The Psychological Adjustment of Siblings of Children with Disabilities: The Role of the Family and the Wider Social Community

Submitted in partial fulfilment of the requirements of the Degree of Doctor of Psychology

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Declaration of Authorship

Thesis title: The Psychological Adjustment of Siblings of Children with Disabilities: The Role of the Family and the Wider Social Community

Candidate’s name: Kate Emily Davis

I declare that this thesis:
- Is the result of my own research
- Does not contain any materials written or produced by another person except where due reference is made in the text
- Does not contain work submitted previously, in whole or in part, to qualify for any other academic award
- Is the result of work conducted since the official commencement date of the approved research program
- Was conducted in accordance with the principles of the ethical treatment of human subjects as approved by the RMIT Human Research Ethics Committee and the Department of Education and Early Childhood Development (DEECD)

Signed: _______________________

Date: ________________________
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Abstract

Research has consistently shown that siblings of young children with a developmental delay or disability are impacted in various ways by growing up with a brother or sister with a disability. While most siblings of children with disabilities adapt relatively well, a small percentage of siblings are vulnerable to developing adjustment problems. Despite this vulnerability, previous research in the area has focused predominately on the support needs of parents and the child with the disability, and less attention has been given to the psychological adjustment of siblings. Therefore, a greater understanding of siblings’ reported experiences and factors that influence sibling adjustment in families of young children with disabilities is needed.

Until recently, researchers have also studied siblings in isolation, ascribing little meaning to the family system surrounding them. With a greater emphasis given to ecological models of disability; however, both researchers and practitioners have identified the importance of the family context in promoting sibling development and adjustment. Nevertheless, the role of the wider social environment, including siblings’ experiences in the community and interactions with friends, continues to be overlooked. Such an approach to understanding the intricacies underlying sibling adjustment is at odds with Bronfenbrenner’s Ecological Systems Theory, which highlights the importance of the family in steering child development, as well as the significance of external environmental influences. Expanding upon current conceptual and empirical findings, a search for explanations for the variability found in sibling adjustment is necessary. Such information is fundamental for the development of evidence-based intervention programs targeted towards sibling adjustment and overall family quality of life.

The present thesis incorporates six chapters, which together aim to understand the experiences of siblings growing up with a brother or sister with a disability, and also the
contributing factors to psychological adjustment. Chapter 1 introduces the concept of sibling psychological adjustment, and adopts the developmental psychopathology perspective as an organising framework in understanding the range of factors that have been associated with sibling psychological outcomes. This chapter incorporates literature on typical child development, and argues that disability adds an extra dimension that has the potential to impact adjustment beyond that of children without the experience of a family member with a disability. The strengths of sibling research are also reviewed, as well as the shortcomings, providing a basis for the rationale behind the current thesis.

The rationale is then articulated in Chapter 2, incorporating Bronfenbrenner’s (1979, 1992, 1999) Ecological Systems Theory, the ‘Daily Events’ paradigm and principles of stress and coping. These theories provided a framework for the current research, and guided the development of the three individual studies which comprise this thesis. The aims and research questions of each of these studies are outlined in Chapter 2.

Study 1, entitled ‘A qualitative study to understand siblings’ experiences in the context of disability’ is the focus of Chapter 3. The aim of Study 1 was to investigate siblings’ experiences (hassles and uplifts), both within and outside the family environment, which are specific to their brother or sister with a disability. Seven siblings were recruited for this study, and siblings shared a range of daily hassles and uplifts associated with growing up with a brother or sister with a disability in face-to-face semi-structured interviews. Some of the identified uplifts included thoughts about feeling valued and ‘special’ among friends for understanding their brother or sister with a disability, as well as being actively involved in different organisations associated with disability (e.g., Down syndrome Victoria). Daily hassles included limited opportunities for outings as a family, disruption of time with friends, as well as enduring the reactions of others when in public.
The experiences shared by siblings were used to develop a self-report measurement tool, entitled ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’. The psychometric properties of this newly developed measure were assessed as part of Study 2, and are presented in Chapter 4. Results in Study 2 revealed that the ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’ has high internal reliability across most of the individual subscales (e.g., Family, Community), as well as the total hassles and uplifts scales. Each item within the hassles and uplifts scales provide a unique contribution while sharing communality with other items within the scale. The ‘Me and My Sib’ scale also has good face and content validity, as well as convergent and divergent criterion-related validity. This newly developed measure was incorporated into Study 3.

The sample for Study 3 (Chapter 5) encompassed 78 sibling-parent dyads who were recruited from several early childhood intervention centres, a special school, and other major organisations (e.g., Down syndrome Victoria, Autism Victoria, Very Special Kids) in the State of Victoria, Australia. The primary aim of this study was to identify the factors at a sibling, family and community level which contribute to the psychological adjustment of brothers and sisters of children with a disability. Siblings and parents each completed a self-report questionnaire, which elicited information about factors at a sibling level (i.e., temperament, coping, daily hassles and uplifts), family level (e.g., family functioning, parental wellbeing, differential parenting), and wider social community level (hassles and uplifts experienced by siblings in their interactions within the community; sibling and parents’ perceived connectedness to their support network). Sibling temperament, parental wellbeing, differential parenting, and siblings’ perceived connectedness to supports were shown to be predictive of adjustment. Results also revealed that various factors across a sibling, family and wider social community level were associated with different sibling
psychological adjustment outcomes (e.g., adaptive and maladaptive outcomes). A general
discussion of findings and their conceptual, methodological and practical implications are
presented in Chapter 6, as well as the strengths and limitations of the current research and
directions for future research.
Chapter 1

Sibling Adjustment in Families of Children with Disabilities

Families of children with developmental delays or disabilities\(^1\) are confronted with ongoing challenges that can impact various aspects of family life, as well as the adjustment and wellbeing of family members, including siblings (Dykens, 2005; O’Brien, Duffy, & Nicholl, 2009; Schuntermann, 2007). Research has consistently shown that while most siblings adjust relatively well to having a brother or sister with a disability, other siblings have a limited capacity to mentally, socially and physically adapt to the environment, leaving them vulnerable to adjustment difficulties (Ferraioli & Harris, 2010; Jackson, Richer & Edge, 2008). Despite the variability in sibling adjustment reported in numerous studies, little research has extended beyond sibling factors and explored the broad range of experiences siblings encounter on a daily basis within and outside the family environment that may be contributing to this discrepancy.

The aim of this chapter is to review the literature on sibling experiences and psychological adjustment in families of children with disabilities. First, theories and concepts underpinning child and adolescent adjustment from a developmental psychopathology perspective will be presented to provide a foundation for this thesis. Second, sibling adjustment will be defined, followed by a review of the factors across a sibling, family, and community level that have been shown to be associated with sibling outcomes. Reference will be made to studies that incorporate siblings of typically developing children, to highlight established empirical findings for all children.

Childhood is a critical time of development and intervention, with evidence suggesting that a significant proportion of childhood disorders (e.g., depression, anxiety)

\(^1\) Throughout this thesis, the terms “disability” and “developmental delay” will be used interchangeably to encompass those children with a range of physical, sensory, and intellectual problems.
have a chronic course, and although they may alter in form, continue into adulthood (Mash & Wolfe, 2002; American Psychiatric Association, 2000). The developmental psychopathology perspective has gained considerable attention in the literature as an approach to understanding disorders of childhood and adolescence, and the trajectory of these disorders into adulthood (Dishion & Stormshak, 2007; Muris, 2006). It emphasises the importance of the context and developmental process, as well as the influence of multiple and interacting experiences in determining adaptive and maladaptive outcomes (Bronfenbrenner, 1979, 1992, 1999; Darling, 2007; Shrink, Talmi, & Olds, 2000). In addition, it highlights the complexity and interplay of biological (e.g., genetic predisposition to mental health problems; brain development; temperament), familial (e.g., relationship processes) and sociocultural (e.g., school, community) factors in predicting and understanding both adaptive and maladaptive childhood development. Embedded within this definition is the notion that psychopathology is a consequence of multiple influences, and that both adaptive and maladaptive adjustment is important in conceptualising the development and progression of psychopathology. Multiple studies have provided evidence for this framework across a range of outcomes for typical children growing up outside the context of disability. To illustrate, Muris (2006) was guided by the developmental psychopathology approach in explaining the development and maintenance of childhood anxiety disorders. Muris’ review examined a range of risk and protective factors associated with the development of childhood anxiety disorders. Vulnerability factors identified included negative life events and family influences, whereas protective factors incorporated perceived and effortful control. Muris (2006) also discussed perpetuating factors, including avoidance and cognitive biases.

Despite a consensus that anxiety disorders and other mental health problems are a function of a range of influences, a limitation identified in Muris’ review is that most research has considered the multiple vulnerability and protective factors in isolation, with few studies
focusing on the sociocultural environment. As such, little is known about the interactive and unique contribution that different factors play in influencing adaptive and maladaptive development. It is plausible that these limitations also apply to the field of sibling research in the context of disability. Thus, the adoption of a developmental psychopathology perspective provides a useful organising framework to understand the dynamic, multidimensional process leading to adjustment in siblings of children with a disability.

Adjustment has been defined as the ability to respond to stress with respect to mental, physical and social aspects (Jackson et al., 2008). It encompasses the process by which individuals manage the perceived discrepancy between stressful life events, daily hassles and available resources (Frydenberg & Lewis, 1993; Thompson, Gustafson, Hamlett & Spock, 1992). Applied to siblings of children with disabilities, if the demands of the environment (e.g., growing up with a brother or sister with a disability) exceed the perceived resources needed to manage the circumstances (e.g., perceived connectedness to supports, appraisal of the situation), adjustment difficulties may occur. In contrast, if there is congruence between the demands of the environment (e.g., identified demands of growing up with a brother or sister with a disability) and the available resources, the sibling is more likely to cope adaptively with the experience and is likely to be well adjusted.

Studies that have focused on adjustment have varied extensively, and as such there is no uniform measure of sibling adjustment in families of children with a disability. Researchers have generally been guided by the assumption that siblings of children with disabilities are an ‘at risk’ population (Hannah & Midlarsky, 1985). Measures of adjustment outcomes have reflected this, and have included emotional distress, externalising behaviour problems and peer relationship difficulties (Sharpe & Rossiter, 2002). Until recently, the positive experiences and outcomes of growing up with a brother or sister with a disability have been largely overlooked (Dykens, 2005; Stoneman, 2005).
Contemporary studies have adopted a more strength-based approach to reviewing adjustment, with the positive consequences of growing up with a sibling with a disability gaining increasing attention (Labay & Walco, 2004; Stoneman, 2005; Taunt & Hastings, 2002). Obtaining a comprehensive understanding of sibling adjustment is a primary focus of the current thesis, and as such literature addressing the positive experiences (e.g., daily uplifts) and outcomes (e.g., self-concept) of growing up with a sibling with a disability are reviewed. Constructs used to assess sibling adjustment is discussed in the following section, in order to provide a foundation for assessing variables shown to contribute to the psychological adjustment of siblings of children with disabilities.

The Psychological Adjustment of Siblings of Children with Disabilities

Emotional Distress and Externalising Problems

Researchers contend that most behaviour problems can manifest either internally or externally (Achenbach & Edelbrock, 1983; Mash & Wolfe, 2002; Rossiter & Sharpe, 2001). Emotional distress refers to internal difficulties and are characterised by depression, somatic complaints, and anxiety (Achenbach & Edelbrock, 1983; Dishion & Stormshak, 2007). By contrast, externalising problems are characterised by distress being directed outwards towards others, and encompasses verbal aggression, non-compliance, oppositional defiance and conduct problems (Achenbach & Edelbrock, 1983; Mash & Wolfe, 2002).

Several studies have shown that both internalising and externalising problems are common in siblings of children with various disabilities, including autism, Down syndrome, and intellectual disability (Cuskelly & Dadds, 1992; Hasting, 2003; Rossiter & Sharpe, 2001; Verte, Roeyers, & Busse, 2003). Williams (1997) completed a meta-analysis that examined 43 studies incorporating children with a chronic illness, and found that 60% of studies reported an increased risk of adjustment problems for siblings. In addition, siblings were found to be at an increased risk of having internalising and externalising behaviours when
compared with siblings without a brother or sister with a chronic illness. In a recent study, Petalas, Hastings, Nash, Lloyd and Dowey (2009) explored the emotional and behavioural adjustment of siblings of children with an intellectual disability ($N = 24$) and those with a diagnosis of autism and an intellectual disability ($N = 25$). Siblings of children with both an intellectual disability and autism were found to have more behavioural and emotional problems (as measured by the Strengths and Difficulties Questionnaire) when compared to normative data or to siblings of children with an intellectual disability in isolation. These elevated scores for the autism/intellectual disability group were shown to be stable across time, as demonstrated by data obtained in an 18-month follow-up.

Other studies have revealed that siblings of children with disabilities are at no greater risk of developing internalising or externalising behavioural problems when compared to siblings of typically developing children (Benson, Gross, & Kellulfm, 1999; Ross & Cuskelley, 2006). Ross and Cuskelley (2006) used the Child Behaviour Checklist with a sample of siblings ($N = 25$) aged between 8 and 15 years, and found that mean scores on internalising and externalising were within the non-clinical range. However, there was high variability in the adjustment of siblings, with 40% of typically developing siblings having scores in the borderline and clinical ranges. These findings are consistent with a recent study conducted by Wood, Sherman, Hamiwka, Blackman and Wirrell (2008). The authors recruited 37 siblings (aged between six and 18 years) of children with intractable epilepsy. Through parent and sibling self-reports, information about symptoms of depression and anxiety among siblings was elicited. The results revealed that siblings were relatively well adjusted, with no sibling scoring in the clinical range on the Children’s Depression Inventory, and only a small percentage (6%) scoring in the clinical range on the Revised Children’s Manifest Anxiety Scale.
Based on this finding and those of others (Stawski, Auerbach, Barasch, Lerner, & Zimin, 1997), it can be concluded that disability may not be a risk factor in itself for the development of sibling psychopathology. Rather, studies on sibling adjustment may represent typical developmental variability in association with a range of risk and protective factors as they are experienced in the general population. It follows that it may be more informative to utilise concepts and measures that are sensitive to the experiences of siblings of children with disabilities (Stoneman, 2005), and not necessarily bound by categorical conceptualisations of psychopathology.

Both within the typical development and disability literature, there is considerable research on the manifestation of externalising behaviours in children and adolescents (Achenbach & Edelbrock, 1983; Berk, 2006). However, there has been less emphasis on emotional distress and internalising problems (Berk, 2006). This variation is likely to be a consequence of externalising behaviours being overt and disruptive for parents, teachers, and the wider community. Internalising problems, however, do not necessarily spill over to influence others, and as such conditions such as anxiety disorders can go undetected (Silverman & Treffers, 2001; Vasey & Dadds, 2001). Further research in the area of internalising problems is needed, particularly in the sibling field in order to improve the empirical foundation for the design of effective interventions for this population.

**Self-Concept and Self-Esteem**

Researchers now contend that sibling psychological adjustment encompasses dimensions beyond externalising and internalising behaviours (Moore & Keyes, 2003). One aspect related to adjustment found in the literature on typical development is concerned with the notion of how children perceive themselves (Mash & Wolfe, 2002; Moore & Keyes, 2003). This is referred to as self-concept, and encompasses knowledge and evaluation of one’s own values, qualities and strengths. Self-concept is closely related to self-esteem,
which has been defined as one’s own judgement of self-worth (Berk, 2006; Mash & Wolfe, 2002).

In the context of disability, studies have shown that siblings of children with a disability have an increased risk of presenting with lower self-confidence and self-worth when compared to their same age peers who grow up without a brother or sister with a disability (Gamble & McHale, 1989; Lavigne & Ryan, 1979). Gamble and McHale (1989) compared self-esteem, as measured by the Harter's Perceived Competence Scale, across siblings of children with and without an intellectual disability. Each group had a sample size of 31 and the mean age of siblings was 12 years. A group by gender interaction was found, whereby female siblings of children with an intellectual disability experienced lower global self-esteem when compared to male siblings of children with a disability and the control group.

Other studies in this area have revealed that siblings of children with disabilities are indistinguishable from their peers in regards to self-concept and self-esteem (Rodrique, Geffken, & Morgan, 1993; Singhi, Malhi, & Dwarka, 2002; Verte et al., 2003). Mates (1990) found that when reported by parents and teachers, siblings (aged between 5 and 17 years) of children with autism had comparable scores to the normative sample on a measure of self-concept. Recent reviews have also suggested that some siblings are not only indistinguishable but find psychological strength from growing up with a brother or sister with a disability (Gallo, Breitmayer, Knafl, & Zoeller, 1993; Stoneman, 2005). Faux (1993) found that when compared with their counterparts, siblings of children with disabilities demonstrated increased empathy for others, were less self-centred, and were protective of their brother or sister with a disability. Research has consistently demonstrated that self-concept and self-esteem are influenced by a range of factors, including the opinions that others make of us, and comparisons and perceptions of the way one is similar to or different to those around
them (Berk, 2006; Bos, Muris, Mulkens, & Schaalma, 2006). Siblings of children with disabilities, like most children, operate within multiple systems, and their self-concept and the way that they understand themselves and manage the environment in which they live will be influenced by their interactions with others (Berk, 2006; Bos et al., 2006; Hoffman, Ushpiz, & Levy-Shiff, 1988). This includes their interactions with their parents, their brother or sister with a disability, peers, and individuals within the wider community (Bos et al., 2006).

An examination of the broad range of possible risk and protective factors across the multiple systems that may be contributing to variability on this psychological adjustment indicator has been scarce. Furthermore, few studies investigating self-concept notions have invited siblings to be informants of their own sense of self. Using sibling reports is particularly important when obtaining information about self-concept, as it is difficult for parents to provide information on siblings’ cognitions. For example, it would be difficult for parents to answer questions such as ‘I like myself’ and ‘I am happy to be me’ on behalf of their child.

Self-esteem and self-concept are important constructs that have been shown to be related to academic achievement, social functioning and the development of psychopathology in children and adolescents (Mash & Wolfe, 2002). Given the role of self-concept, using siblings as informants of their own self-worth, is therefore a primary focus of the current thesis.

Social Competence and Peer Relationships

The development of peer relationships and social competence constitutes another area of investigation in sibling psychological adjustment (Mandleco, Olsen, Dyches, & Marshall, 2003). Current findings suggest no apparent differences in social competence between individuals with typically developing siblings and those with a brother or sister with a
developmental disability (Grissom & Borkowski, 2002). Grissom and Borkowski (2002) compared siblings of children with and without a disability (27 siblings in each group) aged between 13 and 18 years across measures of self-efficacy, peer competence, and maternal attitudes and modelling of prosocial behaviour. The results indicated comparable scores and no significant differences between siblings of children with or without a brother or sister with a disability across each of the domains.

Contrary to these findings, other studies have found that when compared to siblings of children without disabilities, those with a brother or sister with a disability are likely to demonstrate greater social competence (Mandleco et al., 2003). Mandleco and colleagues (2003) investigated 78 parent-sibling dyads (half with and the other half without a family member with a disability) aged between four and 11 years. When compared to the comparison group of siblings of children without disabilities, siblings growing up with a brother or sister with a disability demonstrated more cooperation, assertion and self-control in the classroom, as rated by their schoolteachers. This highlights potential positive consequences of growing up with a brother or sister with a disability, an area that has begun to gain further attention in the literature.

Studies across various dimensions of psychological adjustment highlight that having a brother or sister with a disability is not a risk factor for maladjustment in itself, and that many children can benefit and thrive in a positive way from having a sibling with a disability. However, it is possible that when multiple factors are present (e.g., parental conflict, minimal resources, lack of knowledge about disability), it may be more difficult for the typically developing sibling to address environmental and family experiences associated with a sibling with a disability, which in turn may impact adjustment. Based on the current literature review, and the theoretical framework underpinning this thesis (i.e., developmental psychological perspective, Bronfenbrenner’s Ecological Systems Theory), it can be argued
that a number of other variables are at play, both internal and external to siblings, which are contributing to their psychological adjustment.

**Factors Associated with Sibling Adjustment**

**Sibling Factors**

Within the typical development literature, factors such as stress, cognitive and behavioural coping responses, and temperament have gained attention as potential perpetuating and protective factors in the development of adaptive and maladaptive adjustment (Harmer Cox, Marshall, Mandleco, & Olsen, 2003; Mash & Wolfe, 2002). Researchers have begun to extend these findings and investigate the role of these variables in the development of psychopathology and adjustment in siblings of children with disabilities (Harmer Cox et al., 2003).

Various conceptualisations of stress and more meaningful ways to assess this construct have been proposed in sibling research (e.g., ‘daily life events’ paradigm). The ‘daily events’ paradigm provides a foundation for the current thesis (Caltabiano, Byrne, Martin, & Sarafino, 2002; Giallo & Gavidia-Payne, 2006). Advocates of this framework postulate that it is the constant hassles and frustrations that are encountered on a daily basis that are stressful, and increase the likelihood of adjustment problems more so than major life events (Caltabiano et al., 2002). This paradigm has been applied to different cohorts across the lifespan, including first-year university students, adolescents and adults, with results consistently finding an association between hassles and uplifts, and health and wellbeing (Caltabiano et al., 2002).

Despite the evidence underlying the daily events paradigm, few studies have focused on the daily hassles encountered by siblings (Giallo & Gavidia-Payne, 2006). Of those that have been conducted, some of the daily annoyances that have been identified include the child with a disability taking their brother or sisters belongings, interruptions to family
routines due to appointments for the child with a disability, increased responsibility for the typically developing child and the need to take on a care-takers role (Gamble & McHale, 1989; Kramer, 1984). Research investigating daily hassles and frustrations for siblings has generally been confined to the child with a disability, overlooking experiences and interactions at a family and wider social community level (Giallo & Gavidia-Payne, 2006). Further, little effort has been devoted to linking these experiences to outcomes (e.g., self-concept, internalising and externalising problems), and thus the relationship between daily hassles and uplifts and sibling adjustment remains unclear. In this context, the role of coping in alleviating the impact of daily hassles and annoyances on adjustment also need to be considered.

It has been well documented that cognitive and behavioural responses can mediate the relationship between stress and psychological adjustment (Harmer Cox et al., 2003). This process is known as coping, and can be characterised as the siblings attempt to deal with stressful events and daily hassles. Harmer Cox and colleagues (2003) examined the coping responses of 46 siblings of children with a disability who were aged between six and 16 years. Siblings self-reported on their methods of coping by responding verbally to a sentence-completion activity. Four categories of coping were then identified using cluster analysis. These included proactive (e.g., figure out how to solve the problem), interactive (e.g., get help), internally reactive (e.g., get mad, frustrated), and non-active (e.g., ignore it) coping. Harmer Cox and colleagues (2003) noted that most responses (66%) were consistent with a proactive coping style, demonstrating that siblings of children with a disability are more likely to engage in problem-solving and/or physical activities when confronted with a stressful event. This is in contrast to the findings of Kendall (1999) who found that siblings of children with ADHD used avoidant strategies to cope, or accommodated to the child’s aggression and hyperactivity by giving their sibling want he or she wanted. Essentially, this
behaviour was likely to reinforce the child’s aggression, and lead to adverse consequences for the siblings, given that avoidant coping strategies have generally been linked to poorer adjustment (Frydenberg & Lewis, 1993).

The studies conducted by Harmer Cox and colleagues (2003) and Kendall (1999) raise several implications about the factors that may contribute to the adoption of different coping strategies. It is possible that avoidant coping strategies are employed when an individual perceives the stressful situation as being out of his or her control (Hardy, Power, & Jaedicke, 1993). Applying this premise to siblings of children with disabilities, avoidant coping may be used by siblings when they perceive that their brother or sister’s behaviour is beyond their control. Different temperament profiles (e.g., persistence) may also play a role in coping, which is another sibling characteristic that has recently been recognised as an important developmental variable in the literature (Rivers & Stoneman, 2008).

Temperament is biologically based, relatively stable, and has been shown to influence the way individuals regulate emotions, interact with others, and understand the world around them (Gallagher, 2002; Lengua, 2006; Lengua & Long, 2002). Across sibling research, temperament profiles have been shown to be associated with different outcomes for children, parents and the wider family system. To illustrate, high reactivity, emotional instability, irritability, and low persistence, defined as an inability to sustain attention and difficulty with self-regulation, have consistently been associated with poorer emotional and social functioning, and behaviour problems (Lemery & Goldsmith, 2001; Stoneman & Broady, 1993).

Rivers and Stoneman (2008) recently investigated the impact of different temperament styles on the sibling relationship across 50 children with an autism spectrum disorder and their siblings. Persistence was found to be an important predictor of positive sibling relationships, with higher scores on this domain of temperament for siblings being
associated with lower scores on negative relationship quality. Rivers and Stoneman (2008) provide an explanation for this finding, suggesting that typically developing siblings who are more persistent may be determined to connect with their sibling with an autism spectrum disorder, and engage in a particular task until a response is elicited. An interaction effect was also found, whereby high scores on the persistence scale for both the child with an autism spectrum disorder and the sibling contributed significant variability in predicting sibling relationship quality. The authors argue that children with an autism spectrum disorder may be able to respond to the social invitations of their typically developing sibling, and even initiate social interactions, thus building on the sibling relationship. These findings show a direct relationship between the temperament of both the child with a disability and the typically developing sibling, and the perceived quality of the sibling relationship. It is likely that temperament will indirectly influence the sibling relationship and adjustment through its association with other factors such as parenting and family functioning.

**Family Factors**

Families of young children with disabilities are confronted with ongoing challenges and stressful life events that can disrupt most aspects of their home and community life (Blacher, Neece, & Paczkowski, 2005; Guralnick, 2004). While some families accommodate and adjust their lifestyle to overcome the stressors that are associated with raising a child with a disability, others are not so resilient, and are at risk of experiencing adverse family outcomes and an unbalanced family system (Smith, Oliver, & Innocenti, 2001; Walsh, 2003). This can have implications for the health and wellbeing of all family members, including siblings. These assumptions have been generally framed within *family systems theory*, which emphasises the importance of family interaction and how family members are impacted by one another (Rosenbaum, King, Law, King, & Evans, 1998; Turnbull, Turnbull, Erwin, & Soodak, 2006). According to proponents of this theory, a child with a disability can *directly*...
impact the psychological development and functioning of their typically developing sibling. It is also based on the premise that siblings of children with disabilities can be indirectly influenced by the family environment, as well as interactions and relationships with other family members such as parents (Turnbull et al., 2006).

Consistent with the view regarding indirect influences in the family context, parents of young children with disabilities are often exposed to a range of stressors, which may include coming to terms with their child’s diagnosis, the long-term implications of the child’s disability, networking the best professional supports, and finding the resources needed to partake in these programs (Guralnick, 2004). Meeting these demands while simultaneously promoting the wellbeing of other family members can be a difficult task for parents and the cumulative effect of these stressors can precipitate episodes of depression, anger, anxiety, and marital problems at a parent level. This in turn is likely to impede on parental confidence and parent-child interactions, resulting in adverse psychological outcomes for siblings (Benson & Karlof, 2009; Ishizaki et al., 2005; Kagan & Lewis, 1996; Quintero & McIntyre, 2010).

Quintero and McIntyre (2010) compared maternal wellbeing and sibling social, behavioural and academic adjustment across families of children with (n = 20) and without (n = 23) an autism spectrum disorder. Results revealed elevated scores on daily hassles, life stress, and depression among mothers of children with an autism spectrum disorder when compared to their counterparts without a child with a disability. Maternal wellbeing was shown to be significantly related to sibling behavioural adjustment, with poorer wellbeing being associated with greater behavioural problems. In a similar study, Jackson and colleagues (2008) conducted a study on 41 families of children with Type 1 diabetes mellitus. Results revealed that parental stress as well as the siblings’ understanding and perceptions of diabetes significantly predicted sibling adjustment. Elevated parental levels of stress can also have
implications on parenting practices including differential parental treatment, which has been associated with sibling adjustment (Wolf, Fisman, Ellison, & Freeman, 1998).

Given the extra demands and resources needed to care for a child with a disability, parents are often apprehensive about whether typically developing siblings are receiving adequate attention (Naylor & Prescott, 2004; Parker & Stimpson, 2002; Strohm, 2002; Wolf et al., 1998). While differential parent treatment is evident in most families, Bischoff and Tingstrom (1991) found that siblings of children with a brother or sister with a disability reported greater inconsistency in parenting than their counterparts with typically developing siblings. That is, children perceived that when compared to themselves, the child with a disability was receiving more parental attention and preferential treatment. Different treatment can have a negative impact on psychological adjustment, as demonstrated by McHale and Gamble (1989). These authors found that typically developing siblings are vulnerable to experiencing anxiety and depression if they perceive that their brother or sister with a disability is being treated more favourably. Wolf and colleagues (1998) reported that greater perceptions of differential treatment were associated with internalising and externalising behaviour problems across siblings of children with a brother or sister with a disability. This finding has been replicated in families of children without disabilities, with differential treatment being associated with low self-esteem and adjustment problems (McHale, Updegraff, Jackson-Newsom, Tucker, & Crouter, 2000).

Rivers and Stoneman (2008), in the study described earlier, also investigated the role of differential treatment, and its interaction with sibling level factors, including temperament. These authors found that persistence influenced how siblings viewed parenting practices. Siblings who scored lower on persistence (as measured by parents and siblings) reported greater dissatisfaction with differential parenting than their counterparts who were higher on persistence. This in turn had a negative impact on the perceived quality of the sibling
relationship, and had the potential to influence adjustment (Brody, 2004; Powell & Gallagher, 1993). The spill over effect into sibling adjustment has been supported by literature focusing on typical sibling dyads where no sibling has a disability, and as such may be evident in families of children with disabilities (Jenkins & Smith, 1990).

Rivers and Stoneman (2008) considered the relationship between persistence and differential parenting for both the child with a disability and the typically developing sibling. These authors noted that siblings who score high on persistence are less likely to be concerned about the amount of time parents are spending with the child with an autism spectrum disorder when they are preoccupied with other activities and not concerned about spending time alone. Conversely, when the child with a disability has elevated scores on persistence and is engaged in other activities, parents may be more able to dedicate additional time to the sibling. This is turn is likely to result in more favourable options of parenting practices, and consequently the sibling relationship and adjustment.

While Rivers and Stoneman (2008) obtained a measure of sibling satisfaction with differential parenting, few studies have elicited information from siblings and identified whether typically developing siblings are able to provide an accurate reflection of what is occurring within the family unit, and further how this influences their psychological adjustment. This is a critical question as it may be siblings’ perceptions and the attributions that typically developing siblings attach to parental practices that determine whether such treatment has an adverse effect on their psychological adjustment. In a sample of 21 typically developing siblings of children with cancer, Havermans and Eiser (1994) found that 12 siblings identified that they were receiving differential treatment from their parents, which they attributed to the child’s illness. While some of these children reported feeling ‘jealous’ and believed that they were being ‘left out’ from activities, others perceived that their sibling with cancer ‘needed more attention’ and that ‘it was fair’. As a result of these positive
thoughts (e.g., brother/sister with a disability needed it more) around differential parenting, these siblings were not as distressed about the additional attention that their sibling with cancer was receiving when compared to those siblings with more negative thoughts (e.g., being left out).

Adopting a cognitive-behaviour perspective, it is likely that the appraisal that siblings attach to differential treatment is going to influence their feelings and consequently behaviour and adjustment. Interpreting differential parent treatment as justifiable in terms of meeting the needs of the individual child with the disability may shield the sibling from unfavourable consequences, as it is likely to result in more positive feelings. This is an important line of inquiry in terms of sibling intervention; however, little research has been conducted to ascertain the relationship between siblings’ thoughts around differential treatment and adjustment. Communicating and facilitating discussions with siblings around differential treatment may also be valuable, providing siblings with the resources needed to have more positive thoughts in regards to their situation (Havermans & Eiser, 1994). Communication within the family unit is another factor at the family level that will now be reviewed.

Open communication, defined as making information, ideas, thoughts, and feelings transparent within the family, as well as the freedom to express emotions within the family system, have been associated with greater adjustment in siblings of children with a disability (Gold, 1993; Powell & Gallagher, 1993). Open communication has been shown to promote siblings’ expression of their emotions, provide assurance, comfort, and knowledge and information about disability (Gibbs, 1993). Havermans and Eiser (1994) found that communication with parents about their sibling’s illness was associated with less general impact of the illness on the siblings’ lives. General impact was measured by asking siblings to rate the extent to which they perceived the illness has affected their lives on a 5-point Likert scale.
At times, parents may elect not to communicate information about the child with a disability to other members of the family and attempt to separate the family from the community in an effort to preserve the ‘family’s secret’. Engaging in these behaviours further contributes to a lack of information and understanding for the sibling which in turn can result in a number of unfavourable consequences including somatic complaints and feelings of depression (Powell & Gallagher, 1993). Without sufficient information, siblings of children with disabilities are unable to modify their thoughts and feelings, and have difficulty developing a rational interpretation of the impact that the individual with a disability is having on family life (Howlin, 1988; Lobato & Kao, 2002). Some siblings may also be reluctant to talk to their parents, as they do not want to trouble them with their concerns, and consequently they are limited in the people they have available to confide in. This can lead to unexpressed emotions as siblings may fear that if they talk to their parents about the child with a disability, they may say something wrong and get into trouble (Opperman & Alant, 2003). A greater understanding about the factors that are contributing to parents choosing to either share or withhold information about disability would provide a valuable contribution to interventions in this field.

It is important to acknowledge that while open communication is an essential element in facilitating sibling adjustment, research has shown that one of the strongest factors that influences sibling acceptance of their brother or sister with a disability is parental attitudes (Powell & Gallagher, 1993). Parental attitudes is characterised by parents’ thoughts and feelings about the child with the disability. If parents are having difficulty accepting the child’s disability and perceive it to be a burden on the family, this attitude may be captured and embraced by other members of the family (Powell & Gallagher, 1993). Evidence for this premise has been generated by studies indicating that parental optimism and a positive outlook are associated with enhanced adjustment in siblings of children with disabilities and a
more positive sibling relationship (Powell & Gallagher, 1993). By contrast, if parents are having difficulty accepting the situation and relay this to other members of the family, siblings may be at greater risk of adjustment problems.

Family cohesiveness and adaptability are other factors at a family-level that have gained attention (Walsh, 2003). Family cohesiveness can be defined as the family connectedness and ability of family members to provide support to one another. Adaptability can be understood as the ability for the family system to remain flexible in response to the environment and associated stressors (Olson, Russell, & Sprenkle 1989). Cohen and colleagues (1994) recruited 129 siblings of children with cancer, and found that family cohesion and adaptability mediated the impact of a cancer diagnosis on sibling adjustment. Results indicated that higher cohesion and adaptability were associated with greater adjustment, as measured by the Child Behaviour Checklist. Family cohesiveness and adaptability serves a protective role, and can facilitate movement to and sustainability of the system at a desired level. It can also facilitate healthy relationships and minimise family and marital conflict which is another factor at a family level which warrants consideration.

Siblings are sensitive to conflict within the family and conflict arising from within the marital relationship (Gibbs, 1993; Gold, Treadwell, Weissman, & Vichinsky, 2008). This in turn has been shown to compromise sibling psychological adjustment, with studies demonstrating more externalising problems as well as poor self-concept and social competence in siblings exposed to an environment characterised by conflict (Rodrique et al., 1993). Rodrigue and colleagues (1993) found that the age of the sibling and the quality of the marital relationship were the only variables that predicted adjustment for siblings of children with autism. In their absence, these individuals were at no greater risk of adjustment problems then were children from families with typically developing siblings or those with Down syndrome. This is consistent with findings in the literature on typical child
development, with marital stress being shown to be related to inconsistent and dysfunctional parenting, and consequently adjustment concerns (Stoneman & Brody, 1993). Based on these findings, a strong marital relationship may serve a protective role and help parents to cope with the demands of daily life, thus allowing parents to meet the needs of other family members including siblings.

In summary, many factors at a family level, including differential parenting, open communication, as well as quality of the parent relationship can influence sibling adjustment. While researchers have begun to capture the importance of the family system in influencing sibling outcomes, little research has been conducted to ascertain the influence of these factors on siblings’ own perceptions of self-worth, and positive psychological outcomes. The interactive nature of family and wider social community-level factors has also received little attention, with social support and its association with sibling adjustment being another area of interest within the current thesis.

Social Support

Research has consistently shown that social supports can directly and indirectly (e.g., through parent-sibling interactions) influence sibling psychological adjustment (Hastings, Thomas, & Delwiche, 2002; Rivers & Stoneman, 2008). Social support can be defined as an interpersonal exchange between two or more people that is intended to enhance wellbeing (Caltabiano et al., 2002). Both informal and formal support falls under the umbrella of social support. Formal supports encompass professionals, for example the early childhood intervention team (e.g., psychologists, speech therapists, occupational therapists), whereas informal supports include people such as grandparents and friends. Within the general population, social support has been found to serve as a buffer to mental and physical illness and has been associated with decreased feelings of loneliness (Caltabiano et al., 2002).
Loneliness is characterised by an upsetting feeling that occurs subsequently to perceiving that one’s social needs (e.g., the quantity and even more so the quality) are not being fulfilled by one’s social relationships (Hawkley & Cacioppo, 2010). Some theorists advocate that perceived loneliness is comparable to feeling unsafe, and this triggers hyper-vigilance for social threats in one’s surrounding. Individuals proceed to unconsciously screen the environment for social threats, which elicits cognitive biases. When compared to their counterparts who feel socially connected, lonely individuals perceive their environment as threatening, anticipate that they will encounter negative social interactions, and focus on negative social experiences. In an attempt to protect themselves, lonely individuals avoid social situations and consequently opportunities to engage with other people. This is often referred to as the self-reinforcing loneliness loop, which has been shown to be associated with a range of feelings including anger, anxiety, decreased feelings of self-esteem, and depression. Neurobiological changes as a consequence of loneliness have also started to gain attention (Hawkley & Cacioppo, 2010).

The direct association between social support, perceived social connectedness, decreased feelings of loneliness and psychological adjustment in siblings of children with disabilities has been considered, however studies have been scarce (Mascha & Boucher, 2006; Kaminsky & Dewey, 2002). In one of the few studies that have been conducted in this area, Kaminsky and Dewey (2002) recruited a sample of 90 siblings aged between eight and 18. A primary aim of this study was to ascertain whether feelings of loneliness and social support were associated with psychological adjustment across three groups, including siblings of children with autism, Down syndrome, and those without a brother or sister with a disability. This study found that perceptions of social support were consistent across the three groups, and that decreased feelings of loneliness, as measured by the Loneliness and Social Dissatisfaction Questionnaire, were associated with higher levels of social support, as
measured by the Social Support Scale for Children. Interesting, this study found that both social support and social connectedness were not associated with psychological adjustment, as measured by the Achenbach Child Behaviour Checklist. Kaminsky and Dewey (2002) provide an explanation for this, hypothesising that this finding may be the result of a well-adjusted sample.

Research has also revealed that siblings exhibit more positive feelings and develop an enhanced tolerance towards their brother or sister with a disability when professionals include typically developing siblings into their programs (Mascha & Boucher, 2006). Mascha and Boucher (2006) indicate that this is associated with siblings having an opportunity to explore and express their emotions about the child with a disability and their impact on the family system. In the absence of feeling connected to a secure social network, siblings may be vulnerable to depressive symptoms which may be further exacerbated if they are subjected to a challenging environment outside the home.

Little research has been conducted on siblings’ perceived level of loneliness and its association with psychosocial adjustment. In the typical development literature, loneliness is reported to be common, with 80% of individuals under 18 expressing feelings of loneliness at some stage. This is of particular concern considering that loneliness in children and adolescents has been associated with adjustment problems, anxiety, depression, and increased rates of suicide and absenteeism from school (Davis, 1990; Hymel, Rubin, Rowdem, & LeMare, 1990; Parker & Asher, 1987). Given the trajectory of loneliness, research is needed to ascertain if siblings of children with disabilities are at an increased risk of loneliness and further how this relates to their adjustment. Given that few studies have invited siblings to be informants of their perceived connectedness to those around them, the conclusions and implications that can be drawn from current research remains limited.
Based on the interactive nature of relationships within the family unit, it is also possible that social support available to parents will be associated with parent psychological wellbeing, which will indirectly influence sibling adjustment. It has been well established in the literature that social connectedness and support from extended family members (e.g., grandparents) may help parents to cope with the extra demands of raising a child with a disability. To illustrate this, Hastings and colleagues (2002) found that positive perceptions of grandparent support were associated with enhanced emotional wellbeing and less stress in mothers caring for a child with Down syndrome. White and Hastings (2004) also found that after controlling for the child’s adaptive and problem behaviours, informal support was negatively associated with parental scores of anxiety, depression, and stress. In a recent study by Benson and Karlof (2009), social support was most effective in reducing stress proliferation, known as the tendency for an initial stressor to spill over and create additional stressors in other aspects of the individual’s life. Social support was also related to alleviations in depressed mood in parents of children with less severe autism. This raises an interesting question in terms of the mechanism through which social support has an effect, with some studies demonstrating that in the context of extreme stress, social support has little or no impact on wellbeing (Cutrona, 1986). It is likely that parents need to perceive that they are connected to their support team for social support to have a positive influence of physical and mental health. Specifically, when parents perceive that they are connected, feelings of loneliness are likely to decrease, resulting in positive psychological outcomes for parents (Cacioppo, Fowler, & Christakis, 2009; Hawkley & Cacioppo, 2010; Siklos & Kerns, 2006). Conversely, when conflict arises from within this form of support or when the support is perceived as unhelpful, parents may not feel connected and perceive that they do not have the resources available to meet their own needs and those of other family members, including siblings. As such, and consistent with the theoretical underpinning of this thesis (i.e.,
Bronfenbrenner’s Ecological Systems Theory, Family Systems Theory), adverse parent outcomes are likely to indirectly influence sibling adjustment in a negative direction. Other factors, aside from social support and connectedness operating at a wider community level will now be considered.

**The Wider Social Community**

A large body of research has identified risk and protective factors at a family level that have been shown to be associated with sibling adjustment (Giallo & Gavidia-Payne, 2006; Quintero & McIntyre, 2010; Rodrigue et al., 1993). Given these family level-findings, and the interactive nature of the multiple systems that children operate within, it is possible that factors outside the family context may contribute to the psychological adjustment of brothers or sisters of children with a disability. Influences outside the family environment, defined in this thesis as community level factors, incorporate interactions with friends, school, and the social environment. Conceptually, this is a context which has the potential to nurture and reinforce positive psychological outcomes in children.

Despite the rationale and theoretical argument (e.g., Bronfenbrenner’s Ecological Systems Theory) that sibling adjustment is shaped by siblings’ experiences and interactions within the wider social system, few studies have focused on community level factors, and sibling adjustment (Barr & McLeod, 2010; Guse & Harvey, 2010; Mascha & Boucher, 2006; Ryan, 2005). Mascha and Boucher (2006) conducted a qualitative study with 14 siblings (10 females and four males) of children with either Autism of Asperger’s syndrome, with siblings ranging in age from 11 to 18 years (mean = 14.73 years). The primary aim of this study was to elicit information from siblings about those aspects of growing up with a brother or sister with a disability they find rewarding, and those that they find difficult to deal with. Using a semi-structured interview format, information was obtained about siblings’ experience both within and outside the family environment. Results indicated that 72% of individuals with a
sibling with a disability were bothered by the attitudes of others, and also embarrassed as a result of their sibling behaving inappropriately in public or in the presence of their friends.

In the same vein, other research indicates that siblings are often reluctant to invite friends over to their houses or go out as a family as they are fearful of what may happen whilst they are outside of the home (Seligman, 1983; Strohm, 2002). Opperman and Alant (2003) conducted a qualitative study that focused on the experiences of 19 adolescents (aged between 12 and 15 years) growing up with a brother or sister with a severe disability. These authors found that 89% of participants felt that others did not accept their sibling with a disability without discrimination. A comment that supports this contention includes “…the boy told a lot of other people and they started to tease him…I don’t like that” (Opperman & Alant, 2003, p. 447). Consistent with these findings, Pit-ten Cate and Loots (2000) found that the awkward reactions of outsiders were associated with feelings of annoyance and distress in a sample of 10 to 18-year-old individuals who had a sibling with a physical disability (e.g., spina bifida, cerebral palsy). Furthermore, the majority of siblings in Stalker and Connors (2004) study reported adverse reactions to seeing their sibling with a disability being ‘abused’ or ‘humiliated’ by others, and often took steps to protect their sibling or retaliate against the perpetrators. In a recent study, Barr and McLeod (2010) considered siblings’ experiences within the wider community, focusing on their interactions with strangers, peers and also the family. Using thematic analysis, the contributions made to a children’s internet sibling support site were analysed. Results revealed that siblings were embarrassed when stared at by strangers, and were upset by the negative attitudes strangers have towards people with a disability. At a peer level, siblings felt that their friends had difficulties relating to them, used words that upset them, and described being teased about having a brother or sister with a disability.
Considering that it is often difficult to change societal views and reactions towards individuals with a disability, support provided to family members may need to focus on altering the way in which they interpret the actions of others in order to promote greater psychological adjustment. A study by Ryan (2005), evaluated how mothers are impacted and shaped by the reactions of others towards their child with a disability, and the role of appraisal and interpretation of the situation. All mothers within this study reported several occasions where their child with a disability was confronted with stares as well as rude and insensitive comments when they were in public. Some mothers interpreted such reactions as a direct reflection of their incompetence as a parent and their inability to control their child’s behaviour; whereas others perceived the reactions of others as permissible and understandable given that their child was behaving in a manner that might be considered out of the ordinary. Although this is only speculative (as the influence of the wider social community on sibling adjustment has been scarcely examined), it is likely that it is the manner in which an individual appraises the behaviour of others and the coping strategies that they employ which predicts their wellbeing. Further research needs to consider sibling perceptions of outsiders’ reactions, and understand sibling experiences, including both hassles and uplifts within a community context. To date and with few exceptions (Barr & McLeod, 2010; Giallo & Gavidia-Payne, 2006), siblings have not been interviewed about their own experiences, and have not been encouraged to talk openly about the broad range of hassles and uplifts that they encounter on a daily basis. Further, no study has examined siblings’ self-reported experiences outside the family environment and linked these experiences to sibling psychological outcomes. Without this information, it is difficult to obtain a holistic understanding of the broad range of experiences that siblings encounter across the multiple systems that they operate, and subsequently the risk and protective factors associated with adjustment. In addition, characteristics of the child with the disability (e.g.,
severity of the disability, behavioural concerns) may influence siblings’ interactions with the wider community, and therefore it is important to take these characteristics into consideration.

**Disability Factors**

Children with disabilities are unique and have specific characteristics that influence sibling adjustment in diverse ways (Macks & Reeve, 2007; Stoneman, 2005). When evaluating sibling adjustment, researchers have typically collapsed a small number of children with different disabilities into one group and have overlooked the individual differences that are associated with different disability types (Fisman, Wolf, Ellison, & Freeman, 2000). This is a shortcoming of the research in this area as specific child characteristics such as the severity of the child’s disability, defined as the degree of disruption on daily life due to impairment of child functioning across different developmental domains, may be one of the explanations behind why some children adjust more favourably to having a sibling with a disability than others (Floyd & Gallagher, 1997). For instance, a child with more severe disabilities may require greater support and parental attention, which may result in increased stress, and consequently influence parent-sibling interactions and adjustment.

Challenging behaviours, including those exhibited by many children with autism and other disabilities, is a key aspect of severity and is another child characteristic that may be troublesome for siblings and the family system as a whole (Floyd & Gallagher, 1997). For parents, child behavioural difficulties including self-injurious behaviours and aggression towards others have been associated with a variety of negative outcomes including increased feelings of burden, depressive symptoms, and poorer family quality of life (Davis & Gavidia-Payne, 2009; Essex, Seltzer, & Krauss, 1999; Lecavalier, Leone, & Wiltz, 2006). The presence of behavioural problems has been associated with greater disruptions in family
functioning and few recreational activities as parents and siblings are often worried that the child with a disability may act out in public (Ishizaki et al., 2005). Ross and Cuskelly (2006) found that aggression is the most common type of stressor that siblings of children with autism have to manage in their interactions with their brother or sister, with 84% reporting that it was a concern. Consequently, it may be more informative to focus on how behavioural problems impact sibling adjustment rather than focusing exclusively on disability group membership (Floyd & Gallagher, 1997).

Other unique characteristics of a child’s disability may influence the nature of the sibling relationship and provide an explanation for the variability in sibling psychological adjustment (Stoneman, 2005). Some of the defining characteristics of autism are impaired communication and limited social skills, both of which have the potential to impede on the sibling relationship and wellbeing. Kaminsky and Dewey (2001) compared sibling relationships in families of children with autism, Down syndrome, and typically developing children, and found that sibling relationships in families of children with autism were characterised by less intimacy, prosocial behaviour and nurturance. Building on this finding, Hastings (2003) reported that siblings of children with autism had more behavioural problems and displayed less pro-social behaviour when compared to siblings of typically developing children. Further research into the area of specific disability characteristics (e.g., behaviour of the child with a disability, severity, disability type), may provide a greater understanding of the variability across measures of sibling adjustment.
Demographic Factors

Demographic characteristics and their association with sibling adjustment have received considerable attention within the sibling literature (Macks & Reeves, 2007). Several studies have revealed that the psychological adjustment of siblings of children with disabilities is dependent on factors such as gender, birth-order, socioeconomic status (SES) and family size (Macks & Reeves, 2007). However, in a similar fashion to other research studies with siblings, findings have been mixed, with some reporting that there are no associations between demographic variables and sibling adjustment (Gold, 1993; Mates, 1990). Macks and Reeves (2007) recently compared the psychosocial and emotional development of 51 siblings of children of with autism with 35 siblings of typically developing children. Results revealed that multiple demographic risk factors were predictive of psychosocial and emotional adjustment difficulties for siblings of children with autism. The demographic characteristics found to have a compounding effect on sibling adjustment included being male from a low SES, being older than the child with autism, and having only one sibling. Researchers have endeavoured to find an explanation for this finding, with some advocating that in families where there is more than one sibling, household chores and responsibilities are likely to be shared, and siblings will have others they can relate to and compare themselves against (Randall & Parker, 1999). However, some researchers have found no relationship between family size and sibling adjustment (Mates, 1990; Ferrari, 1984), whilst others have found that scores on measures of depression and anxiety in siblings of children with disabilities increase as a function of family size (Thompson, Curtner, & O’Rear, 1994).

Socioeconomic status may need to be taken into consideration when assessing the relationship between family size and sibling adjustment. Socioeconomic status has been linked to a range of outcomes including, family quality of life and emotional wellbeing, and
consequently families with higher incomes may have more resources available to them to meet the needs of all family members (Turnbull & Turnbull, 1990). Despite these findings, other studies have generated contrasting results. Van Riper (2000) recruited 41 siblings of children with Down syndrome, and found that demographic characteristics such as family income, sibling age, age of the child with Down syndrome, and number of children in the family were not associated with sibling adjustment. Adjustment was characterised by scores on the Child Behavior Checklist (Achenbach & Edelbrock, 1983), and the Piers-Harris Children’s Self-Concept Scale (Piers & Harris, 1986). As such, it is possible that socioeconomic status indirectly influences sibling adjustment, and further investigation in this area is warranted.

The studies by Macks and Reeves (2007) and Van Riper (2000) also investigated sibling age and birth order effects as possible correlates of sibling adjustment. Hamana, Ronen and Feigin (2000) controlled for age, and assessed self-control, anxiety, and loneliness in 62 siblings (aged between nine and 18 years) of children with cancer. The results revealed that younger siblings, aged between nine and 16 years reported greater feelings of loneliness than their older counterparts (aged between 14 and 18). By contrast, Madan-Swain, Sexson, Brown and Ragab (1993) found that older siblings were more withdrawn and perceived themselves to be less involved with the family than their younger counterparts.

In an investigation of sibling birth order, Hastings (2003) recruited 22 families of children with autism, and found that typically developing siblings who were younger than their brother or sister with autism engaged in less pro-social behaviour than their typically developing counterparts who were older than their sibling with a disability. By contrast, Hamana and colleagues (2000) found no association between birth order and scores on sibling adjustment with respect to anxiety. This demonstrates that different factors may be
contributing to various sibling outcomes, and as such researchers need to extend beyond measuring sibling adjustment as a single construct.

**Conceptual and Methodological Limitations Arising from the Literature Review**

A range of factors across the multiple systems that siblings function within appear to be related to the psychological adjustment of siblings of children with disabilities. Factors at a sibling and family level have gained increasing attention and have been shown to be associated with sibling outcomes. However, sibling interactions within the wider social community have been largely overlooked. Based on current theoretical frameworks and evidence provided by contemporary literature, connectedness to social supports, and interactions with friends and the community surface as possible influences on sibling adjustment. Failure to take these community level factors into consideration may account for some of the mixed findings in sibling research. Sibling adjustment has also been narrowly defined, with few studies assessing both adaptive and maladaptive adjustment for this population. This shortcoming within sibling studies may be contributing to the discrepancy on measures of psychological adjustment, as well as other methodological limitations.

A range of methodological issues have gained considerable attention within sibling research (Cuskelly, 1999; Cuskelly & Gunn, 2006; Hodapp, Glidden & Kaiser, 2005). Hodapp and colleagues (2005) identified the use of small convenience samples, inability to generalise results, and type of control group as shortcomings of sibling research. Research in the area has typically included between 20 and 50 participants (Hodapp et al., 2005), which decreases the power of analyses, the ability to identify risk and protective factors in sibling adjustment, and the generalisation of findings beyond the sample under investigation. Control group comparisons have been inconsistent, with some studies utilising normative data, others implementing typically developing sibling dyads and different disabilities types, whilst others have excluded a control group altogether.
Measurement raises another concern within sibling research. There are a range of methods that can be utilised to elicit information about sibling adjustment (for example, observations, questionnaires, and interviews). Despite this, studies have failed to understand siblings self-reported experiences and obtain a measure of siblings’ own perceptions of their adjustment. This presents a concern as discrepancies have been found between parent and sibling reports in those studies that have incorporated multiple informants (Hodapp et al., 2005). Some studies have found that parents are more likely to over-report adjustment problems when compared to siblings, while other studies have found the opposite, that parents underestimate the difficulties of their children (Berg-Nielsen, Vika, & Dahl, 2003; Guite, Lobato, Kao, & Plante, 2004). This could account for variability in sibling psychological outcomes, and obtaining information from few informants is another identified measurement concern within the literature. Minimal consistency between different respondents is one explanation, as well as the limited information and insight that is obtained from one respondent.

Hodapp and colleagues (2005) noted that identifying changes in sibling adjustment across the lifespan is an underdeveloped area. Understanding this will have implications for support services, and in the absence of this information it is difficult to know whether support needs change across the lifespan, and in turn how to best support siblings throughout development. Having a balanced view of sibling outcomes, and identifying the positives aspects of growing up with a family member who has a disability is another ingredient in delivering supports. Ascertaining the benefits can strengthen siblings and families, providing them with the resources to manage the undesirable outcomes. This limitation of sibling research has been emphasised throughout this review, providing a foundation for the current study, which is adopting a strength-based approach. Overall, researchers have provided explanations for the mixed results in sibling research and it is essential that these limitations
are not only acknowledged, but also addressed. These components along with other factors provide a rationale for the current research, which will be the focus of Chapter 2.
Chapter 2: Rationale, Aims, and Research Questions

Chapter 1 summarised child adjustment from a developmental psychopathology perspective (Dishion & Stormshak, 2007), providing the current thesis with a conceptual framework for understanding the influence of the multiple factors that may be contributing to adjustment. Chapter 1 reviewed the research on sibling adjustment, taking into consideration its strengths and also conceptual and methodological shortcomings. On this basis, Chapter 2 provides a rationale for the aims and objectives of the current thesis. The overall theoretical underpinnings of the current research will be presented, followed by a review of each of the studies that comprise the current thesis, including the aims and research questions.

Theoretical Underpinnings of the Current Research

The present thesis is informed by three key theoretical frameworks: (1) the developmental psychopathology perspective; (2) Bronfenbrenner’s ecological systems theory and (3) the daily events approach to assessing hassles and positive daily experiences. These organising frameworks complement each other in understanding the psychological adjustment of siblings of children with disabilities. Specifically, siblings experience a broad range of daily hassles and uplifts across several interactive systems (e.g., family, peers, wider social community), that have the potential to influence both positive (e.g., Self-Concept) and adverse (e.g., Total Difficulties) psychological outcomes for siblings of children with disabilities.

The developmental psychopathology perspective has provided a foundation for understanding the origins of adaptive and maladaptive adjustment (Cicchetti & Cohen, 1995), highlighting the influence of multiple and interacting experiences in predicting psychological outcomes (Dishion & Stormshak, 2007). This conceptualisation is consistent with Bronfenbrenner’s Ecological Systems Theory, which provides an overarching theoretical framework for the present thesis (Bronfenbrenner, 1979, 1992, 1999). Bronfenbrenner’s
Ecological Systems Theory has been defined as “…the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded…” (Bronfenbrenner, 1979, p. 21). According to this definition there are multiple systems interacting both within and outside the family to influence a child’s development and either reduce or increase the likelihood of adjustment problems. Although not specifically alluded to in the definition above, genetic vulnerability also needs to be taken into consideration when conceptualising child adjustment, as it has implications on the manner that a child interacts within the multiple interactive systems. For example, a child with a temperamental predisposition to mental health problems (e.g., anxiety, depression, psychosis) may be at an increased risk of dysfunctional interactions across the various subsystems. It is possible that in addition to this child’s vulnerability, he also experiences a perceived lack of social support, and is thus at greater risk of exhibiting emotional distress and adjustment problems, when compared to another individual with comparative lack of social support in the absence of genetic vulnerability (Dishion & Stormshak, 2007).

Four interactive subsystems comprise the Ecological Systems Theory (Bronfenbrenner, 1979, 1992, 1999). The microsystem is the inner most level and is characterised by the person’s immediate environment. The mesosystem incorporates connections between the immediate environments, for example immediate family and childcare/school. The exosystem encompasses the social setting whilst the macrosystem incorporates values, customs, and laws that influence interactions at the inner levels. At each of these levels, risk and protective factors interact. Risk factors can be defined as influences within the environment that have the potential to adversely impact on child development, daily functioning, and adjustment to stressors. By contrast, protective factors are
characterised by positive influences that have the potential to shield against, or negate the negative influence of risk factors, and promote positive development and resilience to daily stressors and stressful life events.

In the context of typically developing families, each member develops within a system of relationships, which are affected by the multiple levels. For example, parents may seek additional support from extended family and friends in raising their children. This extra support, operating at the mesosystem, will directly or indirectly impact interactions at the microsystem level, and consequently impact on child development. Families of children with disabilities and typically developing families share many of the characteristics that have the potential to influence child development (Berk, 2006). These include, temperament, parenting practices (e.g., parent-child interactions), parental wellbeing, and interactions with teachers, friends, and the wider community.

Childhood disability adds a series of dimensions that introduce other risk and protective factors across each of Bronfenbrenner’s levels that are specific to families of children with disabilities (Bronfenbrenner, 1979, 1992, 1999). The diagnosis of disability in a child has the potential to elicit a range of emotions ranging from positive to largely negative emotions across the family system. For example, the birth of a child with a disability may constitute a crisis that requires psychological adjustment and accommodations for one family, whereas another family may view the situation as unfortunate, however find psychological growth and unity as a family (Bronfenbrenner, 1979, 1992, 1999). The type and severity of disability, sibling temperament, attitudes of friends, experiences and connectedness to supports services, and hassles and uplifts within the wider community may also contribute to the wide range of behavioural and emotional responses, and adjustment outcomes for all family members, including siblings. The exploration of these factors constitute the focus of the current thesis, with the aim of generating a greater understanding of why some siblings of
children with disabilities are resilient and thrive while others are vulnerable to adverse circumstances (Bronfenbrenner, 1979, 1992, 1999; Howard, Dryden, & Johnson, 1999). Each of these factors are outlined in Figure 1 below.

![Figure 1: An ecological perspective of sibling development and adjustment.](image)

Available empirical studies provide support for working through the layers of the Ecological Systems Theory and identifying the risk and protective factors associated with sibling psychological adjustment. To the author’s knowledge however, little research has been devoted to understanding siblings’ experiences beyond the family environment, and how this relates to adjustment. Without this, it is difficult to ascertain how factors at the exosystem (contact with friends) and the macrosystem levels (i.e., how people with disabilities are portrayed by the media) directly influence adjustment, and how they interact.
with those factors at a microsystem and mesosystem level to influence adjustment. In the absence of this information, and without consideration of all the potential risk and protective factors across the different levels of Bronfenbrenner’s Ecological Systems Theory (1979, 1992, 1999), conceptualisations of sibling experiences will be limited.

The conceptualisation of stress according to the ‘Daily Events’ paradigm is another guiding premise in the current thesis (Caltabiano et al., 2002). As mentioned in the introductory chapter, this theory is based on the assertion that minor, frequently occurring annoyances and frustrations (e.g., household chores, paying bills, and supermarket shopping) can occur on a daily basis, and have the potential to result in adverse consequences and adjustment problems. In addition to acknowledging the frequency and intensity of daily hassles, the ‘Daily Events’ theory also takes into consideration uplifts encountered on a daily basis. For example, positive parent-child interactions (e.g., the child smiling or taking a relaxing bath) are likely to build an individual’s resources and mitigate the negative association between daily hassles and adjustment. This approach, characterised by measuring the frequency and intensity of daily hassles and uplifts has been shown to be more informative and predictive of psychological adjustment when compared to assessing ‘Life Events’ (e.g., birth of a child with a disability; child being diagnosed) (Caltabiano et al., 2002; Kanner, Coyne, Schaefer, & Lazarus, 1981). Advocates of the ‘Life Events’ approach argue that single stressful life events will result in adverse consequences and adjustment problems (Holmes & Rahe, 1967). In families of children with disabilities, researchers and practitioners contend that it is not merely the presence of a child with a disability that results in stress. This is supported by research that has found that while some families accommodate and adjust their lifestyle to overcome the stressors that are associated with raising a child with a disability, others are not so resilient, and experience an unbalanced family system (Kearney & Griffin, 2001; McCubbin, McCubbin, Thompson, Han, & Allen, 1997). There are significant
differences (e.g., family functioning, coping) between families of children with disabilities that accounts for the variability in adjustment at a family level, and also for individual members such as siblings. As a consequence of these intervening variables and individual differences, research has consistently shown that major life events are not predictive of adjustment problems (Caltabiano et al., 2002). Taking into consideration the theoretical underpinning (daily events’ paradigm, the developmental psychopathology perspective, and Bronfenbrenner’s Ecological Systems Theory) of the current thesis, and limitations identified in the literature review, directions for present research will now be considered.

**Rationale and Aims of the Current Research**

As identified in Chapter 1, findings about the psychological adjustment of siblings of children with a disability are mixed (Yirmiya, Shaked, & Erel, 2001). Some studies indicate that adjustment between siblings of children with and without disabilities is comparative, while others suggest marked differences (Hastings, 2003). A number of explanations have been provided for the mixed findings, which were outlined in Chapter 1 (Hodapp et al., 2005). These included methodological issues, such as small sample sizes, inconsistent control groups, and different informants (Hodapp et al., 2005). In addition, the research on sibling outcomes has focused predominately on the adverse consequences of growing up with a brother or sister with a disability (e.g., externalising problems), and has neglected to account for positive psychological adjustment (e.g., self-concept). This approach to evaluating sibling psychological outcomes is inconsistent with the guiding principles of the developmental psychopathology perspective, which emphasises the importance of both adaptive and maladaptive adaptation in conceptualising the development of psychopathology.

Limited endeavours to account for uplifts and positive experiences of growing up with a brother or sister with a disability may also provide some explanation for the mixed findings. Conceptually, this is at odds with the developmental psychopathology perspective as well as
Bronfenbrenner’s Ecological Systems Theory. These theories emphasise the importance of considering the interplay of a range of risk and protective factors in predicting adaptive and maladaptive childhood development. Highlighted in these theories is the role of biological (e.g., genetic predisposition to mental health problems; brain development; temperament), familial (e.g., relationship processes) and sociocultural (e.g., school, community) factors in influencing child outcomes. In the typical developmental literature, the socio-cultural environment has received little attention, and this limitation also applies to research conducted on siblings of children with disabilities. Developmentally, as children grow they spend less time with family members, and peers become increasingly important and influential (Berk, 2006). As such, overlooking the importance of the wider social community (e.g., coping with the reactions of the broader community) as a potential contributing factor of sibling adjustment is a shortcoming of the research in this area.

The current thesis endeavours to address these limitations by broadening the conceptualisation of adjustment (e.g., measuring both positive and adverse outcomes); incorporating other child development dimensions that have received little attention; increasing the sample size; and using different informants (both parents and siblings). These are key characteristics of the current research, which overall aims to link siblings’ experience across the multiple systems they operate within, as well as other sibling, family and community level factors to psychological adjustment. To address this aim, the current research adopted a mixed method design. The first study is qualitative in nature, and guided the design of a quantitative study, with the aim of examining the predictors of sibling psychological adjustment across an individual, family and wider social community level. Each study and the associated research questions are presented next.

**Study 1:** The first study was exploratory, and sought to understand the experiences (hassles and uplifts) of siblings’ growing up with a brother or sister with a disability. The
qualitative study examined the hassles and uplifts encountered by siblings of children with disabilities within and outside the family environment. The following research questions were posed.

1. As reported by siblings’, what are the perceived hassles and uplifts related to their brother or sister with a disability?
2. What are siblings’ perceived hassles and uplifts within the family home that are specific to their brother or sister with a disability?
3. What hassles and uplifts do siblings identify in relation to friendships that are specific to their brother or sister with a disability?
4. If siblings attend the same school as their brother or sister with a disability, what hassles and uplifts do they identify?
5. What are siblings’ perceived hassles and uplifts within the wider social community that are specific to their brother or sister with a disability?

The information obtained from this study guided the development of a measurement tool entitled ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’, which was incorporated into Study 2.

**Study 2:** The aim of the second study was to develop and validate the ‘Me and My Sib’ scale. A summary of the research questions follow.

1. Does the ‘Me and My Sib’ scale demonstrate adequate internal reliability across the individual subscales and the hassles and uplifts total scores?
2. Does the ‘Me and My Sib’ scale demonstrate face, content, and convergent and divergent criterion-related validity?
3. Does the newly developed ‘Me and My Sib’ scale demonstrate psychometric properties that warrants its inclusion in Study 3 (e.g., examination of the relationship between daily hassles and uplifts and sibling adjustment)?
Study 3: The primary aim of the third study was to identify the extent to which different factors across individual, family and the wider community levels contribute to sibling psychological adjustment. Research questions that were addressed include:

1. What is the relationship between sibling individual level (e.g., coping, temperament, daily hassles and uplifts) factors and adjustment?
2. What is the relationship between family level variables (e.g., differential parenting, family functioning, parental wellbeing) and sibling adjustment?
3. What is the association between factors at a wider social community level (e.g., social support, daily hassles and uplifts outside the family environment) and sibling adjustment?
4. What is the relationship between demographic variables and sibling adjustment?
5. What are the predictors of sibling adjustment across individual, family and wider social community level factors?

In summary, the overall aim of the current thesis was to expand contemporary explanations of sibling adjustment by identifying the risk and protective factors at the sibling, family and community level that contribute to positive and adverse psychological outcomes for siblings of children with a disability. To date, sibling research has focused on a limited range of risk and protective factors, primarily socio-demographic variables, and as such understanding of the broad range of experiences within and outside the family environment is limited. Exploring the daily hassles and uplifts more broadly within and outside the family context is an important first step in being able to identify the factors that contribute to the psychological adjustment of siblings of children with a disability.
Chapter 3 – Study 1: A Qualitative Study to Understand Siblings’ Experiences in the Context of Disability

Study 1 adopts a qualitative approach and aims to identify both the daily hassles and uplifts experienced by siblings of children with disabilities. Measuring daily hassles and uplifts is a recognised approach, and has been noted to be more informative and predictive of psychological adjustment when compared to assessing stressful or positive life events (Kanner et al., 1981). Despite this recognition, the majority of research across the disability field and other areas of endeavour have focused on negative events, and as such little is known about the positive (uplifts) and negative (hassles) experiences that siblings encounter on a daily basis.

Being guided by the developmental psychopathology perspective as well as Bronfenbrenner’s Ecological Systems Theory (Bronfenbrenner, 1979, 1992, 1999; Dishion & Stormshak, 2007), this study aims to understand the broad range of experiences siblings encounter across the multiple and interactive systems they operate within. Building on past research, this study also endeavours to elicit information from siblings about their experiences within the socio-cultural environment. It is plausible based on the conceptualisation of this thesis that siblings’ experiences within the wider social context have the potential to influence adaptive and maladaptive adjustment; however few studies have taken into consideration factors beyond a family level in predicting child outcomes (Barr & McLeod, 2010; Dishion & Stormshak, 2007).

Few studies have also invited siblings to be informants of their own experiences, despite researchers advocating that self-report information from siblings is unique, and is not interchangeable with reports provided by parents (Flannery, 1990). Researchers have predominately focused on parents as informants, which has generated some controversy in the literature. Research has indicated that at times parents have a tendency to overestimate the
degree of difficulties in their child, which can often be perpetuated by parental mental health problems and potentially frustration and anger towards the child (Foster & Cone, 1995; Rutter, 1980). This study will extend beyond past research by utilising siblings as informants of their own experiences by using a qualitative research design.

Qualitative research methodology can be employed to develop a broader understanding of a particular topic or phenomena (Rubin & Rubin, 2005). Qualitative studies are exploratory, and generally use interviews or focus groups to develop an understanding and build theories based on patterns in the data (Rubin & Rubin, 2005). Applied to the current study, interviewing siblings and obtaining a comprehensive evaluation of their experiences is necessary, as there is no well established alternative of identifying daily hassles and uplifts beyond the family environment without asking siblings. Further this information from siblings is essential in being able to answer the overarching question of this thesis, why do some siblings develop adjustment problems while others thrive when growing up with a brother or sister with a disability?

Method

Participants

Siblings were recruited from eight Early Childhood Intervention programs in the state of Victoria, Australia. The recruitment process was not specific to age, gender, or disability type. It was a random sample of siblings and families who chose to participate. All families who chose to be apart of the research were included in the study. There was a nine percent response rate, with seven siblings with a brother or sister with a disability choosing to participate in the study. Siblings were recruited from five different families; two families with two typically developing siblings each participated in the study. Demographic characteristics of the siblings, as well as their brother or sister with a disability are presented in Table 1.
Table 1

*Demographic Characteristics for Siblings and the Child with a Disability*

<table>
<thead>
<tr>
<th>Sibling age (months)</th>
<th>Sibling sex</th>
<th>Child with a disability- age (months)</th>
<th>Child with a disability - sex</th>
<th>Disability</th>
<th>Severity of disability (as rated by parent)</th>
<th>Sibling birth order relative to child with a disability</th>
<th>Member of sibling support group</th>
</tr>
</thead>
<tbody>
<tr>
<td>160</td>
<td>Male</td>
<td>126</td>
<td>Male</td>
<td>Cerebral palsy</td>
<td>Severe</td>
<td>Older</td>
<td>Yes</td>
</tr>
<tr>
<td>126</td>
<td>Male</td>
<td>126</td>
<td>Male</td>
<td>Cerebral palsy</td>
<td>Severe</td>
<td>Twin</td>
<td>Yes</td>
</tr>
<tr>
<td>146</td>
<td>Female</td>
<td>99</td>
<td>Female</td>
<td>Down syndrome</td>
<td>Moderate</td>
<td>Older</td>
<td>No</td>
</tr>
<tr>
<td>124</td>
<td>Male</td>
<td>99</td>
<td>Female</td>
<td>Down syndrome</td>
<td>Moderate</td>
<td>Older</td>
<td>No</td>
</tr>
<tr>
<td>101</td>
<td>Male</td>
<td>66</td>
<td>Male</td>
<td>Autism spectrum disorder</td>
<td>Moderate</td>
<td>Older</td>
<td>No</td>
</tr>
<tr>
<td>156</td>
<td>Female</td>
<td>40</td>
<td>Female</td>
<td>Global developmental delay</td>
<td>Severe</td>
<td>Older</td>
<td>No</td>
</tr>
<tr>
<td>162</td>
<td>Male</td>
<td>145</td>
<td>Male</td>
<td>Autism spectrum disorder</td>
<td>Very severe</td>
<td>Older</td>
<td>No</td>
</tr>
</tbody>
</table>
As shown in Table 1, more male siblings participated in this study when compared to females, and most siblings were older than their brother or sister with a disability. A range of disabilities were represented, and most siblings (71%) were not engaged in a support group.

**Materials**

Qualitative data were collected via a semi-structured interview with each participant. The development of the interview schedule was guided by the literature on conducting qualitative research (Hsieh & Shannon, 2005; Pit-ten Cate & Loots, 2000; Rubin & Rubin, 2005), and also sibling research (Opperman & Alant, 2003; Stoneman, 2005). Items within the interview were examined by researchers and clinicians working in the area of early childhood intervention to ascertain whether they adequately assessed hassles and uplifts experienced by siblings of children with disabilities. The interview schedule incorporated several open-ended questions, and responses to each question were clarified with follow-up questions where appropriate (Refer to Table 2 for the interview schedule). Interviews were recorded onto an audio tape, and then transcribed verbatim and coded by the primary investigator. As recommended for qualitative data (Rubin & Rubin, 2005), all identifying information, including siblings names and names of family members were removed from the transcripts prior to coding.
<table>
<thead>
<tr>
<th>Area of Interest</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rapport building exercise</td>
<td>Siblings traced their hand and wrote the answer to each question in their fingers (name; favourite sport; members of their family; best thing about going up in their family?; something that bothers them about growing up in their family)</td>
</tr>
<tr>
<td>Questions specific to child with a disability</td>
<td>Tell me what it is like having a brother or a sister with a disability?</td>
</tr>
<tr>
<td>Questions related to experiences within the family environment</td>
<td>Tell me about your family? / What is it like having a brother or a sister with a disability in your family? / Positive aspect? / Do you think it prevents you from doing some activities as a family?</td>
</tr>
<tr>
<td>Questions related to experiences with friends</td>
<td>Tell me how your brother or sister with a disability acts around your friends? What are your thoughts around this, how does that make you feel?</td>
</tr>
<tr>
<td>Questions related to experiences at school</td>
<td>Do you have friends over to play? / Tell me what that is like with your brother or sister with a disability?</td>
</tr>
<tr>
<td>Questions related to experiences in the wider community</td>
<td>Have you ever been a position where your brother or sister was being teased? / What did you do when you were in this situation? / What kinds of things were you worried about?</td>
</tr>
<tr>
<td></td>
<td>Have you even been teased about your brother or sister with a disability? What did you do / say when you were in this situation?</td>
</tr>
<tr>
<td></td>
<td>Do you attend the same school as your brother or sister with a disability? Talk me through that.</td>
</tr>
<tr>
<td></td>
<td>Tell me it’s like to go out with your brother or sister with a disability</td>
</tr>
<tr>
<td></td>
<td>Tell me what it is like walking down the street with your brother or sister with a disability</td>
</tr>
</tbody>
</table>
Procedure

Following ethics approval from the RMIT Human Research Ethics Committee and the Department of Education and Early Childhood Development (DEECD), the directors of several Early Childhood Intervention programs, Special Schools and other major organisations in the State of Victoria, Australia were contacted to obtain permission to recruit families from their programs (Refer to Appendix A). With the directors’ approval, parents and siblings aged between 8 and 16 years were sent a letter of invitation to participate (Refer to Appendix B). Those families who chose to participate forwarded their contact details in the supplied reply-paid envelope. These families were then contacted to provide further information about the study, and to schedule an interview. Interviews were conducted in the sibling’s family home by the primary investigator and each went for approximately 45 to 60 minutes. Prior to the interviews being conducted, an information sheet was completed by parents (Refer to Appendix C), which obtained demographic information about siblings and their brother or sister with a disability. The limits of confidentiality between parents and siblings were also discussed, and both siblings and parents had an opportunity to ask any questions about the study. A plain language statement was also provided to families, in order to assist their understanding of the study aims; management of the information shared with the investigator; and their right to withdraw at any time. The benefits of participating in the study were also outlined in the plain language statement (Refer to Appendix D) and informed consent was obtained from both parents and siblings prior to conducting the interviews (Refer to Appendix E).
Data Analysis

Data was analysed according to the guidelines for managing qualitative data (White & Marsh, 2006). Content analysis was used, which is a research methodology that has been widely utilised to examine qualitative data, and extract common meaning from the text (Braun & Clarke 2006; Hsieh & Shannon, 2005). Within the umbrella term of content analysis, there are a number of elements, including identifying the construct of interest, conducting interviews and collecting data, developing a coding system and identifying themes across the information that is shared by participants.

In the context of this study, hassle and uplifts across the various levels (wider community, family, friends, school, and disability) were the constructs of interest. Responses that were obtained from siblings in relation to these identified constructs were then analysed for common themes. Each theme identified was provided with a label, and where possible was based on the language used by siblings. This is consistent with the recommendation of Richards (2005) in terms of analysing qualitative data. The primary researcher and research supervisor discussed the emerging themes and a coding system was developed. An independent researcher with experience in the area of qualitative research and also siblings of individuals with a disability also coded the transcripts to ensure inter-rater reliability.

Utilising a statistical package (e.g., NVivo) for analysing qualitative data was considered; however, after consultation with researchers who had extensive experience with qualitative analyses, it was decided to analyse the data without the aid of these packages. The primary reason for following this path was the relatively small sample size and being able to analyse constructs and common themes manually.
Results

Based on similarities in content, the responses across each of the areas of interest (hassles and uplifts specifically related to the brother/sister with a disability; hassles and uplifts at a family level related to the brother/sister with a disability; hassles and uplifts at a friendship and wider social community level) were grouped together and given a label to reflect the theme. The main themes will be presented, as well as quotes to illustrate the daily hassles and uplifts for siblings of children with a brother or sister with a disability. To begin, daily uplifts will be reviewed and are presented in Table 3.
<table>
<thead>
<tr>
<th>Uplifts</th>
<th>N</th>
<th>%</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uplifts related to child with a disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning a new skill</td>
<td>3</td>
<td>42.86</td>
<td>“…And she used to go to the park and could never use to be able to climb the ladder. But now we have supported her and she knows how to climb up the ladder by herself. Its really good”</td>
</tr>
<tr>
<td>Greater understanding of disability</td>
<td>2</td>
<td>28.57</td>
<td>“…I have learnt a lot of things that I wouldn’t have know if she didn’t have a disability – Like I wouldn’t know what Down’s Syndrome.”</td>
</tr>
<tr>
<td>Uplifts at a family level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling relationship</td>
<td>1</td>
<td>14.29</td>
<td>“…You know I love my sister because she is cute and fun to play with. I would love to squeeze her but I can’t because I would probably hurt her”</td>
</tr>
<tr>
<td>Being praised</td>
<td>1</td>
<td>14.29</td>
<td>“…Like I say I cleaned my room and she would be like it’s good T, its good”</td>
</tr>
<tr>
<td>Uplifts at a friendship/school level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being valued for understanding the brother or sister with a disability</td>
<td>2</td>
<td>28.57</td>
<td>“…They want to know how to do things with her and how to play with her and all this type of things and I get treated a bit more like I’m special and people want to know those things ‘cos I’m like the only person who really knows, so I kind of feel special”</td>
</tr>
<tr>
<td>Uplifts at a wider social community level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being a part of different organisations associated with disability</td>
<td>2</td>
<td>28.57</td>
<td>“…She has a disability but most of the time we’re just normal people leading full lives but then there’s the things like C does like she has to go to ECI and she does special things and we get involved in all those things like DS Victoria and all those things and – I would never have got to go to all these special things and stuff that I’ve done that I wouldn’t have got to experience – probably changed me cos I know a lot about something I probably wouldn’t have been interested in”</td>
</tr>
</tbody>
</table>
As shown in Table 3, a number of daily uplifts were identified across the various areas of interest. Learning a new skill, and the positive feelings (e.g., proud) associated with this event was the most frequently reported uplift associated with the child with a disability. Positive characteristics of the sibling relationship, being valued among friends for being “...special” for understanding their brother or sister with a disability, as well as being actively involved in different self-help organisations were also identified as positive experiences encountered by siblings on a daily basis. Daily hassles are reviewed in Table 4.
<table>
<thead>
<tr>
<th>Uplifts</th>
<th>n</th>
<th>%</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hassles related to child with a disability</td>
<td></td>
<td></td>
<td><strong>Tantrum / Non-compliance</strong></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>42.86</td>
<td>“…No my sister has her own room and trashes it when she gets angry … When she gets angry she opens her draws and pulls her cloths out. Then mum has to go and pick them up, fold them…..That’s her little tantrum…Or she will bite, pull your hair, pinch you”</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>28.57</td>
<td>“…Pulling my hair, she has kicked me, bitten me, pinched me, and I can’t fight back cause I am 10 times the size of her”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“…I can’t ask her. And we can’t ask her you know, what she wants, the only possible way we can find out is if we take her to that place…But sometimes she will be pointing to something and we don’t know what she wants. So she starts screaming”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“…Sometimes like you know um instead of…usually with the normal kids you would like be able to you know tell her something and she would be able to reply…but she can’t really reply because she can’t talk…its sorta annoying because you can’t ask her where she has put things, or you can’t ask her where um she has hidden something or something like that”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“…Cos sometimes she can’t say words properly and she’s trying to talk to you and you just don’t understand what she’s saying and then she gets all frustrated”</td>
</tr>
<tr>
<td>Hassles at a family level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>--</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Limited opportunity for family outings</td>
<td>4</td>
<td>57.14</td>
<td></td>
</tr>
<tr>
<td>“…Some things we can’t do as a family cause she might get scared or she might go and have a little tantrum and say I don’t want to do this…yeah but most of time she will do stuff but some things like going to the movies can be a bit hard cause she doesn’t like the dark and loud noises…so we can’t really go to the movies”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family accommodations</td>
<td>3</td>
<td>42.86</td>
<td></td>
</tr>
<tr>
<td>“…But sometime she takes my stuff…we have to put latches on every door, like every time we get out of a door we have to latch it… oh, it’s really annoying”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased responsibility / completing chores around the home</td>
<td>2</td>
<td>28.57</td>
<td></td>
</tr>
<tr>
<td>“…Usually I have to do things that my mum asks me…Like put the rubbish in the bin or can I clean my room”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“…Yeah like she was drawing one day she was drawing on her hands and I was going to take it off her…but she just went psycho…so mum was like just give her the pen back…..so we gave her the pen back. But I am also trying to teach her that she can’t always get what she wants…cause then she is going to grow up thinking that she can get anything she wants”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concerns / worries about parental wellbeing</td>
<td>2</td>
<td>28.57</td>
<td></td>
</tr>
<tr>
<td>“…I can look after A for a bit, or put her into my room because she is a big handful for my mum. And she is on her feet all day”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“…Yeah ‘cos she can’t do everything by herself because C can be a bit of a handful sometimes like she can be extremely naughty and cheeky and she can wrap you around her little finger”</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Sibling relationship

If K was non-autistic It would mean I had a brother. I could do stuff with him. He wouldn’t have mood swings and stuff like that

Hassles at a friendship/school level

Disruption of time with friends

She would get really annoying and I would beat her up because I want to play with my friend and she’s not letting me

…I am pretty bothered that I can’t have my friends over when T is home. They might think I’m not going to come over here again

Anticipation of getting teased

…Because overall you would think that you would get teased once

Hassles at a wider social community level

Enduring the reactions of others

…It can be a bit embarrassing because she doesn’t listen or she would run away you have to try and find her. Sometimes people might stare at you because you’re trying to find your sister

…Sometimes if she doesn’t have something she wants she screams… and that’s really embarrassing. Cause she is sorta like dragging attention to us

…Cause everyone looks at us and yeah it is just embarrassing by they way they look at us. You know, like we can’t control her or something

…they shouldn’t stare

…He drags the food in front of everyone. People just start staring and it’s just terrible – because everyone just – everyone just looks at you like ‘what’s going on"
As shown in Table 4, having a tantrum (characterised by screaming, pulling siblings’ hair) was identified as one of the most frequent daily hassles related specifically to the child with a disability. At a family level, limited opportunity for outings was noted as a common hassle, and was attributed to the child with a disability (“...It’s easier to stay at home and muck around at home than going out to places”). Other common hassles reported by siblings include disruption of time with friends, as well as enduring the reactions of other when out in public.

Discussion

The primary aim of the current study was to explore the daily hassles and uplifts siblings experience in relation to their brother or sister with a disability both within and outside the family environment. Given the lack of research that has focused on the broad range of hassles and uplifts encountered by siblings of children with disabilities, a qualitative research design was incorporated to identify common experiences among this population. Siblings shared daily experiences were defined as ‘uplifts’ and ‘hassles’ across a range of different areas of their lives.

For a number of siblings, supporting their brother or sister to learn a new skill and having knowledge about disability that may otherwise not be present if they were not growing up with a family member with a disability were identified as uplifts. For example, one sibling (female, 12 years old), noted “…she [child with a disability] used to go to the park and would never be able to climb the ladder. But now we have supported her and she knows how to climb up the ladder by herself. It’s really good”. Being guided by a cognitive-behavioural perspective, it is anticipated that these thoughts are going to elicit pleasant emotions (e.g., happy, proud), and positive psychological adjustment. In addition, the sibling relationship is often the longest lasting of all family relationships, and research has shown that the quality of the relationship between brothers and sisters can influence psychological
adjustment (Brody, 2004; Ross & Cuskelly, 2006). It can be inferred based on this body of literature that as siblings engage in a greater number of desired behaviours (e.g., sibling with a disability learning new skills), the quality of the sibling relationship is likely to become stronger, resulting in a positive sense of self and adaptive psychological outcomes. In the case of the current example, the sibling also reported a sense of ownership (e.g., “…we have supported her [child with a disability]”), which is likely to be associated with positive emotions.

In terms of uplifts at a family level, the sibling relationship, being praised by parents, and having time to do activities during respite were identified. One sibling (male, 10 years old), noted that during respite “…at least we get a break and time to relax, do stuff, do things and yeah it’s good”, thus expressing the benefits of having an opportunity to engage in activities that may otherwise not be possible. This finding is not surprising given that disruptions to family routines are a commonly reported hassle by siblings (Barr & McLeod, 2010; Cunningham, Betsa, & Gross, 1981; Kramer, 1984), and it can be inferred that the converse would be associated with pleasant feelings and potentially positive psychological outcomes.

Of particular interest to this thesis, and the need to conceptually extend beyond sibling and family level factors, emphasis was given to the wider social community and friendships. Being valued among friends and feeling “…special” for having a unique experience beyond their same age peers, in addition to being a part of different organisations were identified as uplifts. These statements were consistent with findings by Opperman and Alant (2003) who reported that 63% of their sample felt as though their peer group respected and thought highly of them because of the way they managed and coped with having a brother or sister with a disability. In this context, admiration and esteem from one’s peers are likely to contribute to more positive attributes in siblings of children with a disability. The contribution of eliciting
information about positive experiences as reported by siblings is essential in guiding evidence-based practice, and the role of uplifts in countering the adverse consequences of hassles and providing a buffer to mental and physical illness has been well documented in the literature (Kanner et al., 1981).

Siblings identified a number of daily hassles across the various areas of interest. In regards to hassles related specifically to the child with a disability, siblings emphasised the difficulties encountered with tantrums and also frustration surrounding communication problems with their brother or sister with a disability. One sibling (male, 10 years old) shared his experience and noted, “…well I suppose he [child with a disability] doesn’t tell you what he wants – he just, I suppose, bites his hand and bangs on the wall until he gets what he wants, I suppose, but sometimes he doesn’t say what he wants – gets irritated because we don’t know what he wants because he’s not telling us what it is he wanted”. Limited opportunity for family outings, increased responsibility, and concerns about parent mental health were commonly reported hassles and worries at the family level. This is illustrated by a 12-year old female sharing, “…usually, I have to do things that mum asks me…Like put the rubbish in the bin or can I clean my room, can I look after X [child with a disability] for a little, or put her in her room because she is a real big handful for my mum. And she [mother] is on her feet all day. She [child with a disability] is touching things constantly”. This is consistent with other studies, which have found that siblings can often become involved in types of care that are developmentally inappropriate, and consequently jeopardise their psychological health and wellbeing (Feathersone, 1980; Opperman & Alant, 2003). For example, Opperman and Alant (2003) found that 37% of siblings felt as though their care-taking roles and responsibilities were excessive for their age of development. Taking on extra responsibilities around the home also has the potential to influence the amount of time siblings can engage in activities with peers, which could impact their perceived
connectedness to their social network (Nixon & Cummings, 1999; Siegel & Silverstein, 1994). An investigation of increased responsibility, disruption of time with peers, and connectedness to support groups is warranted, and the relationship between these factors and sibling psychological outcomes will be a focus of upcoming studies in this thesis.

At a friendship level, disruption of time with friends and anticipation about being bullied were identified as hassles. One sibling noted that he avoids inviting friends over in fear of how his brother will behave, which coincides with Seligman’s (1983) findings. Working through the layers of the Ecological Systems Theory, enduring the reactions of others in the community was identified by over half of siblings as a hassle. One sibling (male, 10 years old) noted that his brother “…drags the food in front of everyone. People just start staring and it’s just terrible – because everyone just – everyone just looks at you like what’s going on”. This is consistent with previous research conducted by Mascha and Bouncher (2006), who found that 72% of siblings of children with Asperger’s were bothered by the attitudes of others and also embarrassed as a result of their sibling behaving inappropriately in public or in the presence of their friends.

Within the hassles and uplifts paradigm, it has been documented that cognitive and behavioural responses can medicate the impact of daily hassles on psychological adjustment (Harmer Cox et al., 2003). Barr and McLeod (2010) identified a range of strategies that siblings had employed or considered utilising when out in public. These included staring back, distancing themselves from their brother or sister with a disability and portraying that they are not related. These behavioural responses were also evident within the current study, with cognitive aspects to managing daily hassles also emerging. One sibling in the current study explained, “…we have to be curious to live in this world….and its natural instinct if something is happening just to have a look”, whereas another sibling stated, “... I am not really sure why they stare, maybe because they think we are not controlling her or
something”. These shared experiences highlight the importance of taking into consideration the cognitive characteristics of coping. These two siblings have been exposed to a similar situation; however, it is the interpretation and meaning attributed to the event which is going to influence their feelings and subsequent behaviour. It is possible that a thought such as “…we are not controlling her or something” is going to be associated with feelings of helplessness, whereas a thought such as “…it’s a natural instinct for people to look”, will be followed by more neutral or positive feeling.

Being guided by a cognitive-behavioural model (Friedberg & McClure, 2002) it is likely that siblings’ thoughts, feelings and behaviour around hassles and uplifts are going to influence their adjustment. However, to date, little research has attempted to understand siblings’ experiences beyond the family environment, and ascertain siblings’ thoughts, feelings and behaviours associated with different situations (Barr & McLeod, 2010; Giallo & Gavidia-Payne, 2006; Mascha & Bouncher, 2006).

**Limitations, Future Research, and Implications for Practice**

Prior to considering the implications of this qualitative study, several limitations need to be highlighted. The sample size was small, and consequently it may not be representative of the experiences of all siblings of children with disabilities. However, qualitative methodology places less emphasis on representativeness and generalisability, and highlights the need to focus on the depth of information elicited (Silverman, 2010). In addition, there may be variability in hassles and uplifts reported by siblings as a function of different disability types, and it is not possible to identifying such variation from the current study. The intensity of different hassles and uplifts were also not identified, and as such, it is difficult to ascertain the experiences that are influencing sibling adjustment and consequently where to intervene.
Despite these limitations, the current study has addressed its primary aim of extending our understanding of siblings’ experiences beyond those occurring within the family environment. This exploratory study has broadened the conceptualisation of siblings’ experiences, and has identified implications for interventions designed to obtain the best possible outcomes for siblings and the wider family system. In this context, this study has provided further evidence to extend beyond the family environment and continue to obtain a greater understanding of siblings’ experiences outside the family environment. Siblings shared experiences guided the development of a measurement tool designed to quantitatively assess the hassles and uplifts encountered by siblings of children with disabilities, which will be presented in Study 2.
Chapter 4 – Study 2: The Development and Validation of the ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’

Conceptually, there are multiple risk and protective factors across the different domains of life that have the potential to influence sibling adjustment (e.g., family, school, wider community) (Barr & McLeod, 2010; Ryan, 2005). However, to date, few researchers have worked through the multiple layers of the ecological systems theory to understand and measure sibling experiences. Understanding more broadly the interwoven relationship between siblings and their environment (e.g., wider social community) could serve as a source of explanation for the mixed findings across the various indicators of sibling adjustment. A child’s environment is constantly changing, and as children grow they spend less time with family members, and thus time spent with peers and the wider community becomes increasingly important and influential (Berk, 2006). As such, acknowledging the importance of the wider social community, and having an assessment tool available to quantitatively assess sibling experiences will address this shortcoming in the literature. Study 2 was guided by the information shared by siblings in Study 1, and aimed to develop and validate a new tool designed specifically to measure the broad range of daily hassles and uplifts for siblings of children with disabilities. Characteristics of the tool entitled, the ‘Me and My Sib’ scale will be presented in this chapter, including a detailed psychometric analysis that incorporates internal reliability, face validity, content validity, as well as convergent and divergent criterion-related validity. The following research questions are addressed:

1. Does the ‘Me and My Sib’ scale demonstrate adequate internal reliability across the individual subscales and the hassles and uplifts total scores?

2. Does the ‘Me and My Sib’ scale demonstrate face, content, and convergent and divergent criterion-related validity?
3. Does the newly developed ‘Me and My Sib’ scale demonstrate psychometric properties that warrants its inclusion in Study 3 (e.g., examination of the relationship between daily hassles and uplifts and sibling adjustment)?

Method

Participants

Seventy-eight families of children with a disability participated in this study. Families were recruited from 10 Early Childhood Intervention programs, a Special School (Concord Special School), and other organisations (Very Special Kids, Down syndrome Victoria, Autism Victoria) designed to support children with disabilities and their families in the State of Victoria, Australia. Other special schools were contacted to participate in the research, however declined the invitation noting that they were already committed to ongoing projects and did not want to overwhelm families. Collectively, 16% of all families of children with disabilities invited to participate in the study completed the questionnaire.

Characteristics of Children with a Disability

Children in the current sample with a developmental delay or disability (30 females and 48 males) ranged in age from 42 months to 381 months ($M = 121$ months, $SD = 53$ months), and had been affiliated with a program (e.g., Early Childhood Intervention) for between 1 and 108 months ($M = 38$ months, $SD = 24$ months). Contact with members from the programs was found to occur regularly, with most parents reporting weekly or more frequent contact (61.9%). The most prominent disability diagnosis, as reported by parents, was Down syndrome ($n = 32$), followed by an autism spectrum disorder ($n = 30$), speech or language impairment ($n = 17$), global developmental delay ($n = 12$), cerebral palsy ($n = 5$), visual disability ($n = 4$), heart condition ($n = 2$), attention-deficit hyperactivity disorder ($n = 2$), epilepsy ($n = 2$), acute lymphoblastic leukemia ($n = 1$), DiGeorge syndrome ($n = 1$), and lissencephaly ($n = 1$). The severity of the developmental delay/disability was described as
moderate by just under half of the sample (45%), and severe for about one fifth (21%). Few parents reported that their child had a very severe (6%) or mild developmental delay (9%).

**Sibling and Family Characteristics**

Siblings of children with a developmental delay or disability (40 females and 38 males) ranged in age from 96 to 214 months ($M = 147$ months, $SD = 31$ months). In relation to sibling order, most siblings (61.3%) were older relative to the child with a disability. Approximately 5% of siblings had attended a sibling support group in the past, and 17% were current members of a support group. For more information about siblings, as well as parent and family factors refer to Table 5. As shown, most respondents were biological mothers (97.4%), and ranged in age from 34 to 53 years ($M = 43$ years, $SD = 4.74$ years). Families had between two and seven ($M = 3.12$) children living at home, which included their child with a disability.
## Table 5

*Parent/Family Demographic Characteristics*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Respondent’s relationship to sibling</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological mother</td>
<td>76</td>
<td>97.4</td>
</tr>
<tr>
<td>Biological father</td>
<td>2</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>Respondent’s country of origin</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>65</td>
<td>83.3</td>
</tr>
<tr>
<td>England</td>
<td>5</td>
<td>6.4</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>10.3</td>
</tr>
<tr>
<td><strong>Respondent’s education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than Year 12</td>
<td>18</td>
<td>23.1</td>
</tr>
<tr>
<td>High school graduate, Year 12</td>
<td>9</td>
<td>11.3</td>
</tr>
<tr>
<td>TAFE graduate</td>
<td>14</td>
<td>18.0</td>
</tr>
<tr>
<td>Undergraduate qualifications</td>
<td>17</td>
<td>21.8</td>
</tr>
<tr>
<td>Postgraduate qualifications</td>
<td>20</td>
<td>25.6</td>
</tr>
<tr>
<td><strong>Respondents employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>18</td>
<td>23.1</td>
</tr>
<tr>
<td>Part-time</td>
<td>33</td>
<td>42.3</td>
</tr>
<tr>
<td>Not employed (retired, stay home parent or caregiver)</td>
<td>27</td>
<td>34.6</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with a partner</td>
<td>73</td>
<td>93.6</td>
</tr>
<tr>
<td>Not living with a partner</td>
<td>5</td>
<td>6.4</td>
</tr>
<tr>
<td><strong>Household income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $25,000</td>
<td>3</td>
<td>4.0</td>
</tr>
<tr>
<td>Between $25,001 and $45,000</td>
<td>9</td>
<td>11.8</td>
</tr>
<tr>
<td>Between $45,001 and $55,000</td>
<td>5</td>
<td>6.6</td>
</tr>
<tr>
<td>Between $55,001 and $75,000</td>
<td>9</td>
<td>11.8</td>
</tr>
<tr>
<td>Greater than $75,001</td>
<td>50</td>
<td>65.8</td>
</tr>
<tr>
<td><strong>Formally diagnosed mental illness in the immediate family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>24</td>
<td>31.6</td>
</tr>
<tr>
<td>No</td>
<td>52</td>
<td>68.4</td>
</tr>
</tbody>
</table>

### Materials

The ‘Me and My Sib’ scale as well as the ‘Loneliness & Social Dissatisfaction Questionnaire’ were completed by siblings. The ‘Loneliness and Social Dissatisfaction Questionnaire’ was incorporated into this chapter to assess convergent and divergent criterion-related validity of the ‘Me and My Sib’ scale.
Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities. The ‘Me and My Sib: The Daily Experiences for Siblings of Children with Disabilities’ extended on the work of Giallo and Gavidia-Payne (2006) and was developed to assess the daily hassles and uplifts experienced by siblings of children with a disability. The measure is unique as it provides further insights into siblings’ experiences beyond the family environment and explores hassles and uplifts within the wider social community.

Items included in the measure were constructed based on the content disclosed by siblings recruited in Study 1. More specifically, siblings’ responses to interview-based items and discussions about their experiences of having a sibling with a disability were transformed into statements to incorporate in this newly developed tool. The ‘Me and My Sib’ scale is a 58-item self-report questionnaire (35 hassles, 23 uplifts) which requires siblings to rate both hassles and uplifts on a five point scale in terms of frequency (How often does this happen? 1 = Never, to 5 = Always) and intensity (How bothered or upset does this make you feel? 1 = Not bothered or upset, to 5 = Very bothered or upset; How happy does this make you feel? 1 = Not very happy, to 5 = Very happy). Items within the Hassles scale focus on experiences that are a source of stress, or upset the sibling within and outside the family environment (e.g., when we go out my brother or sister with a disability does strange things). The Uplifts subscale items focus on experiences that make the sibling happy (e.g., my friends make me feel special because I know how to manage my brother or sister with a disability) both within and outside the family environment.

Individual subscales were also constructed as part of the development process of the ‘Me and My Sib’ scale. These include Community (siblings’ experiences with respect to the wider community, for example, interacting with friends or other people within the community), Family (sibling experiences specific to family life), Friends (sibling experiences with friends, inviting them over, friends interactions with the brother or sister with a disability).
disability), School (sibling experiences in the school environment with their brother or sister with a disability), and Disability (sibling experiences specific to the child with a disability).

The Beck Self-Concept Inventory for Youth (BSCI-Y). The BSCI-Y was completed by siblings and was used to explore siblings’ own perceptions of competency, and positive self-worth (Beck, Beck, Jolly, & Steer, 2005). The inventory contains 20 items which are measured on a 4-point scale, ranging from 1 = ‘Never’ to 4 = ‘Always’. Example items include, ‘I feel proud of the things I do’ and ‘People want to be me’. This inventory has been standardised on children and adolescents aged 7 to 18 years and has been shown to have sound psychometric properties (Beck et al., 2005). The BSCI-Y was one measure used to evaluate criterion validity with the ‘Me and My Sib’ scale. Evaluating the relationship between the ‘Me and My Sib’ scale and the Beck Self-Concept Inventory for Youth was guided by research which has consistently demonstrated that people who report lower self-concept are more likely to be lonely than their counterparts with higher feelings of self-worth (Hymel et al., 1990; Kaliopuskas & Laitinen, 1991).

The Loneliness and Social Dissatisfaction Questionnaire. The Loneliness and Social Dissatisfaction Questionnaire consists of 24-items and was used to assess feelings of loneliness and dissatisfaction with peer relations (Cassidy & Asher, 1992). Eight of the 24 items are filter items, designed to make the child feel relaxed and focus on interests (e.g., do your like music). Items are rated on a 3-point scale, ranging from ‘no’ to ‘yes’. Higher scores on this measure indicate greater loneliness and social dissatisfaction. The questionnaire has demonstrated good internal reliability, with a Cronbach’s alpha coefficient of .79. The questionnaire has also been reported to correlate strongly with teacher reports of social behaviour in the child (Cassidy & Asher, 1992). This measure was considered appropriate to assess the criterion validity of the ‘Me and My Sib’ scale given that both measures evaluate social
domains (e.g., family, friends, community), and in addition, were both completed using the sibling as the informant.

**Procedure**

Following ethics approval from the RMIT University Human Research Ethics Committee and the Department of Education and Early Childhood Development (DEECD), the directors of several Early Childhood Intervention programs and major organisations (e.g., Very Special Kids, Down syndrome Victoria, Autism Victoria, Concord Special School) were contacted to obtain permission to recruit families from their centre (Refer to Appendix F). With the directors’ approval, parents and siblings aged between 8 and 16 years old were sent a letter of invitation to participate (Refer to Appendix G). Those families who chose to participate forwarded their contact details in the supplied reply-paid envelope. These families were then contacted to provide further information about the study, and to obtain contact details to mail out a questionnaire package.

The questionnaire package included the questionnaire booklets for parents and siblings, a plain language statement, a consent form, and a reply-paid envelope. The parent questionnaire booklet required approximately 45 minutes to complete, whereas the sibling questionnaire required approximately 20 minutes. The development and validation of this newly developed tool formed part of a larger study (refer to Study 3 in Chapter 5), and as such, the ‘Me and My Sib’ scale was distributed with a range of other assessment tools.

Prior to the questionnaires being completed, a plain language statement was reviewed which informed families that the information obtained would remain confidential, and that they had the right to withdraw at any time. The benefits of participating in the study were also outlined. As recommended by the RMIT University Human Research Ethics Committee a separate plain language statement was provided to both parents (Refer to Appendix H) and siblings (Refer to Appendix I). Informed consent was also obtained from both parents and
siblings prior to the questionnaires being completed (Refer to Appendix J). Once completed, questionnaire booklets and consent forms were returned in the supplied self-addressed envelopes. Questionnaires were stored in a locked filing cabinet at the RMIT University Bundoora West Campus, and only the primary investigator and supervisor had access to the information.

Results

The psychometric properties of the ‘Me and My Sib’ scale were assessed in order to ascertain its reliability and validity. Reliability will firstly be presented, followed by a review of the validity of this newly developed scale.

Reliability Analysis of the ‘Me and My Sib’ Scale

To evaluate the reliability of the ‘Me and My Sib’ scale, an analysis of internal reliability was undertaken. In addition, an item analysis was completed to ascertain those items that are most closely linked to the total score as well as identifying whether certain items were negatively impacting on the overall reliability of the measure.

Internal Reliability. Internal consistency analysis was used to ascertain whether items are equivalent and are measuring a single underlying construct (Tabachnick & Fidell, 2001). In the context of the current study, internal consistency measures the degree to which all items in the hassle scale and conversely the uplift scales are related and are being responded to in a consistent manner. In addition, it is a method of ascertaining how closely related individual items are within each of the subscales. Internal consistency is measured using Cronbach’s alpha coefficient. A Cronbach’s alpha of .70 is considered acceptable, whereas a Cronbach’s that exceed .80 is regarded as high. Internal reliability coefficients were calculated for each of the subscales within the ‘Me and My Sib’ scale. A separate analysis was conducted for both frequency and intensity and the results are displayed in Table 6.
Table 6  
*Cronbach’s Alpha Coefficient for Each Subscale Within the ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Number of Items</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hassles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency – Community</td>
<td>7</td>
<td>.80</td>
</tr>
<tr>
<td>Intensity – Community</td>
<td>7</td>
<td>.84</td>
</tr>
<tr>
<td>Frequency – Family</td>
<td>7</td>
<td>.77</td>
</tr>
<tr>
<td>Intensity – Family</td>
<td>7</td>
<td>.85</td>
</tr>
<tr>
<td>Frequency – Friends</td>
<td>6</td>
<td>.65</td>
</tr>
<tr>
<td>Intensity – Friends</td>
<td>6</td>
<td>.76</td>
</tr>
<tr>
<td>Frequency – School</td>
<td>7</td>
<td>.70</td>
</tr>
<tr>
<td>Intensity – School</td>
<td>7</td>
<td>.87</td>
</tr>
<tr>
<td>Frequency – Disability</td>
<td>8</td>
<td>.77</td>
</tr>
<tr>
<td>Intensity – Disability</td>
<td>8</td>
<td>.84</td>
</tr>
<tr>
<td><strong>Uplifts</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency – Community</td>
<td>3</td>
<td>.17</td>
</tr>
<tr>
<td>Intensity – Community</td>
<td>3</td>
<td>.57</td>
</tr>
<tr>
<td>Frequency – Family</td>
<td>5</td>
<td>.63</td>
</tr>
<tr>
<td>Intensity – Family</td>
<td>5</td>
<td>.72</td>
</tr>
<tr>
<td>Frequency – Friends</td>
<td>8</td>
<td>.67</td>
</tr>
<tr>
<td>Intensity – Friends</td>
<td>8</td>
<td>.75</td>
</tr>
<tr>
<td>Frequency – School</td>
<td>3</td>
<td>.18</td>
</tr>
<tr>
<td>Intensity – School</td>
<td>3</td>
<td>.60</td>
</tr>
<tr>
<td>Frequency – Disability</td>
<td>4</td>
<td>.68</td>
</tr>
<tr>
<td>Intensity – Disability</td>
<td>4</td>
<td>.70</td>
</tr>
</tbody>
</table>
As shown in Table 6, with the exception of two of the uplift subscales (Frequency-Community and Frequency-School), the Cronbach’s alpha coefficients ranged from satisfactory to high for each of the subscales. In addition to measuring internal reliability at a subscale level, an overall total score was generated for Hassles and Uplifts. Items within the School scale were not included in calculating the total scores due to the small percentage (19%) of siblings attending the same school as their brother or sister with a disability. Internal reliability coefficients were calculated for the frequency and intensity of both the Hassles and Uplifts scales and are displayed in Table 7.

Table 7

_Cronbach’s Alpha Coefficients for Total Scores on the ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’_

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number of Items</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hassle: Frequency – Total</td>
<td>28</td>
<td>.91</td>
</tr>
<tr>
<td>Hassle: Intensity – Total</td>
<td>28</td>
<td>.94</td>
</tr>
<tr>
<td>Uplift: Frequency – Total</td>
<td>20</td>
<td>.81</td>
</tr>
<tr>
<td>Uplift: Intensity – Total</td>
<td>20</td>
<td>.88</td>
</tr>
</tbody>
</table>

As shown in Table 7, internal consistency coefficients were moderate to high for each of the total scores on the Hassles and Uplift scales (Frequency and Intensity). To ascertain whether the internal reliability of the Hassles and Uplifts scales would increase as a function of removing individual items an item analysis of the scale was conducted. The item analysis for both the frequency and intensity of the Hassles scale is presented in Table 8.
Table 8
*Item Analysis for both Frequency and Intensity of the Hassles Scale*

<table>
<thead>
<tr>
<th>Item</th>
<th>Item-Total Correlation – Frequency (Intensity)</th>
<th>Alpha if Item Deleted – Frequency (Intensity)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brother/sister does strange things</td>
<td>.57 (.69)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>Brother/sister runs away</td>
<td>.48 (.45)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>Brother/sister draws attention to us</td>
<td>.46 (.58)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>People stare or look at us</td>
<td>.52 (.62)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>I don’t feel ‘normal’</td>
<td>.68 (.63)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>We have to stop what we are doing</td>
<td>.64 (.62)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>Brother/sister takes things from the shelves</td>
<td>.37 (.54)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We can’t do things that other families can do</td>
<td>.45 (.72)</td>
<td>.91 (.93)</td>
</tr>
<tr>
<td>I have to do more jobs/chores around the home</td>
<td>.43 (.61)</td>
<td>.91 (.93)</td>
</tr>
<tr>
<td>I worry that my mum and dad don’t get enough rest</td>
<td>.63 (.57)</td>
<td>.90 (.94)</td>
</tr>
<tr>
<td>We miss out on things</td>
<td>.46 (.57)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>We have to change our plans all the time</td>
<td>.64 (.71)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>I feel like I don’t have time to myself</td>
<td>.62 (.70)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>My parents won’t let me do things that my brother/sister can’t do</td>
<td>.36 (.40)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td><strong>Friends</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have to talk about my brother/sister’s disability or illness</td>
<td>.10 (.47)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>Brother/sister does embarrassing things</td>
<td>.57 (.70)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>I don’t invite them over because of the way my brother/sister with a disability will behave</td>
<td>.48 (.58)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>I worry that they will tell other people about my brother or sister with a disability and I will get teased</td>
<td>.46 (.42)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>I worry that they won’t want to come back and play if they come over and see my brother/sister</td>
<td>.57 (.58)</td>
<td>.90 (.94)</td>
</tr>
<tr>
<td>I get sad when they say mean things about people with Disabilities</td>
<td>.29 (.24)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td><strong>Child with Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hurts, hits, pushes, scratches or kicks me or others</td>
<td>.63 (.58)</td>
<td>.90 (.94)</td>
</tr>
<tr>
<td>Touches or takes my things</td>
<td>.45 (.66)</td>
<td>.91 (.93)</td>
</tr>
<tr>
<td>Always gets his/her own way in order to stop a tantrum</td>
<td>.48 (.59)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>Doesn’t know how to talk properly so I don’t know what he/she wants or needs</td>
<td>.47 (.52)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>Does annoying things until he/she get what they want</td>
<td>.53 (.60)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>Wakes me up early in the morning</td>
<td>.43 (.56)</td>
<td>.91 (.94)</td>
</tr>
<tr>
<td>Makes me feel like I don’t have a ‘real’ brother/sister because they have a disability.</td>
<td>.56 (.68)</td>
<td>.90 (.93)</td>
</tr>
<tr>
<td>Makes me miss out on things that other brothers and sisters can do because he/she has a disability.</td>
<td>.50 (.46)</td>
<td>.91 (.94)</td>
</tr>
</tbody>
</table>
Results of the item analysis revealed that all items within the Hassles scale contributed to the overall alpha coefficient for both frequency ($\alpha = .91$) and intensity ($\alpha = .94$). Support for this is provided by the finding that removing items would reduce the internal consistency of the scale. For example, if the item ‘when we are out people stare or look at us’ was removed the overall alpha would decrease from .91 to .90 for hassles – frequency and from .94 to .93 for hassles – intensity. This is further supported by the finding that with the exception of one item (‘with my friends I have to talk about my brother or sister’s disability’) the strength of the item-total correlations was moderate to high. This highlights that each item is at least moderately correlated with the overall scale score, and as such is having a unique contribution while sharing communality with other items within the scale. The item analysis for both frequency and intensity of the Uplifts scale is displayed in Table 9.
Table 9
Item Analysis for both Frequency and Intensity of the Uplifts Scale

<table>
<thead>
<tr>
<th>Item</th>
<th>Item-Total Correlation – Frequency (Intensity)</th>
<th>Alpha if Item Deleted – Frequency (Intensity)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get to be part of different groups (e.g., Down Syndrome Victoria, because of my brother or sister with a disability.</td>
<td>.18 (.29)</td>
<td>.82 (.89)</td>
</tr>
<tr>
<td>I know and understand a lot about disability</td>
<td>.26 (.51)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td>My brother or sister with a disability is happy</td>
<td>.53 (.59)</td>
<td>.80 (.88)</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get to spend time alone with my mum and dad while my brother or sister with a disability is being looked after by somebody else</td>
<td>.28 (.55)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td>I get to share experiences and do things with my family (for example., go on a holiday, go on bike rides)</td>
<td>.47 (.53)</td>
<td>.80 (.88)</td>
</tr>
<tr>
<td>My mum/dad are in a good mood</td>
<td>.52 (.54)</td>
<td>.80 (.88)</td>
</tr>
<tr>
<td>My mum/dad tell me that I am being a big help</td>
<td>.40 (.44)</td>
<td>.80 (.88)</td>
</tr>
<tr>
<td>My mum and dad tell me how happy they are of me (for example., for getting a good grade at school)</td>
<td>.28 (.42)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td><strong>Friends</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>They understand my brother or sister with a disability.</td>
<td>.36 (.53)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td>They get along and play nicely with my brother or sister with a disability.</td>
<td>.59 (.61)</td>
<td>.79 (.87)</td>
</tr>
<tr>
<td>I can trust they won’t make fun of me or tease me because of my brother or sister with a disability.</td>
<td>.37 (.50)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td>They don’t treat me differently because I have a brother or sister with a disability</td>
<td>.07 (.41)</td>
<td>.83 (.88)</td>
</tr>
<tr>
<td>I get to spend time alone with them without my brother or sister with a disability</td>
<td>.26 (.41)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td>They show an interest in my brother/sister with a Disability.</td>
<td>.58 (.35)</td>
<td>.80 (.88)</td>
</tr>
<tr>
<td>They make me feel special because I know how to Manage my brother or sister with a disability.</td>
<td>.48 (.63)</td>
<td>.80 (.87)</td>
</tr>
<tr>
<td>I go to their house and I am able to feel ‘normal’ with another family</td>
<td>.22 (.22)</td>
<td>.81 (.89)</td>
</tr>
<tr>
<td><strong>Child with disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learns something new (e.g., a new word, good math or writing)</td>
<td>.30 (.53)</td>
<td>.81 (.88)</td>
</tr>
<tr>
<td>Does cute things.</td>
<td>.50 (.49)</td>
<td>.80 (.88)</td>
</tr>
<tr>
<td>Is in a good mood and is smiling.</td>
<td>.65 (.63)</td>
<td>.79 (.87)</td>
</tr>
<tr>
<td>Plays with me like other brother and sisters.</td>
<td>.56 (.63)</td>
<td>.79 (.87)</td>
</tr>
</tbody>
</table>
Results in Table 9 revealed that the majority of items within the Uplifts scale contributed to the overall alpha coefficient for both frequency ($\alpha = .81$) and intensity ($\alpha = .88$). Two items within the Uplifts scale were found to impede on the alpha coefficient, with the removal of these items increasing the internal reliability of the scale. These include, “when we go out, I get to be apart of different groups (e.g., Down syndrome Victoria, Autism Victoria) because of my brother/sister with a disability” and “with my friends they don’t treat me differently because I have a brother or sister with a disability”. After careful consideration a decision was made not remove the two items from the measure. This is based on the rationale that removing these two items would only marginally improve the overall internal reliability coefficient (increase of .1) at the expense of reducing the content of the measure.

**Validity Analysis of the ‘Me and My Sib’ Scale**

To assess the validity of the ‘Me and My Sib’ scale, that is, whether it measures what it has been purported to measure, an evaluation of the face, content, and criterion-related validity of this measure was undertaken. Whilst the sample size limits a comprehensive assessment of the validity of the measure, this analysis provides a preliminary examination of the robustness of the ‘Me and My Sib’ scale as a self-report measure in the field of sibling research and intervention.

**Face Validity.** On face value, items within the ‘Me and My Sib’ scale appear to evaluate what they purport to measure. As part of the development process and prior to distributing the scale as part of Study 2, independent researchers assessed the items within the scale. The items were deemed relevant to the overall scale, as well as the individual areas of interest (e.g., Community). It was noted that the language of certain items in the pool was not tailored towards 8-16 year olds, and as such these items were reviewed and re-phrased to ensure that the level of comprehension was congruent with the target population.
Content Validity. Content validity of the ‘Me and My Sib’ scale was assessed to determine whether the content domains measured by this scale examine elements of the overall construct (Tabachnick & Fidell, 2001). Literature reviews were conducted to establish a foundation and understanding of siblings’ experiences across the various domains of interest (e.g., school, community). Other measures of daily hassles and uplifts were also reviewed, for example, the Daily Life Stressors Scale (Kearney, Drabman, & Beasley 1993) and The Positive (Uplifts) and Negative (Hassles) Event Scales (Maybery, Jones-Ellis, Neale, & Arentz, 2006; Maybery, Neale, Arentz, & Jones-Ellis, 2007). An identified limitation in the literature on previous hassles and uplifts scales is that interpersonal events are often overlooked and secondary appraisals (e.g., resources needed to manage the stressful event) are emphasised. The ‘Me and My Sib’ scale aimed to overcome this shortcoming by including content associated with the Community, Family, Friends, and attending the same School as the child with a disability. In addition, previous measures have often overlooked theory and research guiding the implementation of an Uplift (positive event) scale. The ‘Me and My Sib’ scale addresses this shortcoming by incorporating items that consider the frequency and intensity of both daily Hassles and Uplifts.

Convergent and Divergent Criterion-Related Validity. Criterion-related validity was measured by using the Beck Self-Concept Inventory for Youth (Beck et al., 2005) and the Loneliness and Social Dissatisfaction Questionnaire (Cassidy & Asher, 1992). The results revealed a significant positive correlation between Self-Concept and both Uplifts-Frequency, \( r(N=78) = .41, p < .001 \), and Uplifts-Intensity, \( r(N=78) = .53, p < .001 \). In contrast, Self-Concept was negatively correlated with Hassles-Frequency \( r(N=78) = -.37, p = .001 \) and Hassles-Intensity \( r(N=78) = -.37, p = .001 \). The results also demonstrated a significant negative correlations between scores on the Loneliness and Social Dissatisfaction Questionnaire and both Uplifts-Frequency, \( r(N=78) = -.46, p < .001 \), and Uplifts-Intensity,
Conversely, significant positive relationships were found between the scores of Loneliness and Social Dissatisfaction Questionnaire and Hassles-Frequency, \( r(N=78) = .32, p = .001 \), and Hassles-Intensity, \( r(N=78) = .48, p < .001 \). Overall, the moderately strong correlations between the ‘Me and My Sib’ scale and these two well-established measures provides preliminary evidence for the convergent validity of the measure. Further research that incorporates a different sample and other measures are likely to add to the scope of the current findings.

**Discussion**

The aim of the present study was to develop and examine the psychometric properties of the ‘Me and My Sib’ scale. This tool evaluates the daily hassles and uplifts experienced by siblings of children with a disability across different domains of life, including the family environment, friends, the community, as well as being at school with their brother or sister with a disability. To the researcher’s knowledge, no other study has moved beyond the examination of factors at a family level in constructing a measurement tool, to include the assessment of risk and protective factors within the broader social community.

The psychometric characteristics of the newly developed scale are promising, with high internal reliability being displayed across most of the individual subscales, as well as the total Hassles and Uplifts scales. Cronbach’s alpha coefficients for the total scores on this measure were largely comparable to those obtained with the original measure, the ‘Sibling Daily Hassles and Uplifts Scale’ (Giallo & Gavidia-Payne, 2006). Specifically, Cronbach’s alpha coefficients were equal for the Hassle-Frequency and Hassle-Intensity scales, and were marginally different for the Uplift-Intensity scale. The Cronbach’s alpha coefficient for the Uplift-Frequency scale was higher for the ‘Sibling Daily Hassles and Uplifts Scale’ (Giallo & Gavidia-Payne, 2006) when compared to the newly developed ‘Me and My Sib’ scale.
Two items within the Uplift scale were found to impede on the alpha coefficient, with the removal of these items increasing the internal reliability of the scale. However, after lengthy consideration and the finding that removing the two items would only marginally improve the overall internal reliability at the cost of limiting the pool of items, it was decided that these items would remain in the scale. Findings from the reliability analysis also demonstrated that each item provides a unique contribution while sharing communality with other items within the scale.

In terms of validity, the ‘Me and My Sib’ scale has adequate face and content validity, as well as encouraging convergent and divergent criterion-related validity. These psychometric properties provide some preliminary evidence for the robustness of the measure in assessing the daily hassles and uplifts experienced by siblings across the multiple and continuously changing systems they operate within.

Being able to conduct factor analyses would have made a substantial contribution to the development and validation of the newly developed measure. Employing factor analysis techniques would have enabled the individual subscales as well as the two factor structure of the hassles and uplifts scales to be statistically assessed. However, due to the small sample size, conducting this analysis was not possible. Continuing to validate and explore the factor structure of the measure is an area for future research that incorporates larger sample sizes will aid in the assessment of the frequency and intensity of daily hassles and uplifts experienced by siblings of children with disabilities.

Despite this shortcoming, the ‘Me and My Sib’ scale has addressed some of the methodological and conceptual limitations identified in the literature. Specifically, the tool was developed based on siblings’ own account of the positive (uplifts) and adverse (hassles) experiences of growing up with a brother or sister with a disability, and was reported by siblings to be easy to navigate through and complete. This measure can be easily incorporated
into future research and clinical practice when working with families and children with disabilities. This psychometrically sound measure has provided an avenue to quantitatively assess the frequency and intensity of daily hassles and uplifts experienced by siblings of children with disabilities. Assessing these experiences is an important first step prior to ascertaining how these daily occurrences relate to psychological adjustment. Consistent with this, the ‘Me and my Sib’ scale has provided a pathway to be able to link a breadth of sibling experiences to psychological outcomes (e.g., Self-Concept and Internalising and Externalising Problems), which has received minimal attention in the literature and in empirical studies. Drawing on the conceptualisation of the developmental psychopathology perspective and the ecological systems theory (Bronfenbrenner, 1979, 1992, 1999; Dishion & Stormshak, 2007), it is important to relate siblings’ shared experiences with psychological adjustment. Consideration of potential risk and protective factors across the multiple and interactive systems that siblings function within and their association with adjustment would allow for a greater understanding into why some siblings thrive when growing up with a brother or sister with a disability while others have significant adjustment problems. The relationship between sibling experiences and adjustment will be a focus of Study 3.
Chapter 5 – Study 3: Sibling, Family, and Community Characteristics as Predictors of Sibling Adjustment

Past research has focused primarily on psychological adjustment and support needs of both parents and the child with a developmental delay or disability (Rosenbaum et al., 1998; Turnbull et al., 2006). Consequently, the experiences of other family members have been largely overlooked (Dykens, 2005). Researchers have shifted in their approach, and currently acknowledge the importance of understanding the experiences and the psychological adjustment of siblings in particular. This is consistent with proponents of family system approaches, which emphasise the importance of family interactions, and how family members are impacted by one another (Rosenbaum et al., 1998; Turnbull et al., 2006). The sibling subsystem is an important part of families, and it is well recognised that sibling relationship quality and interactions are pivotal to child and adolescent development (Brody, 2004; Powell & Gallagher, 1993; Stoneman, 2005).

Studies focusing on sibling adjustment in families of children with disabilities have yielded diverse outcomes (Kaminsky & Dewey, 2002; Meadan, Stoner, & Angell, 2010). Some studies have demonstrated that siblings of children with disabilities are at an increased risk of developing adverse psychological outcomes (Bagenholm & Gillberg, 1991; Hastings, 2003; Jones, Welsh, Glassmire, & Tavegia, 2006; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002), while others have found few differences between siblings of children with and without disabilities (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Rodrigue et al., 1993). The risk and protective factors that may explain these discrepancies in sibling adjustment within the family context (e.g., family functioning, differential parenting) have gained some attention; however those factors within the wider social community have been disregarded. Conceptually, this is at odds with the developmental psychopathology perspective and Bronfenbrenner’s Ecological Systems theory, which emphasise the interplay
of a range of risk and protective factors in predicting adaptive and maladaptive childhood
development and adjustment (Bronfenbrenner, 1979, 1992, 1999; Dishion & Stormshak,
2007). Embedded within these theories is the role of biological (e.g., genetic predisposition to
mental health problems; brain development; temperament), familial (e.g., relationship
processes) and sociocultural (e.g., school, community) factors in influencing child outcomes.

Despite the emphasis on assessing both adaptive and maladaptive adjustment,
measures of psychological adjustment in siblings of children with disabilities have generally
focused on negative psychological outcomes, with the positive consequences of growing up
with a brother or sister with a disability only gaining attention in recent years (Labay &
Walco, 2004). This approach to sibling research is incongruent with the developmental
psychopathology perspective, which highlights the importance of both adaptive and
maladaptive adjustment in conceptualising the development and progression of sibling
psychological outcomes.

The current study endeavours to extend beyond past research by assessing a broad
range of risk and protective factors across the multiple and interactive systems that siblings
function within that have the potential to influence adjustment. The inclusion of factors at a
sibling level, including coping, temperament, and responses to daily hassles and uplifts, as
well as family level factors such as differential parenting, family functioning, and parent
mental health have been incorporated based on their association with adjustment within the
typical childhood development literature (Harmer Cox et al., 2003; Mash & Wolfe, 2002).
These factors also have the potential to influence child development and adjustment in
families of children with a disability. In the same vein, siblings’ interactions with the wider
social context also have the potential to influence adjustment, however to date, no study has
linked community level factors with sibling psychological outcomes.
The primary aim of this study was to identify the extent to which different factors across a sibling, family, and wider social community level are contributing to the psychological adjustment of siblings of children with disabilities. The study also aimed to broaden the conceptualisation of sibling adjustment by focusing on both positive and adverse psychological outcomes for this population. The research questions that are addressed include:

1. What is the relationship between sibling individual level (e.g., coping, temperament, daily hassles and uplifts) factors and adjustment?
2. What is the relationship between family level variables (e.g., differential parenting, family functioning, parental wellbeing) and sibling adjustment?
3. What is the association between factors at a wider social community level (e.g., social support, daily hassles and uplifts outside the family environment) and sibling adjustment?
4. What is the relationship between demographic variables and sibling adjustment?
5. What are the predictors of sibling adjustment across individual, family and wider social community level factors?

**Method**

**Participants**

Seventy-eight families of children with a disability participated in this study. The sample for Study 3 was identical to that of Study 2, and thus the child, sibling, and family characteristics of the recruited sample are described in detail in Chapter 4 (p. 77).

**Materials**

Both parents and siblings in the current study completed a questionnaire booklet, and thus two questionnaire booklets were completed by each family. The questionnaire booklets
were completed in a hard-copy format. The measures completed by parents and siblings are outlined in Table 10, which is followed by a detailed description of each psychometric tool.

Table 10
*Measures Administered to Parents and Siblings*

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Measure</th>
<th>Author(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>Strengths and Difficulties Questionnaire (SDQ)</td>
<td>Goodman, Meltzer, &amp; B, 1998</td>
</tr>
<tr>
<td>Parent</td>
<td>Depression, Anxiety and Stress Scale (DASS)</td>
<td>Lovibond &amp; Lovibond, 1995</td>
</tr>
<tr>
<td>Parent</td>
<td>The UCLA Loneliness Scale</td>
<td>Russell, 1996</td>
</tr>
<tr>
<td>Parent</td>
<td>Family Assessment Device (FAD)</td>
<td>Epstein, Baldwin, &amp; Bishop, 1983</td>
</tr>
<tr>
<td>Parent</td>
<td>Revised Dimensions of Temperament Survey (DOTS-R)</td>
<td>Windle &amp; Lerner, 1986</td>
</tr>
<tr>
<td>Parent</td>
<td>Differential Parenting Index</td>
<td>Davis &amp; Gavidia-Payne</td>
</tr>
<tr>
<td>Parent</td>
<td>Knowledge of Disability Scale</td>
<td>Davis &amp; Gavidia-Payne</td>
</tr>
<tr>
<td>Parent</td>
<td>Demographic Questionnaire</td>
<td>Davis &amp; Gavidia-Payne</td>
</tr>
<tr>
<td>Sibling</td>
<td>The Beck Self-Concept Inventory for Youth (BSCI-Y)</td>
<td>Beck, Beck, Jolly, &amp; Steer, 2005</td>
</tr>
<tr>
<td>Sibling</td>
<td>Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities</td>
<td>Davis &amp; Gavidia-Payne</td>
</tr>
<tr>
<td>Sibling</td>
<td>Loneliness and Social Dissatisfaction Questionnaire</td>
<td>Cassidy &amp; Asher, 1992</td>
</tr>
<tr>
<td>Sibling</td>
<td>Adolescent Coping Scale</td>
<td>Frydenberg &amp; Lewis, 1993</td>
</tr>
<tr>
<td>Sibling</td>
<td>Differential Parenting Index</td>
<td>Davis &amp; Gavidia-Payne</td>
</tr>
<tr>
<td>Sibling</td>
<td>Knowledge of Disability Scale</td>
<td>Davis &amp; Gavidia-Payne</td>
</tr>
</tbody>
</table>
Psychometric Measures Completed by Parents

The Strengths and Difficulties Questionnaire (SDQ). The 24-item SDQ was completed by parents in order to obtain a measure of sibling adjustment (Goodman et al., 1998). The SDQ has four problem behaviour subscales which assess Conduct Problems (e.g., ‘often has temper tantrums’), Emotional Symptoms (e.g., ‘many worries, often seems worried’, ‘often unhappy, downhearted or tearful’, ‘nervous or clingy in new situations’), Hyperactivity (e.g., ‘easily distracted’), and Peer Relationships (e.g., ‘has at least one good friend’). For all scales, higher scores indicate more problems, and problem scores are summed to obtain a Total Difficulties score. A Pro-Social Behaviour score can also be generated from this questionnaire. The SDQ is a well-validated measure that has been shown to be as effective as both the Child Behaviour Checklist (Achenbach, 1991) and the Rutter Scales (Elander & Rutter, 1996) in identifying clinically significant levels of behavioural disturbance in children. Cut-off scores that are indicative of clinical level of symptoms of the total problems scale and the five subscales have been provided by Goodman (1997).

Depression, Anxiety and Stress Scale (DASS). The 21-item Depression, Anxiety, Stress Scale (DASS-21), developed by Lovibond and Lovibond (1995), was used to measure general psychopathology. The DASS-21 contains three seven-item subscales designed to measure Depression (dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia), Anxiety (autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect) and Stress (difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/overreactive and impatient) in adults. Parents were required to use 4-point severity/frequency scales to rate the extent to which they have experienced each state over the past week, ranging from 0 = ‘Did not apply to me’ to 3 = ‘Applied to me very much, or most of the time’. The DASS-21 has demonstrated good internal reliability, with Cronbach’s alpha ranging from .88 to .94 for the
subscales (Antony, Bieling, Cox, Enns, & Swinson, 1998). The DASS-21 has also been found to demonstrate moderate to high correlations with the Beck Depression Inventory, Beck Anxiety Inventory, and the State-Trait Anxiety Inventory (Antony et al., 1998; Lovibond & Lovibond, 1995). Cut-off scores have been developed for defining mild, moderate, severe, and extremely severe scores of each DASS scale.

**The UCLA Loneliness Scale - Version 3.** The UCLA Loneliness Scale – Version 3 was used to assess subjective feelings of loneliness or social isolation in parents and obtain a measure of perceived social connectedness (Russell, 1996). The scale consists of 20-items, with each item being rated on a 4-point Likert scale, ranging from 1 = ‘never’ to 4 = ‘always’. Scores on the scale range from 20 to 80 with higher scores reflecting greater loneliness, and a lower degree of social connectedness. The UCLA Loneliness Scale has demonstrated good test retest reliability ($r = .73$ over one year) and internal consistency with Cronbach’s alpha coefficients ranging from .89 to .94 across different studies (Russell, 1996). Convergent validity has also been demonstrated with the UCLA Loneliness Scale being shown to significantly correlate with other measures of loneliness. The UCLA Loneliness Scale has also been shown to correlate with measures of adequacy of an individual’s interpersonal relationship and health and wellbeing, providing evidence for construct validity (Russell, 1996).

**The Family Assessment Device (FAD).** The 60-item FAD is a self-report questionnaire which was used to assess specific aspects of family functioning (Epstein et al., 1983). The FAD is based on the well-conceptualised McMaster Model of Family Functioning, a clinically oriented model of families that assesses structural, organisational, and transactional dimensions that distinguish between healthy and unhealthy families in seven different dimensions. These include General Functioning (the overall health/pathology of the family), Family Problem Solving (the way in which the family resolves problems),
Communication (the clarity and directness of the family’s exchange of verbal information), Family Roles (the clarity and appropriateness of the distribution of family roles), Affective Involvement (the extent to which family members are interested in each other’s activities and concerns), Affective Responsiveness (ability to meet the needs of family members in terms of the quantity and quality of expression of feelings) and Behaviour Control (the clarity of family rules and standards for behaviour of all members). Each of the 60-items are rated on a 4-point Likert scale, where the participant rates his/her agreement with the statement, ranging from 1 = ‘strongly agree’ to 4 ‘strongly disagree’. The FAD has demonstrated good internal consistency with Cronbach’s alpha ranging from .72 to .92 across the subscales. The FAD had been reported to distinguish between individuals from clinical and nonclinical families.

The Revised Dimensions of Temperament Survey (DOTS-R). The DOT-R is a 54-item self-report measure which was used to assess sibling temperament (Windle & Lerner, 1986). The dimensions of the DOTS-R are Activity Level-General (indicative of general activity levels), Activity Level-Sleep (reflective of sleep activity levels), Approach/Withdrawal (higher scores indicate more approach behaviours in a new situation or with strangers), Flexibility/Rigidity (higher scores are suggestive of a flexible behavioural style), Mood (higher scores indicate a more positive mood), Rhythmicity-Sleep (increased scores are a reflection of regularity of sleeping behaviour), Persistence (higher scores are associated with greater persistence), Rhythmicity-Daily Habits (increased scores are a reflection of regularity of daily habits), Task Orientation (higher scores reflect higher persistence and lower distractibility), Distractibility (higher scores are indicative of lower distractibility), and Rhythmicity-Eating (increased scores are a reflection of regularity of eating behaviours). Each of the 54-items are scored on a 4-point scale, where parents rate how true or false each statement is of their child (A = usually false, B = more false than true, C = more true than false, D = usually true). An example of an item in the case of
Rhythmicity-Sleep is ‘My child gets sleepy at a different time each night’. The internal reliability of the DOT-R has been reported to be good, with Cronbach’s alpha coefficients ranging from .54 (Rhythmicity-Daily Habits) to .81 (Activity Level –Sleep) when utilised with a sample of elementary school students (Windle & Lerner, 1986).

**Differential Parenting Index - Parent.** The Differential Parenting Index was developed by the researcher’s based on items adapted from McHale and Gamble (1989). This measure evaluates two dimensions of differential parenting, including the perceived level of differential treatment (e.g., ‘In comparison to your child with a disability, how do you feel you treat your child without a disability?’) as well as satisfaction with treatment (‘Please rate how you believe your typically developing child feels about this treatment’?). Parents were required to rate perceived level of differential treatment and satisfaction on a 5-point Likert scale ranging from 1 = ‘equal treatment’ to 5 ‘very different treatment’ for perceived level of differential treatment, and from 1 = ‘very unhappy’ to 5 = ‘very happy’ for satisfaction.

**The Knowledge of Disability Scale - Parent.** The Knowledge of Disability scale was developed by the researcher’s and was used to measure parents’ perceptions of siblings’ knowledge of disability. Using an analogue scale, parents were required to rate on a scale from 0 = ‘None’ to 10 = ‘The most I feel he/she can know/understand’, how much they felt their typically developing child knows/understands about his/her brother or sister’s disability.

**Demographics Questionnaire.** A demographic questionnaire was also completed to obtain information about the respondents’ age, educational level, as well as birth order of the sibling, age and sex of child with a disability, type and severity of diagnosis, and other family information (e.g., annual family income, marital status).
Psychometric Measures Completed by Siblings

**The Beck Self-Concept Inventory for Youth (BSCI-Y).** The BSCI-Y was completed by siblings and was used to explore siblings’ own perceptions of competency, and positive self-worth (Beck et al., 2005). This measure was included in Study 2, and as such a detailed overview of the measure can be located in Chapter 4 (p. 71).

**Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities.** The ‘Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities’ was used to assess the frequency and intensity of daily hassles and uplifts across a range of different domains (Community; Family; Friends; School; and Disability). Details of this newly developed measurement tool, including its psychometric properties can be found in Chapter 4 (p. 70).

**The Loneliness & Social Dissatisfaction Questionnaire.** The Loneliness and Social Dissatisfaction Questionnaire was used to obtain a measure of siblings’ perceived social connectedness (Cassidy & Asher, 1992). This measure was also utilised in Study 2, and as such a more comprehensive description of this tool and its psychometric properties can be found in Chapter 4 (p. 71).

**The Adolescent Coping Scale – Short Form.** The 18-item Adolescent Coping Scale is designed to measure the frequency of usage of a variety of coping strategies typically used by adolescents (Frydenberg & Lewis, 1993). The authors of this study revised some of the items to be more specific to siblings of children with disabilities (for example, the item ‘wish a miracle would happen’ was amended to ‘wish a miracle would happen so that my brother or sister didn’t have a disability). Items are rated on a 5 point scale, ranging from 1 = ‘doesn’t apply or don’t do it’ to 5 = ‘used a great deal’. A three factor structure has been identified for the Adolescent Coping Scale – Short Form and include Solving the Problem, Reference to
Others, and Non-Productive Coping. Internal reliability coefficients have ranged from .50 to .61 for each of these subscales (Frydenberg & Lewis, 1993).

**Differential Parenting Index - Sibling.** The Differential Parenting Index used for parents was also completed by siblings (McHale & Gamble, 1989). Siblings reported on the two dimensions of differential parenting, including the perceived level of differential treatment (‘In comparison to your brother or sister with a disability, how do you feel your parents treat you?’) as well as satisfaction with treatment (‘Please rate how you feel about this’). Siblings were required to rate perceived level of differential treatment on a 5-point Likert scale, ranging from 1 = ‘equal treatment’ to 5 = ‘very different treatment’. A 5-point Likert scale was also used to yield a measure of satisfaction, and ranged from 1 = ‘very unhappy’ to 5 = ‘very happy’.

**The Knowledge of Disability Scale - Sibling.** The Knowledge of Disability Scale developed by the authors was used to measure siblings own perceptions of their knowledge about their brother or sister’s disability. Using an analogue scale, siblings were required to rate on a scale from 0 = ‘None’ to 10 = ‘The most I feel I can know/understand’, how much they feel they know/understand about their brother or sister’s disability.

Cronbach’s alpha values were calculated for the present sample across each measure. The results revealed that internal reliability co-efficient ranged from .73 (Adolescent Coping Scale) to .96 (The UCLA Loneliness Scale). Given that internal consistency coefficients ranged from moderate to high for each of the measures, it was decided to include all scales in the current research.
Procedure

As noted, parents and siblings each completed a separate questionnaire booklet. These questionnaire booklets were administered as part of Study 2 (the development and validation of the newly developed ‘Me and My Sib’ scale) and Study 3. As such, the procedure outlined in Study 2 (p. 62) is identical to the process implemented in the current study (Study 3).

Results

Data Preparation, Missing Values, and Data Analysis

The data was analysed using the Statistical Package for the Social Sciences (SPSS), Version 17.0. To ensure validity and consistency of the results, the data was screened and cleaned at a holistic level incorporating the entire data set.

Management of Missing Data

The Missing Value Analysis function in SPSS 17.0 was utilised to better understand the degree of missing data and its distribution (Allison, 2001; Tabachnick & Fidell, 2001). Executing this function revealed that only a small percentage of participants had missing data. In order to overcome missing data that was evident, the Expectation Maximisation function was utilised. This is a technique that is used widely with missing data, and overcomes many of the limitations associated with other methods including mean substitution or regression substitution (Tabachnick & Fidell, 2001). Expectation maximization overcomes the problem of generating biased estimates, and underestimating the standard errors which are often characteristic in other techniques (Tabachnick & Fidell, 2001). Missing data points were evaluated and addressed prior to conducting any analyses.

Assumption Testing

To ensure that statistical assumptions underlying the parametric procedures to be conducted were met, exploratory data analysis was completed on the data set. This involved examination of stem-and-leaf and normality plots, as well as statistical analysis of skewness
and kurtosis and normality. Review of the data indicated that there were no major violations in the assumptions for inferential statistics, and therefore the data was analysed in its original form.

The results will now be reviewed and presented in two phases 1) comparison on scores of adjustment between siblings participating in this study and normative data and 2) relationship and predictors of sibling adjustment across factors at an individual, family and wider social community level.

**Comparisons between Sibling Adjustment Scores with Normative Data**

Scores of sibling adjustment among siblings of children with disabilities in the current sample, as measured by the Strengths and Difficulties Questionnaire and also the Beck Self-Concept Inventory for Youth, was compared to normative data. The normative data used for the Strength and Difficulties questionnaire is based on a random sample of 910 children aged between seven and 17 years who were recruited from government schools across Victoria (Mellor, 2005). Table 11 displays the mean and standard deviation scores on the Strengths and Difficulties Questionnaire for siblings of children with a disability and the normative sample. One-sample t-tests were conducted to assess for differences between the two groups, and are displayed in Table 11. Effect size estimates were also calculated, using Cohen’s $d$. The magnitude of each Cohen’s $d$ effect size was evaluated using guidelines provided by Cohen (1988), whereby, 0.2 = small, 0.6 = moderate, 1.2 = large, and 2.0 = very large.
Table 11

Comparison between Scores on the Strengths and Difficulties Questionnaire for the Current Sample and Normative Data

<table>
<thead>
<tr>
<th>Strengths and Difficulties Questionnaire</th>
<th>Current Sample M (SD)</th>
<th>Norms M (SD)</th>
<th>t_{df=77}</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct Problems</td>
<td>1.53 (2.0)</td>
<td>1.50 (1.60)</td>
<td>0.13</td>
<td>0.02 (-.021-0.25)</td>
</tr>
<tr>
<td>Emotional Symptoms</td>
<td>2.65 (2.16)</td>
<td>2.10 (2.00)</td>
<td>2.17*</td>
<td>0.27 (0.04-0.50)</td>
</tr>
<tr>
<td>Hyperactivity/Inattention</td>
<td>3.24 (2.68)</td>
<td>3.10 (2.40)</td>
<td>0.45</td>
<td>0.06 (-0.17-0.29)</td>
</tr>
<tr>
<td>Peer Problems</td>
<td>1.20 (1.48)</td>
<td>1.60 (1.90)</td>
<td>-2.33*</td>
<td>-0.21 (-0.45-0.02)</td>
</tr>
<tr>
<td>Total Difficulties Score*</td>
<td>8.62 (6.42)</td>
<td>8.18 (6.06)</td>
<td>0.58</td>
<td>0.07 (-0.16-0.30)</td>
</tr>
<tr>
<td>Prosocial Behaviour</td>
<td>8.58 (1.82)</td>
<td>8.30 (1.70)</td>
<td>1.31</td>
<td>0.16 (-0.07-0.39)</td>
</tr>
</tbody>
</table>

*p < .05

Note. \* Total score is the sum of conduct problems, emotional symptoms, hyperactivity/inattention & peer relationship problems.

As shown in Table 11, significant differences emerged for the Emotional Symptoms and Peer Problems subscales, however only small effect sizes were evident for these differences. In addition, no significant differences were found between siblings in the current sample and those in the normative sample for the remaining subscales or the Total Difficulties Score.

In regards to the Beck Self-Concept Inventory for Youth, raw scores for each sibling were converted to T scores according to age and sex. This procedure is recommended in the manual and was discussed with a consultant from Pearson, the distributors of this assessment.Sibling T scores were compared to a mean of 50, and a standard deviation of 10, given that a T score of 50 indicates an average score for the normative sample. The average T score for the current sample was 51.65, with a standard deviation of 7.57. A one-sample t-test revealed that there was no significant difference between scores obtained by the current sample and that of the normative sample, \( t(77) = 1.93, p = .058 \).
Categorisation of Siblings into Non-Clinical and Clinical Groups

Sibling scores were categorised into Non-Clinical and Clinical groups for each of the Strengths and Difficulties scales and the Beck Self-Concept Inventory for Youth (Beck et al., 2005; Goodman, 1997). Scores on the Strengths and Difficulties Questionnaire will firstly be presented followed by results for the Beck Self-Concept Inventory for Youth.

Categorising scores into Clinical and Non-Clinical groups on the Strengths and Difficulties Questionnaire was based on recommendations provided by Goodman (1997), with suggested ranges including Non-Clinical, Borderline and Clinical. According to Goodman (1997), approximately 10% of children will score in the Borderline and Clinical Ranges on the SDQ, while 80% will score within the Non-Clinical Range. Given that Goodman (1997) did not adjust these ranges according to sex, independent samples t-tests were firstly conducted to ensure there were no sex differences across the SDQ subscale scores and Total Difficulties. The results revealed no significant sex differences across the subscales or the Total Difficulties scale. Figure 2 graphically represents the percentage of children in the current sample who have scores in the Non-Clinical, Borderline and Clinical Ranges on the Strengths and Difficulties Questionnaire.
Figure 2. Percentage of siblings with scores in the non-clinical, borderline and clinical ranges on the SDQ total difficulties scale and each of the subscales.
The results in Figure 2 indicate that more than 69.2% of siblings scored within the Non-Clinical range on the SDQ Total Difficulties scale and individual subscales. The highest percentage of siblings with scores falling within the Clinical range was found for the Emotional Symptoms subscale; while the lowest was found for the Prosocial Behaviour subscale. For the current sample, the proportion of participants who were categorized into each subcategory was equivalent to the normative proportions for the majority of subscales and the strengths and difficulties total score. This was with the exception of three subscales. For the emotional subscale, 68% of the sample were found to fall in the non-clinical range as compared with 80% of the normative sample, \( p = .015 \). In addition, 22% were classified in the clinical range as compared with 10% of the normative sample, \( p = .004 \). For the prosocial subscale, 90% of participants fell in the non-clinical range, which was significantly more than the normative sample, \( p = .025 \).

As noted, analyses were conducted to ascertain the range of scores on the Beck Self-Concept Inventory for Youth. Raw scores on the Beck Self-Concept Inventory for Youth were converted into T scores (as recommended in the manual), and the severity level of individual sibling scores was determined. Severity levels identified in the manual include Above Average (\( T = >55 \)), Average (\( T = 45-55 \)), Lower than Average (\( T = 40-44 \)), and Much Lower than Average (\( T < 40 \)). Figure 3 graphically represents the percentage of children in the current sample who have scores in each of these ranges on the Beck Self-Concept Inventory for Youth.
Figure 3. Percentage of siblings with scores in the above average, average, lower than average and much more than average ranges on the Beck Self-Concept Inventory for Youth.

The results in Figure 3 reveal that the majority of siblings had scores within the Average to Above Average range of the Beck Self-Concept Inventory for Youth (greater than 78% of siblings). The results also indicate that a minority of siblings scored in the Lower than Average (18%) or Much Lower than Average (4%) range.
### Descriptive Analyses

Descriptive statistics for each of the variables for siblings are displayed in Table 12.

Table 12

**Descriptive Statistics for Sibling Factors (N = 78)**

<table>
<thead>
<tr>
<th></th>
<th>Range of Possible Scores</th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Me and My Sib: The Daily Experience Scale</strong> for Siblings of Children with Disabilities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uplifts (Frequency)</td>
<td>1-115</td>
<td>71.92 (10.43)</td>
<td>40-95</td>
</tr>
<tr>
<td>Uplifts (Intensity)</td>
<td>1-115</td>
<td>80.35 (11.94)</td>
<td>51-98</td>
</tr>
<tr>
<td>Hassles (Frequency)</td>
<td>1-175</td>
<td>65.03 (18.07)</td>
<td>32-104</td>
</tr>
<tr>
<td>Hassles (Intensity)</td>
<td>1-175</td>
<td>60.84 (22.20)</td>
<td>30-123</td>
</tr>
<tr>
<td><strong>Adolescent Coping Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem-solving</td>
<td>3-90</td>
<td>61.76 (12.83)</td>
<td>30-90</td>
</tr>
<tr>
<td>Reference to others</td>
<td>5-100</td>
<td>38.61 (11.63)</td>
<td>20-65</td>
</tr>
<tr>
<td>Non-productive</td>
<td>2-90</td>
<td>41.80 (12.10)</td>
<td>18-78</td>
</tr>
<tr>
<td><strong>Revised Dimensions of Temperament Survey</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity level-general</td>
<td>1-28</td>
<td>16.33 (5.41)</td>
<td>7-28</td>
</tr>
<tr>
<td>Activity level-sleep</td>
<td>1-16</td>
<td>9.59 (3.40)</td>
<td>4-16</td>
</tr>
<tr>
<td>Approach/withdrawal</td>
<td>1-28</td>
<td>20.40 (4.61)</td>
<td>7-28</td>
</tr>
<tr>
<td>Flexibility/rigidity</td>
<td>1-20</td>
<td>15.38 (4.19)</td>
<td>5-20</td>
</tr>
<tr>
<td>Mood</td>
<td>1-28</td>
<td>24.49 (3.98)</td>
<td>12-28</td>
</tr>
<tr>
<td>Rhythmicity-sleep</td>
<td>1-24</td>
<td>17.36 (3.49)</td>
<td>7-24</td>
</tr>
<tr>
<td>Persistence</td>
<td>1-12</td>
<td>8.29 (2.05)</td>
<td>3-12</td>
</tr>
<tr>
<td>Rhythmicity-daily habits</td>
<td>1-20</td>
<td>13.22 (2.63)</td>
<td>7-19</td>
</tr>
<tr>
<td>Distractibility</td>
<td>1-20</td>
<td>11.04 (3.04)</td>
<td>5-18</td>
</tr>
<tr>
<td>Rhythmicity-eating</td>
<td>1-24</td>
<td>16.24 (6.02)</td>
<td>6-24</td>
</tr>
<tr>
<td><strong>Knowledge of Disability Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent perception of siblings knowledge</td>
<td>1-10</td>
<td>6.92 (2.15)</td>
<td>2-10</td>
</tr>
<tr>
<td>Siblings’ self-reported knowledge</td>
<td>1-10</td>
<td>6.55 (2.31)</td>
<td>1-10</td>
</tr>
</tbody>
</table>
Examination of the average scores on the ‘Me and My Sib’ scale indicate that siblings experienced more daily Uplifts than Hassles. Further exploration of the ‘Me and My Sib’ scale revealed that the Frequency of Uplifts, as reported by siblings, was significantly correlated with the Intensity to which Uplifts were perceived, \( r(N = 78) = .82, p < .001 \). A similar relationship was also found between Frequency of Hassles and the Intensity to which the Hassle is interpreted by siblings, \( r(N = 78) = .89, p < .001 \). Given this, further analyses focused on the perceived Intensity of daily Hassles and Uplifts. A moderate to strong significant relationship was also found between parent and sibling reports of Knowledge of Disability, \( r(N = 78) = .57, p < .001 \). As such, analyses utilised siblings’ perceptions of knowledge regarding their brother/sister with a disability.

The results in Table 12 also demonstrate that siblings engage in more Problem-Focused coping strategies when compared to avoidance (Non-Productive Coping) or Reference to Others. In terms of temperament, siblings in the study sample generally report a positive mood, and engagement in approach behaviours rather than withdrawal.

Descriptive statistics for factors at a family and wider social community level will now be reviewed and are presented in Table 13.
Table 13

*Descriptive Statistics for Factors at a Family and Wider Social Community Level (N = 78)*

<table>
<thead>
<tr>
<th></th>
<th>Range of Possible Scores</th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family Assessment Device</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem Solving</td>
<td>1-4</td>
<td>2.21 (.27)</td>
<td>1.17-3.17</td>
</tr>
<tr>
<td>Communication</td>
<td>1-4</td>
<td>2.11 (.34)</td>
<td>1.33-3.22</td>
</tr>
<tr>
<td>Roles</td>
<td>1-4</td>
<td>2.31 (.36)</td>
<td>1.55-3.00</td>
</tr>
<tr>
<td>Affective Involvement</td>
<td>1-4</td>
<td>2.14 (.44)</td>
<td>1.14-3.29</td>
</tr>
<tr>
<td>Affective Responsiveness</td>
<td>1-4</td>
<td>1.90 (.59)</td>
<td>1.00-3.67</td>
</tr>
<tr>
<td>Behaviour Control</td>
<td>1-4</td>
<td>1.72 (.35)</td>
<td>1.00-2.78</td>
</tr>
<tr>
<td>General Functioning</td>
<td>1-4</td>
<td>1.97 (.42)</td>
<td>1.24-3.08</td>
</tr>
<tr>
<td><strong>Differential Parenting Index</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent – Treatment</td>
<td>1-5</td>
<td>2.97 (1.16)</td>
<td>1-5</td>
</tr>
<tr>
<td>Parent – Satisfaction</td>
<td>1-5</td>
<td>3.50 (.89)</td>
<td>1-5</td>
</tr>
<tr>
<td>Sibling – Treatment</td>
<td>1-5</td>
<td>2.71 (1.17)</td>
<td>1-5</td>
</tr>
<tr>
<td>Sibling – Satisfaction</td>
<td>1-5</td>
<td>3.83 (1.09)</td>
<td>1-5</td>
</tr>
<tr>
<td><strong>Depression, Anxiety and Stress Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0-42</td>
<td>9.02 (9.59)</td>
<td>0-34</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0-42</td>
<td>5.46 (7.24)</td>
<td>0-42</td>
</tr>
<tr>
<td>Stress</td>
<td>0-42</td>
<td>14.66 (9.62)</td>
<td>0-42</td>
</tr>
<tr>
<td><strong>The UCLA Loneliness Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Connectedness (Parent)</td>
<td>20-80</td>
<td>42.95 (12.60)</td>
<td>20-66</td>
</tr>
<tr>
<td><strong>Loneliness and Social Dissatisfaction Questionnaire</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Connectedness (Sibling)</td>
<td>16-48</td>
<td>23.65 (3.98)</td>
<td>19-42</td>
</tr>
</tbody>
</table>

The results in Table 13 indicate that family functioning in the current sample was comparable to typical families (Ryan, Epstein, Keitner, Miller & Bishop, 2005). The data also reveals that on average, parents demonstrated higher scores of stress when compared to depression and anxiety, whilst parents and siblings demonstrated moderate scores on the measure of social connectedness. Independent samples *t*-tests were conducted to assess differences in scores of Differential Parenting – Treatment between parents and siblings as well as on scores of Differential Treatment – Intensity. No significant differences in scores on
Differential Parenting – Treatment, $t(154) = 1.40, p = .16, d = 0.21 (-0.09, 0.54)$, or
Differential Parenting – Satisfaction, $t(154) = -2.05, p = .062, d = -0.34 (-0.066, -0.02)$ were found.

**Relationship between Demographic Factors and Sibling Adjustment**

The relationships between sibling adjustment and a range of demographic variables, including birth order, age of sibling and child with a disability, severity of disability, family income, marital status, and involvement in a sibling support group were explored. In regards to scores on Total Difficulties, significant correlations were found with Respondent’s Level of Education, $r(N = 76) = -.28, p = .016$; Total Income, $r(N = 76) = -.36, p = .001$; and Marital Status, $r(N = 78) = .29, p = .011$. In terms of Self-Concept, one significant relationship was found with Respondent’s Level of Education, $r(N = 76) = .26, p = .025$. Due to the number of correlations being conducted, and consequently the increased likelihood of Type 1 error, Bonferroni adjusted alpha were used. The alpha level was reduced to $\alpha = .006$, and as such, the only significant relationship that remained was between scores on Total Difficulties and Family Income.

Whilst not a primary focus of this thesis, differences in score on Total Difficulties and Self-Concept were examined across disability type. Sample sizes were sufficient to compare Autism ($n = 30$) with Down syndrome ($n = 32$), however sample sizes were not large enough in the other disability types (e.g., global developmental delay and cerebral palsy) to justify significance testing. Independent-samples t-tests were used to compare differences in scores on Total Difficulties and Self-Concept for these two groups. A significant difference was found between Autism and Down syndrome on Total Difficulties, $t(60) = 2.85, p = .006, d = 0.85 (0.22, 0.85)$. Examination of descriptive statistics indicated that siblings of children with Autism ($M = 10.04, SD = 6.03$) scored higher on Total Difficulties than siblings of children with Down syndrome ($M = 5.95, SD = 4.83$). A significant difference was also found between
these two groups on Self-Concept, $t(60) = -2.88, p = .006, d = 0.72$ (0.23, 1.26). Follow-up examination of descriptive statistics indicated that siblings of children with Autism ($M = 40.71, SD = 6.21$) scored lower on Self-Concept than siblings of children with Down syndrome ($M = 45.70, SD = 6.94$).

**Sibling, Family, and Wider Social Community Factors and Adjustment**

A series of correlations were conducted among adjustment and sibling, family and wider social community level factors. The aim of this analysis was to determine the strength of the relationship between each of these factors, in addition to exploring potential predictors for inclusion in the hierarchical regression analyses in the next section. Again, due to the number of correlations being conducted and the increased likelihood of Type 1 error, Bonferroni adjusted alpha levels were used for this analysis. Given that thirteen correlations were conducted for each sibling outcome measure (Total Difficulties and Self-Concept), the alpha level was reduced to $\alpha = .004$ (.05/13). The relationships among these factors are displayed in Table 14.
Table 14

*Child, Family and Wider Social Community Characteristics and Sibling Adjustment*

<table>
<thead>
<tr>
<th>Sibling Characteristics</th>
<th>Total Difficulties</th>
<th>Self-Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uplifts – Intensity (Sibling)</td>
<td>-.23</td>
<td>.53**</td>
</tr>
<tr>
<td>Hassles – Intensity (Sibling)</td>
<td>.32*</td>
<td>-.37*</td>
</tr>
<tr>
<td>Coping – Problem Solving (Sibling)</td>
<td>-.39**</td>
<td>.19</td>
</tr>
<tr>
<td>Coping – Reference to Others (Sibling)</td>
<td>.07</td>
<td>-.03</td>
</tr>
<tr>
<td>Coping – Non-Productive (Sibling)</td>
<td>.04</td>
<td>-.28</td>
</tr>
<tr>
<td>Knowledge of Disability (Sibling)</td>
<td>-.09</td>
<td>.33*</td>
</tr>
<tr>
<td>Temperament (Parent)</td>
<td>-.40**</td>
<td>.39**</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Characteristics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Functioning (Parent)</td>
<td>.36**</td>
<td>-.18</td>
</tr>
<tr>
<td>Parent Wellbeing (Parent)</td>
<td>.49**</td>
<td>-.05</td>
</tr>
<tr>
<td>Differential Parenting – Treatment (Sibling)</td>
<td>.42**</td>
<td>-.13</td>
</tr>
<tr>
<td>Differential Parenting – Satisfaction (Sibling)</td>
<td>-.16</td>
<td>.34*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wider Social Community Characteristics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Connectedness (Sibling)</td>
<td>.34*</td>
<td>-.54**</td>
</tr>
<tr>
<td>Social Connectedness (Parent)</td>
<td>.28</td>
<td>.13</td>
</tr>
</tbody>
</table>

Note. *p <.004 **p <.001

The results in Table 14 revealed a significant positive correlation between Daily Hassles – Intensity and scores of Total Difficulties. Problem-Solving and Temperament were also shown to be significantly associated with Total Difficulties. Further analyses were conducted in order to evaluate the association between the various domains of temperament and Total Difficulties. Results indicated that with the exception of Distractibility, all other dimensions of temperament, including Activity Level-General, $r(N=78) = .49, p <.001$; Activity Level-Sleep $r(N=78) = .24, p = .034$; Approach/Withdrawal $r(N=78) = -.37, p =$
Flexibility/Rigidity $r(N=78) = -0.32, p = 0.004$; Mood $r(N=78) = -0.49, p < 0.001$; Rhythmicity-Sleep $r(N=78) = -0.33, p = 0.003$; Rhythmicity-Eating $r(N=78) = -0.33, p = 0.003$; Rhythmicity-Daily Habits $r(N=78) = -0.55, p < 0.001$; and Persistence $r(N=78) = -0.37, p = 0.001$ were significantly related to Total Difficulties.

At a family level, perceived Differential Treatment, as well as overall Family Functioning, and Parental Wellbeing were shown to be associated with scores of Total Difficulties. Again, individual elements of Family Functioning were assessed, and the results indicated significant relationships between Roles $r(N=78) = 0.40, p < 0.001$; Affective Responsiveness $r(N=78) = 0.29, p = 0.011$, Affective Involvement $r(N=78) = 0.29, p = 0.011$ and scores of Total Difficulties. All components of Parental Wellbeing, including Depression $r(N=78) = 0.42, p < 0.001$; Anxiety $r(N=78) = 0.45, p < 0.001$; and Stress $r(N=78) = 0.46, p < 0.001$ correlated significantly with Total Difficulties scores.

The results revealed a significant positive correlation between Daily Uplifts –Intensity and Self Concept, and a negative association between Daily Hassles – Intensity and Self-Concept. Knowledge of Disability was also found to be associated with Self-Concept, with siblings’ scores on Self-Concept significantly increasing as a function of their perceived knowledge. Temperament was related to siblings’ scores on Self-Concept. The dimensions of temperament were explored and it was shown that six of the temperament scales, including Approach/Withdrawal $r(N=78) = 0.40, p < 0.001$; Flexibility/Rigidity $r(N=78) = 0.27, p = 0.017$; Mood $r(N=78) = 0.32, p = 0.004$; Rhythmicity-Sleep $r(N=78) = 0.23, p = 0.042$; Rhythmicity-Daily Habits $r(N=78) = 0.23, p = 0.043$; and Persistence $r(N=78) = 0.36, p = 0.001$ were positively related to Self-Concept. At a family level, positive feelings associated with Differential Treatment, as reported by siblings, were shown to be significantly related to Self-Concept. Finally, a significant association between Social Connectedness and Self-Concept was found,
whereby siblings’ scores on Self-Concept decreased as their perceived Social Connectedness decreased.

**Analyses of the ‘Me and My Sib’ Scale – Sibling Interactions with the Wider Social Community**

To link daily hassles and uplifts within the wider social community with sibling psychological adjustment, analyses were conducted using the Community subscale of the ‘Me and My Sib’ scale. The results revealed a significant positive correlation between Community (Hassles) – Intensity and Total Difficulties $r(N=78) = .24, p = .031$, and a significant negative correlation between Community (Uplifts) – Intensity and Total Difficulties $r(N=78) = -.29, p = .011$. Items that were found to have the strongest relationship with Total Difficulties were ‘Being a part of different groups’ (Uplift), ‘…when we go out my brother or sister with a disability does strange things’ (Hassle), and ‘…when we go out we have to stop what we are doing (for example, leave the supermarket) because of my brother or sister with a disability’ (Hassle). The results also revealed a relationship between Community - Intensity (Hassles and Uplifts) and siblings’ scores on Self-Concept. The results demonstrated a positive correlation between Community (Uplifts) – Intensity and Self-Concept $r(N=78) = .32, p = .004$, and a negative correlation between Community (Hassles) – Intensity and Self-Concept $r(N=78) = -.29, p = .011$. Of interest, the items within the Community subscale demonstrating the strongest association with Self-Concept included ‘…being a part of different groups’ (Uplift), ‘…my brother/sister being happy when we go out’ (Uplift) and ‘…people staring or looking at us when we are out’ (Hassle).
Predictors of Sibling Adjustment

Hierarchical multiple regression analyses were employed to assess the strength of various factors in predicting sibling psychological outcomes (Self Concept and Total Difficulties) in siblings of children with disabilities. Two separate regression models were conducted, with variables more proximal to the sibling (e.g., sibling level factors), entered first, followed by more distal influences (e.g., family level and community level factors).

Sibling level variables that were shown to be significantly associated with Self-Concept (refer to Table 14) included the perceived intensity of hassles and uplifts, temperament, and knowledge of disability, and thus were entered in the first block of predictors for Self-Concept. Sibling satisfaction with differential parenting was the only family factor shown to be significantly related to Self-Concept, and as such was entered in the second block of the regression model (Step 2). Finally (Step 3), perceived connectedness to the community and supports was entered into the model to ascertain whether factors at a wider community level contributed to predicting Self-Concept over and above the variance accounted for by sibling and family characteristics (Refer to Table 15).
Table 15

Summary of the Hierarchical Regression Analysis for Variables Predicting Scores of Self-Concept (N = 78)

<table>
<thead>
<tr>
<th>Model/Predictor</th>
<th>B</th>
<th>( \Delta R^2 )</th>
<th>Model ( R^2 )</th>
<th>Adjusted ( R^2 )</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uplifts Total – Intensity (Sibling)</td>
<td>.31*</td>
<td>.36***</td>
<td>.36</td>
<td>.32</td>
<td>10.15***</td>
</tr>
<tr>
<td>Hassles Total – Intensity (Sibling)</td>
<td>-.10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temperament (Parent)</td>
<td>.24*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge (Sibling)</td>
<td>.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uplifts Total – Intensity (Sibling)</td>
<td>.29*</td>
<td>.001</td>
<td>.36</td>
<td>.31</td>
<td>8.05***</td>
</tr>
<tr>
<td>Hassles Total – Intensity (Sibling)</td>
<td>-.10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temperament (Parent)</td>
<td>.24*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge (Sibling)</td>
<td>.18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Differential Parenting – Satisfaction (Sibling)</td>
<td>.043</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uplifts Total – Intensity (Sibling)</td>
<td>.18</td>
<td>.077**</td>
<td>.44</td>
<td>.39</td>
<td>9.12***</td>
</tr>
<tr>
<td>Hassles Total – Intensity (Sibling)</td>
<td>-.031</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temperament (Parent)</td>
<td>.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge (Sibling)</td>
<td>.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Differential Parenting – Satisfaction (Sibling)</td>
<td>.083</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Connectedness (Sibling)</td>
<td>-.33**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05 **p<.01 ***p<.001
As shown in Table 15, the perceived intensity of uplifts was a significant predictor of Self-Concept during Step 1 and Step 2 of the regression; however, it did not account for a significant proportion of unique variance during Step 3 of the regression model. Temperament was also a significant predictor of Self-Concept during Step 1 and Step 2; however when Social Connectedness was incorporated into the model in Step 3, this variable no longer significantly predicted Self-Concept. Overall, the final model, which contained sibling, family and wider social community factors, accounted for 39% of the variance in sibling Self-Concept scores.

The Prosocial Behaviour Subscale of the Strengths and Difficulties Questionnaire was also considered as an outcome measure of psychological adjustment. A series of correlations were conducted among adjustment (Prosocial Behaviour), and demographic, sibling, family and wider social community level factors to determine the variables to be included into the model. Sibling level variables that were significantly associated with Prosocial Behaviour included problem solving and temperament, and thus were entered into the first block of predictors. Family functioning as well as siblings’ perceptions of differential parenting and satisfaction with differential parenting were family level factors shown to be significantly related to Prosocial Behaviour, and as such were included into the second block of the regression model. No demographic variables (e.g., disability type, income), or factors at a wider social community level were shown to be associated with Prosocial Behaviour. The results revealed that problem solving was the only significant predictor of Prosocial Behaviour in the 2-step regression model. Overall, the final model, which contained problem-solving, accounted for 19% of variance in sibling Prosocial Behaviour Scores. Given the R-square value and lack of significant predictors of Prosocial Behaviour, the Beck Self-Concept Inventory will be used as the primary measure of positive psychological outcomes for siblings in the results and discussions to follow.
The regression model predicting scores of Total Difficulties is shown in Table 16. As noted previously, annual family income was the only demographic variable shown to be significantly associated with scores of Total Difficulties. As a control strategy, this variable was entered in the first block of predictors. The next variables to be entered were those at a sibling level (Step 2), followed by variables at a family level (Step 3) and those at the wider social community level (Step 4).
### Table 16

**Summary of the Hierarchical Regression Analysis for Variables Predicting Scores of Total Difficulties (N = 78)**

<table>
<thead>
<tr>
<th>Model/Predictor</th>
<th>B</th>
<th>ΔR²</th>
<th>Model R²</th>
<th>Adjusted R²</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Income</td>
<td>-.36**</td>
<td>.13**</td>
<td>.13</td>
<td>.12</td>
<td>10.89**</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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**Note.** *p<.05  **p<.01  ***p<.001
As shown in Table 16, family income was a significant predictor of Total Difficulties during Step 1 and Step 2; however it did not account for a significant proportion of unique variance during Step 3 of the regression model when family factors were included. Problem Solving as a means of coping was shown to be a significant predictor of Total Difficulties during Step 2 and Step 3 of the model, however after the inclusion of Social Connectedness this factor no longer contributed to this outcome measure. Temperament was shown to be a significant predictor of Total Difficulties during Step 2 of the model, and continued to be a significant predictor in subsequent steps irrespective of the inclusion of family and community level factors. Parental well-being and sibling perceptions of Differential Parenting were found to be significant predictors of Total Difficulties during Step 3 and Step 4 of the regression model. Overall, the final model, which incorporated sibling and family factors accounted for 46% of the variance in sibling scores of Total Difficulties.

Given the group-based differences in scores of Self-Concept and Total Difficulties across siblings of children with Autism and siblings of children with Down syndrome, regression analyses were conducted to account for disability type. The results revealed that there was no effect for disability type when Self-Concept was entered as the dependent variable in the regression analyses. When Total Difficulties was entered as the outcome variable, Down syndrome was a significant predictor of during Step 1 of the model, however, it did not account for a significant proportion of unique variance during Step 2 to Step 5 of the model. Autism was not found to be a significant predictor of Total Difficulties during any phase of the regression model.

**Discussion**

Enhancing family quality of life and the psychological adjustment of siblings of children with a disability has recently gained increasing attention in the literature (Davis & Gavidia-Payne, 2009; Giallo & Gavidia-Payne, 2006). The aim of the current study was to
identify the factors at a sibling, family and community level that contribute to positive (e.g., Self-Concept) and adverse (e.g., Total Difficulties) psychological outcomes in siblings of children with a disability.

The current study revealed that siblings’ scores on the Strength and Difficulties Questionnaire were comparative to the normative sample of this measure (Mellor, 2005). With the exception of Peer Problems and Emotional Symptoms, no other significant differences were found between siblings of children with a disability and the normative sample. However, for those subscales where a significant difference emerged, only small effect sizes were found, thus indicating that the differences between groups were minor. The finding that no differences were found on the majority of subscales on the Strengths and Difficulties Questionnaire is consistent with those for the Beck Self-Concept Inventory for Youth, with no significant difference found between the current sample and existing standardised data (Beck et al., 2005).

Only a small percentage of siblings scored within the Borderline and Clinical ranges on the Strength and Difficulties Questionnaire, with the majority of siblings having a score within the Normal range on this measure of adjustment (greater than 69% across each of the subscales). This coincides with findings on the Beck Self-Concept Inventory for Youth, with 78% of siblings scoring in the Average to Above Average range on this outcome measure. These results are promising and demonstrate that, at least for this sample, only a small percentage of siblings of children with disabilities have adjustment problems. It is still important, however, to address the needs of siblings, by providing sound assessment of their needs and corresponding evidence-based interventions, given that a proportion of this population is still likely to exhibit adjustment problems.
Sibling Factors

The present study provides evidence to suggest that sibling individual functioning including temperament, daily hassles and uplifts, coping, and siblings’ perceived knowledge of disability are associated with the psychological adjustment of siblings of children with a disability. Reviewing temperament, in particular, was an important element of the thesis, as few studies have examined its role in the psychological adjustment of siblings of children with disabilities (Rivers & Stoneman, 2008). Overlooking the role of temperament is surprising for two reasons: first, a strong body of evidence exists supporting a link between temperament and psychological outcomes in typical childhood development; and second, the intuitive conceptual rationale for this relationship based on the developmental psychopathology perspective. Temperament profiles have consistently been shown to be associated with several psychological outcomes for children (Lemery & Goldsmith, 2001; Stoneman & Broady, 1993), and the results of the current study have provided evidence to suggest that this relationship can be generalised to siblings of children with disabilities. The current results indicated that sibling temperament is a significant predictor of Total Difficulties, a measure of adverse psychological outcomes.

Temperament was also found to be associated with Self-Concept, however, was not shown to be a significant predictor of this positive psychological outcome. Out of all the temperament dimensions, Persistence and Approach-Withdrawal had the strongest relationship with Self-Concept. Specifically, siblings’ own perceptions of competency and positive self-worth increased as a function of persistence and approach behaviours. Rivers and Stoneman (2008) noted that typically developing siblings who are more persistent may be determined to connect to their sibling, and engage in particular tasks until a response is elicited. This explanation can also be applied to the current findings, whereby siblings with
higher persistence scores may be more inclined to persevere with a particular task until success is achieved, resulting in increased thoughts and feelings of self-worth.

The experience of daily uplifts, as measured by the ‘Me and My Sib’ scale was another sibling variable shown to be associated with Self-Concept. Conceptually, this finding extends beyond past research and provides evidence to suggest that siblings’ uplifts that were experienced on a daily basis across different domains of life (e.g., family, friends, and community) are directly related to how they perceive themselves. Despite this association, the regression model demonstrated that while experiencing uplifts was a predictor of Self-Concept, this sibling level variable did not account for a significant proportion of unique variance when siblings’ perceived social connectedness was entered into the model. This finding provides evidence for extending beyond sibling level factors and exploring the risk and protective factors across the multiple systems siblings operate within.

Although not predictive of positive (Self-Concept) or adverse psychological adjustment (Total Difficulties), a negative relationship between Problem-Solving Coping and scores of Total Difficulties was also identified. Problem solving refers to the ability to work through a problem, while remaining positive, fit, calm and connected socially (Frydenberg & Lewis, 1993). Implementing problem-solving to manage the discrepancy between the situation and the perceived resources to manage it is associated with greater control, more positive thoughts (e.g., “I can work through this problem”), and deceased scores of Total Difficulties.

Siblings reported knowledge about their brother or sister’s disability was also shown to be related to sibling adjustment, specifically Self-Concept. Consistent with previous research, when siblings have sufficient information, they are better able to modify their thoughts and feelings, and develop a rational interpretation of the impact that disability is having on family life, as well as their interactions and relationships with people outside the
family system (Howlin, 1988; Lobato & Kao, 2002). As noted, two parents elected for their child not to participate in the study, and expressed anxiety about concerns being raised that to date have not surfaced as an issue. Previous research has demonstrated that parental behaviours that prevent the promotion of open communication and expression of concerns and feelings can result in a number of unfavourable consequences including somatic complaints and depression (Powell & Gallagher, 1993). By incorporating a measure of positive psychological adjustment (Self-Concept), the current study has demonstrated that being informed and having knowledge about one’s brother or sister with a disability is related to positive perceptions of self. Further research is needed to replicate the finding regarding the relationship between knowledge and self-concept, and also evaluate the outcomes associated with providing parents with the tools needed to support and facilitate discussions with their children about disability.

**Family Factors**

Family variables, including parental depression, anxiety, stress and Differential Parenting - Treatment were significant predictors of sibling Total Difficulties. The relationship between parent wellbeing and Total Difficulties is consistent with findings by Jackson and colleagues (2008) that parental distress as measured by the Parenting Stress Index significantly predicted variance in adjustment scores for siblings (as measured by the Strength and Difficulties Questionnaire). Similarly, in a comparison of maternal wellbeing across families of children with and without a diagnosis of an autism spectrum disorder Quintero and McIntyre (2010) recently revealed that maternal wellbeing was significantly related to sibling behavioural adjustment, with poorer parental wellbeing being associated with greater behavioural problems (Quintero & McIntyre, 2010).

Out of the three scales on the DASS, stress was the most elevated among parents in the current study. This coincides with previous studies that have found that parents of
children with disabilities exhibit more stress than their counterparts who are not raising a child with a disability (Smith, et al., 2001). Based on the association between parent wellbeing and adverse sibling psychological adjustment (Total Difficulties), the question arises in regards to the mechanisms by which parental functioning influences sibling scores of Total Difficulties. Based on family systems theory and consistent with past research (Nixon & Cummings, 1999), it is possible that siblings are cognisant of and perceptive to parent mood and wellbeing. This was also evident in Study 1 of the current thesis, whereby siblings reported concerns about parental fatigue (e.g. *she [child with a disability] is a real big handful for mum...she [mum] is on her feet all day*).

Although not directly related to sibling adjustment, those parents experiencing greater levels of social connectedness also reported decreased depression, anxiety and stress. This is consistent with other studies which have found an association between parental wellbeing and social support (Benson & Karlof, 2009; Hastings et al., 2002; White & Hastings, 2004). Feeling connected is subjective, and it does not reflect the size of one’s social network (Hawkley & Cacioppo, 2010). As such, it is important to look beyond a map of what supports parents may report having (e.g., Early Childhood Intervention Key-Worker, extended family), and search for parents’ perceived connectedness to these supports. For example, ascertaining how connected parents feel to their support team is necessary, and asking questions such as, ‘*what would it take for you to feel more connected*’ is likely to have implications in supporting parents, and more broadly siblings and the wider family system.

Interventions that enhance parental wellbeing and social connectedness would also provide parents with the resources needed to manage the needs of not only the child with a disability but those of the entire family (Wolf et al., 1998). This is heavily tied in with differential parenting, a family level factor shown to be a significant predictor of adverse psychological outcomes (Total Difficulties) in the regression model. Specifically, parents
reported greater adjustment problems in siblings (Total Difficulties) who perceived that they were being treated differently to their brother or sister with a disability. This finding is consistent with previous studies reporting that siblings are at risk of developing internalising and externalising problems when they perceive that their brother or sister with a disability is being treated more favourably (McHale & Gamble, 1989; Wolf et al., 1998). In addition, it provides further evidence to suggest that family functioning and wellbeing is associated with the psychological adjustment of siblings of children with disabilities (Giallo & Gavidia-Payne, 2006).

**The Wider Social Community**

Siblings’ perceived social connectedness was found to be the greatest predictor of Self-Concept, over and above individual and family level factors. The current finding coincides with previous research which has found that a child’s self-concept is influenced by his/her relationships and interactions with his/her parents, peers and significant others (Beck et al., 2005; Berk, 2006; Hoffman et al., 1988; Mash & Wolfe, 2002). In addition, the current finding between social connectedness and self-concept emphasises the importance of siblings’ perceptions of school and friends. The value of a stable and responsive environment of relationships within the community, and its influence on psychological adjustment among siblings of children with disabilities has also been demonstrated. Essentially, the finding indicates that siblings’ sense of self worth is defined (at least in part) on the basis of their relationship with others, and in this case, their relationship with friends.

Social connectedness was examined using the Loneliness and Social Dissatisfaction Questionnaire, which emphasises siblings’ interactions and a sense of belonging with friends and the school community (e.g., ‘It is easy for you to make friends at school’; Is it hard for you to get along with kids at school’). According to Hawkley and colleagues (2010), some individuals live solitary lives and rarely experience feelings of emptiness, whereas, others
have a heavy social life and report feeling unconnected and describe having intense feelings of loneliness. Applied to this study, some siblings may have minimal contact with their social group and report feeling connected, whereas, other siblings may have multiple people on their support team and feel isolated. In addition, different support groups exist in society (e.g., friends, internet, Facebook), and ascertaining what is contributing to perceived social connectedness (or lack of) would provide valuable information to sibling research. Given the sample size of siblings of children with Autism (n=30), investigating whether loneliness is a consequence of classic autism phenotype features is also a direction for further research.

The current study is one of the first empirical studies linking sibling daily hassles and uplifts experienced in the wider social community to both positive (Self-Concept) and adverse (Total Difficulties) psychological outcomes. Specifically, the findings demonstrate that the wider social environment is a context that can either nurture and reinforce positive psychological adjustment or contribute to adverse psychological outcomes. While certain hassles in the wider context (e.g. … brother or sister with a disability displaying strange behaviours; having to stop an activity when out as a consequence of the behaviour of the child with a disability) were associated with Total Difficulties, these hassles were not found to be related to Self-Concept. It is possible that different hassles are associated with various outcomes for siblings (Self-Concept and Total Difficulties). However, the current finding may be a function of the different informants completing the outcome measures. Parents completed the Strength and Difficulties Questionnaire (Total Difficulties), whereas, siblings completed the Beck Self-Concept Inventory for Youth (Self-Concept). The finding that different hassles were associated with different outcome measures (Self-Concept and Total Difficulties) also applies to other sibling, family and community factors. Specifically, family variables were predictive of Total Difficulties, whereas, siblings’ perceived connectedness to social support predicted Self-Concept.
Limitations of the Present Study and Directions for Future Research

Although efforts were made to recruit a sample size greater than previous studies in this area, recruiting 78 families limited the type of data analyses that could be conducted. Path analyses, an extension of the regression model, would have been advantageous in order to examine more closely the indirect and direct relationships among the factors predicting Self-Concept and Total Difficulties. However, due to the sample size, this statistical analysis was not possible (Tabachnick & Fidell, 2001). Further research can address the current shortcoming by attempting to recruit a larger sample; however, it is important to acknowledge the difficulties surrounding the recruitment of large samples among this specific population.

Family experiences and adjustment are also likely to vary as a function of other factors, including disability types (Stoneman, 2005). This was indeed evident in the group-based difference found between Autism and Down syndrome on scores of Total Difficulties and Self-Concept. Future research needs to ascertain the relationship between disability type, factors across an individual, family and wider community level, and adjustment in order to address the unique support needs of the family.

Careful consideration was given to the outcome measures of adjustment in order to overcome the shortcomings of previous research and provide a unique contribution to sibling research. Although it would have been advantageous to have siblings and parents complete the Strength and Difficulties Questionnaire, self-completion for siblings is only available for 11-17 year olds. Having different informants on this outcome measure would have strengthened the study, as analyses would have been able to ascertain whether there is congruence between parent and sibling reports on the Strengths and Difficulties Questionnaire. Parent reporting may have influenced the findings of this study, given that those who chose to take part in the study may have had fewer life stressors and more
resources to cope with the demands of parenting than their counterparts who chose not to respond to the invitation to participate. Conversely, parents concerned about their own mental health and the adjustment of their typically developing child may have been more likely to respond to the invitation.

**Practical Implications and Conclusion**

The current study has identified several important implications for practice that can be used to facilitate sibling adjustment. In particular, given that perceived social connectedness was the most significant predictor of self-concept, it is important to facilitate the development of friendships and close relationships with siblings, and ensure that siblings feel connected. Intervening at a family level is also essential, given that parental wellbeing and differential parenting were shown to predict scores of Total Difficulties. Temperament was also shown to be predictive of Total Difficulties, providing further support for the influence of both internal (genetic vulnerability) and external (environmental) factors. These factors should be viewed as vital components for the design of effective interventions for siblings of children with disabilities. Further, evaluation of sibling interventions by practitioners is essential in terms of the effectiveness of intervention on siblings, families and children with a disability.
Chapter 6: Summary and Conclusions

Studies contained in the present thesis have explored the relationships between siblings’ experiences across various contexts, and positive and adverse psychological outcomes. Consistent with previous research (Giallo & Gavidia-Payne, 2006), the current thesis revealed that only a small percentage of siblings are vulnerable to adjustment problems. Specifically, two thirds of siblings in this research had scores in the Non-Clinical Range on the Strength and Difficulties Questionnaire, a measure of adverse psychological outcomes. Further, over three quarters of siblings scored in the Average to Above Average range on the Beck Self-Concept Inventory for Youth, an indicator of positive psychological adjustment.

A series of risk and protective factors across sibling, family, and wider social community levels were identified as predictors of sibling adjustment. Temperament, parental wellbeing, and differential parenting were shown to be significant predictors of Total Difficulties; whereas siblings’ perceived connectedness to social support was a significant predictor of Self Concept. Throughout the current thesis, three studies were presented. This chapter aims to build upon these studies and more broadly discuss the implications of this research at a conceptual, methodological and practical level.

Conceptual and Theoretical Implications

Findings from the current research provide empirical support for adopting the developmental psychopathology perspective and Bronfenbrenner’s Ecological Systems theory as organising frameworks for understanding the psychological adjustment of siblings of children with a disability (Bronfenbrenner, 1979, 1992, 1999; Dishion & Stormshak, 2007). Specifically, various contexts, including the wider social environment were found to be contributing to the psychological adjustment of this population.
In study 1, siblings reported a range of daily hassles and uplifts experienced within and outside the family environment. Some of the uplifts identified include thoughts about being valued and regarded as ‘special’ among friends for understanding their brother or sister with a disability, as well as being actively involved in different organisations associated with disability (e.g., Down syndrome Victoria). Daily hassles included limited opportunities for outings as a family, disruption of time with friends, as well as enduring the reactions of others when in public. The knowledge generated in the study offers a valuable contribution to sibling research, as consideration of all potential influences across various contexts is needed to design effective interventions for siblings.

Study 3 provided further support for the notion that family and contextual factors when assessing sibling adjustment indeed matter. Parent scores on the DASS were shown to be a significant predictor of siblings’ scores of Total Difficulties. This finding ties in with family systems approaches, which emphasise the importance of family interactions, and how family members are impacted by one another (Rosenbaum et al., 1998; Turnbull et al., 2006). While some parents may be able to accommodate and healthily adjust their lifestyles to manage the stressors associated with raising a child with a disability, others may not be as resilient. For some parents, meeting the demands of parenting a child with a disability while promoting the wellbeing of other family members may prove to be a highly difficult task that results in elevated symptoms of depression, anxiety and stress. The pervasive nature of stress in parents of children with disabilities has been consistently documented within the literature (Benson & Karlof, 2009; Smith et al., 2001). It is possible that parents with elevated DASS scores may become oversensitive to sibling difficulties, which in turn exacerbate their level of depression, anxiety and stress, thus resulting in a negative cyclical relationship. It is important to note at this point that while parent wellbeing may either directly or indirectly impact sibling adjustment, the relationship is likely to be bi-directional, whereby sibling
adjustment and other sibling factors including temperament, coping repertoire, and perceived connectedness to social supports is likely to influence parental wellbeing. Irrespective of the direction of the relationship, the results of the current research found that aspects of family psychological adjustment/wellbeing including parental wellbeing and factors within the wider community were found to be associated sibling adjustment. Therefore, it is essential to move beyond the provision of sibling groups as the sole form of support and also intervene at a family level.

Broadening the conceptualisation of adjustment by incorporating measures of both adaptive and maladaptive adjustment was also supported in the present thesis. Advocates of the developmental psychopathology perspective provide a rationale for this approach to research, and argue that positive and adverse psychological outcomes need to be assessed to understand the development and maintenance of childhood disorders (Cicchetti & Cohen, 1995; Dishion & Stormshak, 2007). In this study’s sample, sibling adjustment is shown to be a fluid, multifaceted and changing construct. The positive and adverse consequences of growing up with a brother or sister with a disability were measured in the current thesis, and a range of sibling, family and wider social community factors were differentially associated with sibling outcomes. For example, family variables were implicated in Total Difficulties, whereas siblings’ perceived connectedness was the only significant predictor of Self-Concept. This finding suggests that researchers and practitioners need to move beyond conceptualising sibling adjustment as a single construct and regard it as having multiple dimensions that have the potential to be influenced by a range of different variables.

Methodological Implications

The development of the ‘Me and My Sib’ scale enabled measurement of the risk and protective factors that siblings experience within the various systems they function within. The measurement tool extends beyond previous research and captures siblings’ experiences
within the wider social context. Based on the Ecological Systems Theory (Bronfenbrenner, 1979, 1992, 1999), the characteristics of the ‘Me and My Sib’ scale are shown to suitably capture the richness of the sibling experience. Currently, a psychometrically sound assessment tool is not available to quantitatively assess the broad range of daily hassles and uplifts siblings’ experience. The ‘Me and My Sib’ scale is user-friendly and can be easily incorporated into future research and clinical practice when working with families of children with disabilities. Not only has the current research broadened the conceptualisation of siblings’ experiences, it has provided a tool to assess daily hassles and uplifts for siblings of children with disabilities. Further, it forms a conduit through which siblings’ experiences across various contexts (e.g., family, school, community) can be connected to their psychological adjustment. Siblings’ interactions within the wider social community were related to psychological adjustment. As such, the assessment of sibling adjustment should take into consideration the role of the wider social context. It addition, interventions need to address the broad range of risk and protective factors across the different systems that are contributing to positive and adverse psychological outcomes for this population.

The studies contained in the present thesis utilised siblings as informants of their own experiences and psychological adjustment. In the qualitative component of the research, siblings shared the broad range of experiences encountered on a daily basis, including those within the wider social context. Siblings were then invited to be complete the Beck Self-Concept Inventory for Youth, and report on their own psychological adjustment. As noted, the Beck Self-Concept Inventory for Youth is a measure of siblings’ own perceptions of competency and positive self-worth. Siblings were encouraged to reflect on their strengths and resources and were required to respond to questions such as ‘I am a good person’ and ‘I am happy to be me’. The thesis incorporated the construct of self-concept and allowed siblings to be the respondents of their own psychological adjustment, as opposed to relying
on parent reports which has been common practice (Beck et al., 2005). Siblings’ thoughts around sense of self, strengths and positive self-worth are not readily available to parents or caregivers. Without this measure of psychological outcomes, it would have been difficult to elicit those factors at a sibling, family, and wider social community level that are contributing to positive psychological adjustment as rated by siblings. Integrating this measure also allowed for triangulation to be observed within the data, thus increasing the credibility and validity of the results, with sibling outcomes being predicted by parent reports.

**Implications for Clinical Practice**

**Assessment**

The current research has provided a theoretical and empirical basis for guiding the assessment of the experiences of siblings of children with disabilities and their psychological adjustment. Clinicians need to be familiar with the current literature, including outcomes for siblings as well as the range of influencing factors shown to be associated with adjustment across a sibling, family and wider social community level. It is important that practitioners are aware of the various psychological outcomes, and the potential that various factors generate different sibling outcomes. Factors at a family level were associated with Total Difficulties (characterised by conduct problems, emotional symptoms, hyperactivity/inattention, and peer-problems), whereas sibling connectedness to support was closely related to Self-Concept and more positive perceptions of self. As such, it is essential that these characteristics are considered in the assessment process. Without this knowledge, it is difficult to ask the questions needed to obtain a comprehensive formulation of the sibling and more broadly the family. Having a balanced view of sibling outcomes, from different informants, and identifying the positives of growing up with a family member who has a disability is another ingredient in delivering supports. Ascertaining positive psychological adjustment can strengthen siblings and families, providing them with the resources to manage
undesirable outcomes. This information is vital in guiding the intervention plan for the unique needs of the sibling and broader family, and as such it is an imperative component in supporting families of children with disabilities.

**Intervention**

Given the variation in support needs required by siblings and families of children with disabilities, it is important to be guided by the assessment process. While an intervention was not developed based on the current findings and assessed for effectiveness, practical implications have been identified.

**Communication is the key.** A relationship was found between knowledge of disability (*rate how much you know/understand about your brother or sister's disability*) and self-concept. This finding suggests that siblings would benefit from having age appropriate information presented to them. It is likely that this would help reassure siblings, give siblings the information needed to share with others, and in turn increase confidence and positive perceptions of self. Of interest, two families chose to withdraw from the study, predominately because they chose not to provide consent for their child to participate. The reason expressed was that they were concerned that “...things that aren’t an issue may become one if they are exposed to items within the questionnaire”. For example, one parent expressed that their child has not raised differential parenting as an issues and if they are introduced to this within the questionnaire it has the potential to become an issue. While parents are understandably concerned about their child’s adjustment, it is important to provide psycho-education in terms of the importance of children having a safe environment to discuss positive and negative experiences, normalise sibling experiences, as well as their thoughts and feelings surrounding growing up with a brother or sister with a disability. Communicating and encouraging siblings to openly express their experiences and emotions is an important tool, and is likely to promote social and emotional development. Past research (Barr & McLeod, 2010; Powell &
Gallagher 1993) has identified a range of different emotions that siblings’ experience, and this was also evident within Study 1.

**Finding solutions to problems.** Problem-focused coping was shown to be associated with Total Difficulties, with scores on this outcome measure decreasing as a function of siblings finding solutions to problems. Based on this finding, it is necessary for siblings to explore their coping behaviour, reflect, and with the support of parents and health-care professionals (e.g., psychologists) develop the tools required to engage in problem-focused coping. Siblings and other family members will inevitably benefit from cognitive and behavioural strategies to manage daily hassles associated with disability as well as other life challenges.

**Tune in to sibling temperament.** Temperament was shown to be a significant predictor of scores of Total Difficulties and was related to executing different coping responses (e.g., Problem-Focused Coping). Given this finding, parents and practitioners need to be in tune with the siblings’ temperament and ensure that there is a match between temperament and the demands and expectations of his or her environment. Without acknowledging the role of temperament, there may be incongruence between internal factors (e.g., persistence, activity level) and the environment, increasing the likelihood of adjustment problems (Dishion & Shormshak, 2007). Practitioners need to explore individual dimensions of temperament and consider the child’s temperament profile in the delivery of support services for siblings and families.

**Organise ‘play dates’ with siblings filled with positive interactions.** Perceived differences in treatment (as rated by siblings) were predictive of Total Difficulties. In addition, there was a strong relationship between Differential Parenting – Sibling and Differential Parenting – Parent, which demonstrates that while siblings are reporting variations in parenting practices, parents are cognisant of these difference. Given this, it
important to work with parents to explore the difficulties encountered, problem solve, and devise a plan of how to address the needs of all family members, including siblings. Siblings would inevitably benefit from one-on-one time with parents, which is characterised by engagement and positive interactions. It is likely that the cognitive appraisal made by siblings about differential treatment is contributing to outcomes, and as such it would be beneficial to intervene at a sibling and family level using principles of cognitive-behavioural therapy.

**Building and feeling connected to the support team.** The current thesis revealed that perceived connectedness to supports for siblings and decreased feelings of loneliness was the most significant predictor of positive sibling outcomes with respect to Self-Concept. As siblings self-reported scores of loneliness decreased, siblings own perceptions of competency, strength and positive self-worth increased. Given this, it is important to assess sibling thoughts (e.g., are you good at working with other children at your school?) and feelings around their support team. It is also important to ascertain whether siblings have the tools needed be establish meaningful relationships and feel connected with their support team, and intervene where appropriate. For example, a comprehensive assessment may indicate that the sibling has social skills deficits, and consequently needs support to enhance skills in this area and promote social competence. Working with parents to understand their own support team is also necessary, based on the finding that decreased feelings of loneliness for parents was associated with enhanced parental wellbeing.

**Be a friend to yourself and focusing on parental wellbeing.** Elevated scores on the DASS scale for parents were shown to be the most significant predictor of scores of Total Difficulties for siblings. Given this finding, it is important to work with parents to help minimise their feelings of depression, anxiety, and stress. A comprehensive assessment is essential to ascertain how to best intervene (e.g., perpetuating and protective factors), however it is likely that parents would benefit from integrating pleasant activities into their
daily routines, identifying strengths in their relationships with those close to them, and having the tools needed to maintain a healthy sense of self.

In summary, the current thesis has provided a theoretical and empirical basis for guiding assessment and intervention for siblings growing up with a family member with a disability. It has provided further evidence for family-centered practice, and the interactive nature of the family system and beyond in influencing sibling adjustment.

**Directions for Further Research**

There are several directions for further research that have been identified throughout the current thesis. Future research should continue to adopt a strength-based approach and measure the positive consequences of growing up with a brother or sister with a disability. Identifying sibling strengths and positive outcomes is essential as it can be used to help promote positive psychological adjustment and provide siblings with the resources needed to manage stressful life events when they arise. Conceptually and theoretically, research also needs to build upon the current thesis and continue to explore the broad range of hassles and uplifts siblings’ experience both within and outside the family environment. The ‘Me and My Sib’ scale has provided an avenue to quantitatively assess these daily hassles and uplifts. It has built upon the work of Giallo and Gavidia-Payne (2006) and incorporated items to measure the frequency and intensity of daily hassles and uplifts at a community level. A greater understanding of siblings’ experiences within the wider community and how these relate to sibling psychological adjustment is needed. This is particularly important given the relationship found between social connectedness and self-concept. Longitudinal research could also elicit valuable information about the impact that social connectedness and deceased feelings of loneliness has on perceptions of self-worth over time. More research is also needed to acknowledge contemporary family life and societal pressures, especially as it refers to social support and the wider social context.
Efforts were made to recruit siblings who attended the same school as their brother or sister with a disability; however, as noted the majority of siblings were enrolled in different schools. Limited information in this area makes it difficult to inform parents and teachers of the potential hassles and uplifts siblings’ experience in the school community. This makes it difficult for parents to make an informed choice on whether to enrol their children in the same school, and how to best support siblings. In addition, the sample consisted of those families who volunteered to participate, and as such there may be differences between those families and siblings who were motivated to engage in the study and those who choose to not respond to the invitation. Recruiting a broader sample may prove useful in this regard.

It would also be advantageous to use the research findings to develop an intervention program for siblings. This program would target the various components identified in the current thesis including perceived social connectedness, parental wellbeing and differential parenting. In addition, researchers and practitioners must extend beyond sibling outcomes and evaluate the effectiveness of this program on families, and the child with a developmental delay/disability. Family systems theory provides a rationale for this, as it is likely that sibling functioning and adjustment is going to be associated with outcomes in the child with a disability. This has gained little attention in the research; however, has the potential to provide great insight in how to support children with a disability, siblings, and enhance overall family quality of life.

Given the differences identified in the appraisal of hassles and uplifts in Study 1, it is probable that the interpretation of an event is going to change as a function of age and maturity. Other factors, including knowledge of disability as well as the appraisal of differential parenting are likely to change as a function of the age of the sibling and consequently it would be beneficial to assess the impact of these variables on sibling adjustment across the lifespan. As noted by Hodapp and colleagues (2005) this is an
underdeveloped area, and thus further understanding will have implications for support services, and in the absence of this information it is difficult to know whether support needs change across the lifespan, and in turn how to best support siblings throughout development.

**Conclusion**

Contemporary understandings in various fields of endeavour (e.g., developmental disability service provision, psychology) have led researchers and practitioners to appreciate the importance of focusing on promoting positive family and sibling psychological adjustment in families of children with a disability. The current thesis adopted a mixed method design and aimed to explore siblings’ self-reported experiences of growing up with a brother or sister with a disability, and further develop a psychometrically sound measurement tool to assess the daily hassles and uplifts encountered by siblings. A primary aim of the thesis was also to identify sibling, family and community level factors that are contributing to both positive and adverse psychological adjustment of brothers and sisters of children with a disability. Being conceptually guided by the developmental psychopathology perspective, Bronfenbrenner’s Ecological Systems Theory, the ‘Daily Events’ approach, as well as principles of stress and coping, the three studies addressed these aims.

Overall, it can be concluded that while many parents worry about the psychological adjustment of their typically developing children, most siblings are well adjusted. Further support for previous research (Giallo & Gavidia-Payne, 2006), with only a small percentage of siblings of children with a brother or sister with a disability being vulnerable to adjustment problems, was generated. Conceptually, it has been shown that sibling adjustment is not a single construct, and that different factors predict various outcomes; family factors were closely associated with Total Difficulties, whereas siblings’ perceived connectedness to social supports was related to Self-Concept. A combination of sibling, family and wider social community factors are thus associated with sibling adjustment, and need to be taken
into consideration in the assessment and intervention phases of support. Overall, the current thesis has provided a valuable contribution to sibling research, offering knowledge for the development of evidence-based practices for supporting siblings of children with disabilities. The results emphasise the importance of incorporating a broader approach to intervention that focuses not only on the needs of the child with a disability, but also other family members including siblings.


Barr, J., & McLeod, S. (2010). They never see how hard it is to be me: Siblings’ observations of strangers, peers and family. *International Journal of Speech-Language Pathology, 12*, 162-171. doi: 10.3109/17549500903434133


Appendix A

Letter of Approval from Organisations – Study 1

Title of Project: The Psychological Adjustment of Siblings of Children with a Disability: The Role of the Family and the Wider Social Context

Dear __________________________,

We are seeking permission to recruit families from your centre/school to take part in a study about how siblings are influenced by growing up with a brother or sister with a developmental delay or disability. The only involvement of the centre/school will be to distribute the ‘letter of invitation’ to parents with a supplied self-addressed envelope.

I ______________________________ have read and understood the attached letter of invitation to parents and plain language statement outlining the objectives and procedures of this study. I give permission for the recruitment of families from this centre/school to take part in this research.

Date: ______________________________________

Name: ______________________________________

Organisation: _________________________________

Position within the organisation: _______________

Phone number: _______________________________

Signature: ___________________________________
HELP WANTED
for a study on
SIBLINGS OF YOUNG CHILDREN WITH DISABILITIES

Dear Parents and Siblings,

I’m Kate Davis and I am a Doctoral student supervised by Dr Susana Gavidia-Payne from the School of Health Sciences (Division of Psychology) at RMIT University. We are seeking your participation in a research project to assist us in understanding how siblings are influenced by growing up with a brother or sister with a developmental delay or disability. Your opinions and experiences are important to us and they will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life.

Your opinions and experiences are important to us!

Siblings, we hope you chose to participate in this research and answer some questions about your experiences of growing up with a brother or sister with a disability. Our discussions together will seek information about the positives things about growing up with a brother or a sister with a disability and what types of activities that you do together that you find enjoyable. I will also ask you about any concerns you may have such as how to tell your friends about your brother or sister with a disability and what they may think. The information that is obtained during our discussions will remain confidential and no names or identifying information will be recorded. We will be providing families with a brief report of the findings at the completion of the study.

If you are between 8 and 16 years old and have a brother or a sister with a developmental delay or disability, we would love to hear from you.

Please return the slip attached in the supplied self-addressed envelope.

THANK YOU FOR YOUR INTEREST!

Yes, I would like to participate in the study about the impact of growing up with a brother of sister with a disability on sibling psychological wellbeing.

Parents Names: ______________________
Name of Your Child with a Disability: ______________________ Date of Birth_______
Siblings Name: ______________________ Date of Birth: _______
Telephone: (h) ______________________ (m) ______________________

A follow-up study will also be conducted towards the end of 2008 and we would love for you to be apart of it. Would you like to be contacted at this time? 😊 Yes ☐ ☐ No ☐ ☐
Appendix C
Demographic Questionnaire– Study 1

The Psychological Adjustment of Siblings of Children with a Disability

Date: ---------/----------/----------

Thank you for agreeing to participate in this study. We would like to ask you a few questions about your child with a development delay or disability and also his/her sibling. If you have more than one child with a developmental delay or disability, please consider the one who has the most impact on your family life.

All the information you give us will remain confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that are not applicable to you.

What is your relationship to the child with a developmental delay or disability in your family?

□ Mother  □ Father  □ Other (Please Specify)  ………………………………

What is the gender of your child with a developmental delay or disability?

□ Male  □ Female

When was your child with a developmental delay or disability born? …../…../…..

What would you describe the level of your child’s developmental delay/disability (Please tick the one you consider the closest description)?

□ Mild  □ Moderate  □ Severe  □ Very Severe

What is the nature of your child’s disability (Please tick as many as appropriate)?

□ Autism spectrum disorder  □ Physical disability

□ Global developmental delay  □ Speech or language impairment

□ Down syndrome  □ Visual disability

□ Fragile X  □ Cerebral palsy

□ Hearing disability  □ Other disability (Please specify)

…………………………

□ No specific diagnosis
Sibling Information

What is the gender of your child participating in this study?
□ Male □ Female

When was your child who is participating in this study born? …/…/……

What is this child’s position in the family?
□ First □ Forth
□ Second □ Fifth
□ Third □ Sixth

How many children are there in your family?
□ 2 □ 3 □ 4 □ 5 □ 6 □ 7

Is the child participating in this study older or younger than your child with a developmental delay or disability?
□ Older □ Younger

Does your child with a developmental delay or disability attend the same school as his or her sibling?
□ Yes □ No

Is your child currently a member of a sibling support group?
□ Yes □ No

If yes, please specify ______________________________________________________

____________________________________________________

On a scale from 1-10 please rate how helpful you perceive this support to be in terms of your child’s adjustment?

0 1 2 3 4 5 6 7 8 9 10
Not at all helpful Extremely helpful

Has your child been a member of a sibling support group in the past?
□ Yes □ No

If yes, please specify the type of support received and also the duration of involvement in this group

__________________________________________________________________________

__________________________________________________________________________
On a scale from 1-10 please rate how helpful you perceived this support to be in terms of your child’s adjustment?

0 1 2 3 4 5 6 7 8 9 10
Not at all helpful Extremely helpful

Has your child received any other types of supports in relation to his or her sibling with a disability?

☐ Yes  ☐ No

If yes, please specify the type of support received

___________________________________________________ _______________________________________

On a scale from 1-10 please rate how helpful you perceived this support to be in terms of your child’s adjustment?

0 1 2 3 4 5 6 7 8 9 10
Not at all helpful Extremely helpful

Would you like to tell us anything else, or do you have any other comments?

___________________________________________________ _______________________________________

___________________________________________________ _______________________________________

THANK YOU FOR YOUR TIME AND FOR SHARING THIS INFORMATION WITH US!
Appendix D
Plain Language Statement – Study 1

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT
PROJECT INFORMATION STATEMENT

Project Title:
The Psychological Adjustment of Siblings of Children with Disability: The Role of the Family and the Wider Social Context

Investigators:
Kate Davis (Clinical Doctorate Psychology Student)
Dr Susana Gavidia-Payne (Project Supervisor: Director, EPIC Centre, RMIT University, susana.gavidia-payne@rmit.edu.au, 9925-7393)

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or ‘plain English’. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

Who is involved in this research project? Why is it being conducted?
This research is being conducted by Kate Davis in partial fulfilment of the requirements of the Clinical Doctorate Degree in Psychology at RMIT University and will be closely supervised by Dr Susana Gavidia-Payne and Dr Emma Little. This project has been approved by the RMIT Human Research Ethics Committee.

What is the project about? What are the questions being addressed?
Previous research indicates that different factors, particularly those at a family level are associated with sibling psychological adjustment. However, the risk and protective factors within the social environment have been largely overlooked in the research. The aim of this project is to identify the extent to which factors from the wider social community contribute to sibling psychological adjustment. Among other variables, it will focus on informing friends, community acceptance and available supports. It is anticipated that the information obtained from this study will help develop a questionnaire that can be used to help identify how to best support siblings of children with a disability and enhance their psychological wellbeing.

Why have you been approached?
In order to meet these aims, we are hoping to recruit 10 siblings of children with a developmental delay or disability aged between 8 and 16 years. The directors of several early childhood intervention programs and schools around RMIT University have been contacted. With their approval, families/siblings meeting the criteria for this study have been invited to participate.
If I agree to participate, what will I be required to do?

Siblings, if you agree to take part in this research you will be required to answer some questions about your experiences of growing up with a brother or sister with a disability. This will be conducted in the way of a mini interview requiring approximately 30-45 minutes to complete. Our discussions together will be audio recorded and will seek information about the positive things about growing up with a brother or sister with a disability and what types of activities you do together that you find enjoyable. You will also be asked about any concerns you may have, such as how to tell a friend about your brother or sister with a disability and what they may think.

What are the risks associated with participation?

Engaging in this research does not present any perceived risks outside your normal day-to-day activities. However, if you are unduly concerned about any of the interview items, or if you find participation in the project distressing, you should contact Dr Susana Gavidia-Payne as soon as convenient. Dr Susana Gavidia-Payne will discuss your concerns with you confidentially and suggest appropriate follow up, if necessary.

What are the benefits associated with participation?

There are no direct benefits in participating in this study. However, findings from this research will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life. A brief report with findings will be distributed to you and all participating early childhood intervention programs and schools at the completion of the study.

What will happen to the information I provide?

All the information you provide will be treated confidentially. Only the researcher and supervisor will have access to the information. Additionally, no identifying information will appear on the questionnaires or data sheets in order to ensure anonymity. Any information that you provide can be disclosed only if (1) it is to protect you, your child or others from harm (refer to the Children’s and Young Persons Act, 1989), (2) a court order is produced, or (3) you provide the researcher with written permission. Research data will be kept securely at RMIT University for a period of five years before being destroyed. The final report will only contain group data and may appear in a journal article in the future.

What are my rights as a participant?

Participation in the study is voluntary and you have the right to withdraw your participation at any time, without prejudice. You have the right to have any unprocessed data withdrawn and destroyed, provided it can be readily identified. You also have the right to have any questions answered at any time.

Who should I contact if I have any questions?

If you have any questions about any aspect of the study, please feel free to contact Dr Susana Gavidia-Payne on 9925-7393 or susana.gavidia-payne@rmit.edu.au.

Yours sincerely,

Kate Davis  
B.App.Sci. (Psych) (Hon)

Dr Susana Gavidia-Payne  
B.Psy., M.Sc., Ph.D

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745. Details of the complaints procedure are available from the above address.
Appendix E
Informed Consent – Study 1

RMIT HUMAN RESEARCH ETHICS COMMITTEE

Prescribed Consent Form For Persons Participating In Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information

Portfolio: School of Science, Engineering and Technology
School of: Health Sciences (Division of Psychology)
Name of participant: ________________________________
Project Title: The Psychological Adjustment of Siblings of Children with a Disability: The Role of the Family and the Wider Social Context

Name(s) of investigators: (1) Kate Davis (Student Researcher) Phone: 9925 7393
(2) Dr Susana Gavidia-Payne Phone: 9466 9022

1. I have received a statement explaining the interview/questionnaire involved in this project.
2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.
3. I authorise the investigator or his or her assistant to interview me and audio record it or administer a questionnaire.

4. I acknowledge that:
(a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
(b) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.
(c) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.
(d) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.
(e) The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to all participating early childhood intervention programs and schools. Any information which will identify me will not be used.

Participant’s Consent

Participant: ________________________________ Date: ________________
(Signature)

Witness: ________________________________ Date: ________________
(Signature)

Where participant is under 18 years of age:
I consent to the participation of ________________________________ in the above project.

Signature: (1) ________________________________ Date: ________________
(Signatures of parents or guardians)
(2) ________________________________ Date: ________________

Witness: ________________________________ Date: ________________
(Witness to signature)

Participants should be given a photocopy of this consent form after it has been signed.

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure are available from the above address.
Title of Project: The Psychological Adjustment of Siblings of Children With a Developmental Delay/Disability

I _______________________________ have read and understood the attached letter of invitation to parents and plain language statement outlining the objectives and procedures of this study. I give permission for the recruitment of families from this centre/school to take part in this research.

Date: ________________________________________
Name: _________________________________________
Organisation: _________________________________
Position within the organisation: _______________
Phone number: _________________________________
Signature: _____________________________________
Dear Parents and Siblings,

My name is Kate Davis and I am a Doctoral student supervised by Dr Susana Gavidia-Payne from the School of Health Sciences (Division of Psychology) at RMIT University. We are seeking your participation in a research project to assist us in understanding how siblings are influenced by growing up with a brother or sister with a developmental delay or disability. Your opinions and experiences are important to us, as they will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life.

Parents and siblings, we hope you chose to participate in this research and fill out a questionnaire. The information that is obtained will remain confidential and no names or identifying information will be recorded. We will be providing families with a brief report of the findings at the completion of the study.

We would love to hear from parents and siblings (aged between 8 and 16) of children with a developmental delay or disability.

Please return the slip attached in the supplied self-addressed envelope. Alternately, you can express your interest by contacting Dr Susana Gavidia-Payne on 9925-7710.

Thank you for your interest!

Yes, I would like to participate in the study about the impact of growing up with a brother of sister with a disability on sibling wellbeing.

Parents Names: ______________________
Name of Your Child with a Disability: ___________________ Date of Birth: ________
Siblings Name: ______________________ Date of Birth: ________
Telephone: (h) ______________________ (m) ______________________
Invitation to Participate in a Research Project

Project Information Statement

Project Title:
The Psychological Adjustment of Siblings of Children with a Disability: The Role of the Family and the Wider Social Context

Investigators:
Kate Davis (Clinical Doctorate Psychology Student)

Associate Professor Susana Gavidia-Payne (Project Supervisor: Director, EPIC Centre, RMIT University, susana.gavidia-payne@rmit.edu.au, 9925-7710)

You and your child are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or ‘plain English’. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

Who is involved in this research project? Why is it being conducted?
This research is being conducted by Kate Davis in partial fulfilment of the requirements of the Clinical Doctorate Degree in Psychology at RMIT University and will be closely supervised by Associate Professor Susana Gavidia-Payne. This project has been approved by the RMIT Human Research Ethics Committee.

What is the project about? What are the questions being addressed?
Previous research has shown that siblings of young children with developmental delays or disabilities are impacted in various ways. It demonstrates that while the majority of siblings of children with disabilities are well adjusted, some siblings are at risk of developing adjustment difficulties. The aim of this project is to identify the extent to which different factors from within the family and also the wider community contribute to sibling psychological adjustment. Among other variables, it will focus on parent and family functioning, community acceptance and available supports. It is anticipated that the information obtained from this study will help to identify the best way to support siblings of children with a disability and enhance their psychological wellbeing.

Why have you been approached?
You have been invited to participate in this research as we require families of children with a developmental delay/disability. We are hoping to recruit 100 families (parents and siblings aged between 8 and 16 years) with a child with a developmental delay/disability. The directors of several schools and early childhood intervention centres around RMIT University have been contacted. With their approval, families will be invited to participate.

If I agree to participate, what will I be required to do?
If you agree to take part in this research one parent will be required to complete a questionnaire package, which may be filled out at home and returned to us in a reply-paid envelope. The questionnaire package will ask some general questions about you and your family, the accommodations made in relation to your child with a disability, as well as the adjustment of your typically developing child. In nearly all cases the questionnaire requires that you only tick or circle your response. For example, you will be required to indicate on a 5-point scale how true the
following statement is “we feel that there are professionals we can approach about our child’s disability”. It is expected that the questionnaire booklet will take approximately 40 minutes to complete. In addition, siblings will be required to complete a short questionnaire about their experience of growing up with a brother or sister with a disability. It is anticipated that this will require approximately 20 minutes to complete.

What are the risks associated with participation?
Engaging in this research does not present any perceived risks outside normal day-to-day activities. However, if you are unduly concerned about any of the items, or if you or your child finds participation in the project distressing, you should contact Associate Professor Susana Gavidia-Payne as soon as convenient. Associate Professor Susana Gavidia-Payne will discuss your concerns with you confidentially and suggest appropriate follow up, if necessary.

What are the benefits associated with participation?
There are no direct benefits in participating in this study. However, findings from this research will help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life. A brief report with findings will be distributed to you and all participating early childhood intervention programs and schools at the completion of the study.

What will happen to the information I provide?
All the information you and your child provide will be treated confidentially. Only the researcher and supervisor will have access to the information. Additionally, no identifying information will appear on the questionnaires or data sheets in order to ensure anonymity. Any information that you provide can be disclosed only if (1) it is to protect you, your child or others from harm (refer to the Children’s and Young Persons Act, 1989), (2) a court order is produced, or (3) you provide the researcher with written permission. Research data will be kept securely at RMIT University for a period of five years before being destroyed. The final report will only contain group data and may appear in a journal article in the future.

What are my rights as a participant?
Participation in the study is voluntary and you and your child have the right to withdraw your participation at any time, without prejudice. You have the right to have any unprocessed data withdrawn and destroyed, provided it can be readily identified. You also have the right to have any questions answered at any time.

Who should I contact if I have any questions?
If you have any questions about any aspect of the study, please feel free to contact Associate Professor Susana Gavidia-Payne on 9925-7710 or susana.gavidia-payne@rmit.edu.au.

Yours sincerely,

Kate Davis               Associate Professor Susana Gavidia-Payne
B.App.Sci. (Psych) (Hon)                           B.Psy., M.Sc., Ph.D

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745. Details of the complaints procedure are available from the above address.
INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

PROJECT INFORMATION STATEMENT

Project Title:
The Psychological Adjustment of Siblings of Children with a Disability: The Role of the Family and the Wider Social Context

Investigators:
Kate Davis (Clinical Doctorate Psychology Student)
Associate Professor Susana Gavidia-Payne (Project Supervisor: Director, EPIC Centre, RMIT University, susana.gavidia-payne@rmit.edu.au, 9925-7710)

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or ‘plain English’. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

Who is involved in this research project? Why is it being conducted?
This research is being conducted by Kate Davis in partial fulfilment of the requirements of the Clinical Doctorate Degree in Psychology at RMIT University and will be closely supervised by Associate Professor Susana Gavidia-Payne. This project has been approved by the RMIT Human Research Ethics Committee.

What is the project about? What are the questions being addressed?
Previous research has shown that siblings of young children with and without a developmental delay or disability adjust in various ways. This project forms part of a larger study which aims to identify the best way to support siblings of children with a disability and enhance their psychological wellbeing. In order to achieve this goal, we require a greater understanding of the adjustment and psychological wellbeing of siblings (aged between 8 and 16 years) of children with and without a disability.

Why have you been approached?
You have been invited to participate in this research as you are a sibling (aged between 8 and 16 years) of a child with a developmental delay/disability. We are hoping to recruit 100 children with a brother or sister with a developmental delay/disability. The directors of several schools and early childhood intervention centres around RMIT University have been contacted. With their approval, siblings will be invited to participate.

If I agree to participate, what will I be required to do?
If you agree to take part in this research you will be required to complete a short questionnaire package, which may be filled out at home and returned to us in a replied paid envelope. The questionnaire package will ask some general questions about what grade you are at school and also what it is like growing up in your family. There will also be some questions about how you feel about yourself. For example, you will be required to indicate on a 3-point scale how true the following statement is “I feel proud of the things I do”. It is expected that the questionnaire booklet will take approximately 20 minutes to complete.
**What are the risks associated with participation?**
Engaging in this research does not present any perceived risks outside normal day-to-day activities. However, if you are unduly concerned about any of the items, or if you or your child finds participation in the project distressing, you should contact Associate Professor Susana Gavidia-Payne as soon as convenient. Associate Professor Susana Gavidia-Payne will discuss your concerns with you confidentially and suggest appropriate follow up, if necessary.

**What are the benefits associated with participation?**
There are no direct benefits in participating in this study. However, findings from this research will help us to identify any differences in the wellbeing of siblings of children with and without disabilities. It will also help us to identify the best way to support siblings of children with disabilities and enhance overall family quality of life. A brief report with findings will be distributed to you and all participating families at the completion of the study.

**What will happen to the information I provide?**
All the information you and your child provide will be treated confidentially. Only the researcher and supervisor will have access to the information. Additionally, no identifying information will appear on the questionnaires or data sheets in order to ensure anonymity. Any information that you provide can be disclosed only if (1) it is to protect you or others from harm (refer to the Children’s and Young Persons Act, 1989), (2) a court order is produced, or (3) you provide the researcher with written permission. Research data will be kept securely at RMIT University for a period of five years before being destroyed. The final report will only contain group data and may appear in a journal article in the future.

**What are my rights as a participant?**
Participation in the study is voluntary and you have the right to withdraw your participation at any time, without prejudice. You have the right to have any unprocessed data withdrawn and destroyed, provided it can be readily identified. You also have the right to have any questions answered at any time.

**Who should I contact if I have any questions?**
If you have any questions about any aspect of the study, please feel free to contact Associate Professor Susana Gavidia-Payne on 9925-7710 or susana.gavidia-payne@rmit.edu.au.

Yours sincerely,

Kate Davis
B.App.Sci. (Psych) (Hon)
Associate Professor Susana Gavidia-Payne
B.Psy., M.Sc., Ph.D

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745. Details of the complaints procedure are available from the above address.
Appendix J
Informed Consent – Study 2 & 3

RMIT HUMAN RESEARCH ETHICS COMMITTEE

Prescribed Consent Form For Persons Participating In Research Projects
Involving Interviews, Questionnaires or Disclosure of Personal Information

Portfolio
School of Health Sciences (Division of Psychology)

Name of participant:
The Psychological Adjustment of Siblings of Children with a Disability:
The Role of the Family and the Wider Social Context

Name(s) of investigators:
(1) Kate Davis (Student Researcher) Phone: 9925 7603
(2) Associate Professor Susana Gavidia-Payne Phone: 9925 7710

1. I have received a statement explaining the interview/questionnaire involved in this project.
2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.
3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.
4. I acknowledge that:
   (f) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
   (g) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.
   (h) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.
   (i) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.
   (j) The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to all participating early childhood intervention programs and schools. Any information which will identify me will not be used.

Participant’s Consent

Participant: ___________________________ Date: ___________________________
(Signature)

Witness: ______________________________ Date: ___________________________
(Signature)

Where participant is under 18 years of age:
I consent to the participation of ___________________________ in the above project.

Signature: (1) ___________________________ (2) ___________________________ Date: ___________________________
(Signatures of parents or guardians)

Witness: ______________________________ Date: ___________________________
(Witness to signature)

Participants should be given a photocopy of this consent form after it has been signed.