mentioning either of these key words in the text.

Search Strategy for Stream 1, 3 and 4:

1. (child or children).ti,ab.
2. exp child/ or exp child, preschool/ or exp infant/ or exp infant, newborn/
3. young person.ti,ab.
4. exp Young Adult/ or exp Adolescent/ or exp Child/
5. (adolescen* or young adult* or teen*).ti,ab.
6. (disab* or mental* retard*).ti,ab.
7. exp Learning Disorders/ or exp Cognition Disorders/ or exp Intellectual Disability/ or exp Mental Competency/ or exp Disabled Persons/ or exp Education, Special/
8. (special educational needs or SEN).ti,ab.
9. ((child or children) adj1 disab*).ti,ab.
10. (resili* or hardiness).ti,ab.
11. exp Adaptation, Psychological/
12. (mental wellbeing or psychological wellbeing).ti,ab.
13. exp "Quality of Life"/
14. (cope or coping or coped).ti,ab.
15. Stress, Psychological/pc, px
16. ((psychol* or mental or stress or resil*) adj3 (adapt* or strength)).ti,ab.
17. exp Resilience, Psychological/
18. or/1-5 [combines children terms]

19. or/6-9 [combines disability terms]

20. or/10-17 [combines coping terms]

21. 18 and 19 and 20

Inclusion/exclusion criteria

		Included	**Excluded**
Stream 1 Concepts	**Type of Study**	Studies, policies, websites and researchers who have conceptualised resilience.	Concepts which are not based on theory, evidence or experience.
	Population	Resilience in children (up to 25 years) with disabilities	Acquired disability, not considered disability in DSM?
	Study Focus	Any study that included conceptual definitions or concept clarification	
Stream 2 Policy	**Type of Study**	United Kingdom (UK) national and local policy, United Nations policy will be included when the National Service Framework was based on this.	Policies not relevant or published for the UK and policies that have been replaced by recent versions.
	Population	Children with disabilities aged up to 25	
	Study Focus	This will include all Health, Education and Social Care local and national policies that consider resilience.	Policies which do not consider resilience in any domain.
Stream 3 Measures	**Type of Study**	International studies which have developed or reviewed measures which are aimed for children with disabilities, which incorporate resilience. Published in English/ translated into English	
	Population	Included if for children with disabilities up to 25 years	Above 25 years
	Study Focus	Quantitative and mixed methods.	

Stream 4 *Interventions and process evaluations associated with qualitative studies*	**Type of Study**	Qualitative/Quantitative studies which promote resilience in children with disabilities	
	Population	Children with disabilities aged up to 25 years	
	Study Focus	Qualitative, quantitative and mixed methods	

When interventions that are of interest are compared to interventions which have been excluded, these interventions will be included if the data of interest can be disaggregated. When studies include a population aged above 25 years as well as under, they will be included if the data for those below 25 can be disaggregated. When this is not possible, the studies will be excluded.

SPICE tables, (Booth, 2004)

<u>SPICE TABLE 1 (conceptualisation)</u>

Setting	Perspective	Intervention (problem of interest)	Comparison	Evaluation
Any Context	Researcher, Children, Young people, Parents, Policy, Societal	How resilience is conceptualised from trans various perspectives	No comparison	To gain an understanding of the similarities and differences features which appear in the conceptualisation of resilience

<u>SPICE TABLE 2 (policy)</u>

Setting	Perspective	Problem of interest	Comparison	Evaluation
Information on national policies (UK including Wales, Scotland, Northern Ireland and England) and policy framework surrounding resilience in children with disabilities, guidance and best practice.	3rd sector/ government/ professional bodies in the last 10 years (2001)	Resilience	Comparison of how resilience is stated and conceptualised across policies	None

SPICE TABLE 3 (measures)

Setting	Perspective	Intervention (problem of interest)	Comparison	Evaluation
Exploration of measures used for measuring resilience	Measuring resilience in children and young people, specifically with disabilities	Measuring resilience in children and young people	In comparison to adult measures, psychometric/domains	To compare children's measures for resilience and therefore gain general overall knowledge of the measures available

SPICE TABLE 4 (interventions)

Setting	Perspective	Intervention (problem of interest)	Comparison	Evaluation
Exploration of interventions used for promoting resilience	Knowledge of interventions used for promoting resilience in children and young people, specifically with disabilities	Resilience in children with disabilities		To become knowledgeable of the interventions used for promoting resilience in children with disabilities

Study Selection

The titles and abstracts will be screened by the author and a second reviewer by applying the inclusion and exclusion criteria. If there is any doubt, this will be discussed with a third reviewer. Full paper screening will be carried out by the author (and check with second)?? Inter-rater reliability testing will be carried out?

During the screening process the records will the tagged for relevance to either stream 1, 3 or 4, or a combination. Excluded papers will be retained with reasons for exclusion.

Quality appraisal

Studies will be appraised within each stream separately using relevant versions of the Critical appraisal Skills Programme tool (CASP). Policies and conceptualisation in Stream 1 and 2 will not be appraised.

Data extraction

Stream 2, the policy review will be conducted as a rapid review. The author will decide if the policies are relevant to the UK and up to date, by checking if the documents have been replaced. The data will be extracted in stream 1, 3 and 4 and summarised in separate tables adapted from the National Institute for Health and Clinical Excellence (NICE) Public Health Methods Manual and presented in the Evidence tables. With study characteristics, int and ext valid scores.. outcome measures?

Data Synthesis

First each stream will be synthesised individually. The relevant findings for stream 1 will be presented with the title, author, year of publication and conceptualisation of resilience in the evidence table. Stream 2 will be presented with the title, author, source, year and relevant statement from document in the evidence table. Stream 3 and 4 will be summarised in concise narrative summaries and evidence statements including the message of the evidence, the strength (based on CASP). The following outcomes will be answered:

1. Does the concept of resilience in the literature match the definitions and programme theory of resilience upon which policies are based?

2. Does the concept of resilience in the literature match the definitions and programme theory behind the interventions that promote resilience, if they are using a concept (considering the domains of resilience)?

3. Does the concept of resilience in the literature match the definitions and theory behind the measures if they are using a concept of resilience (considering the domains of resilience)?

Finally an overarching synthesis will take place (narrative synthesis), incorporating the findings from the primary research, to answer the following objectives.

1. To what extent do children and young people's views and meanings of resilience collected in primary research map onto current concepts and definitions in the literature?
2. What are the views of children and young people with disabilities on current resilience promoting interventions, and do their views and experiences match with the programme theory and logic of interventions reported in the literature?
3. If designing a new resilience promoting intervention for children and young people with disabilities - what do children and young people think would work and what would the intervention look like?

***Note: This systematic review was conducted, however, after much discussion the research available did not fit into a systematic review, with a strong methodology and clear results,that was suitable for publication or this thesis. This work was conducted in year one of my PhD Programme.**