RESILIENCE AND VULNERABILITY IN SIBLINGS OF CHILDREN WITH CHRONIC ILLNESS OR DISABILITY

A thesis submitted

by

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to

Faculty of Life and Social Sciences
Swinburne University of Technology

In fulfilment of
the requirement for the
degree of

DOCTOR OF PHILOSOPHY

2007
Abstract

The focus of this research is the stress placed on a child when a sibling in the family has a chronic illness or disability, and analysis of what factors may buffer this stress and be associated with well child resilience in the face of family illness. Several major studies from other countries (Cadman, Boyle, & Offord, 1988; Houtzager, Grootenhuis, Caron & Last, 2005; Laufersweiler-Plass, Rudnik-Schoneborn, Zerres, Backes, Lehmkuhl & von Gontart, 2003; Sharpe & Rossiter, 2002; Williams, Williams, Graff, Hanson et al., 2002) suggest that there may be deleterious outcomes for well children in such families, for example higher rates of anxiety, depression, aggressive behaviour and rule breaking behaviour. However there is a lack of clarity about the processes which lead to these negative outcomes. The current study had two major research aims. The first was to describe social, family and personal characteristics of a group of well children with siblings who have a chronic illness or disability. The second aim was to examine relationships between adjustment problems in these well children and factors relating to the family (income, number of children in family, respite availability and utilisation), parents (stress, parenting style, maternal education, access to support) and children (ill child behaviour, amount of care required, well child age, well and ill child participation in social activities). Adjustment in well-children (n=102) was assessed using child self report, child projective and parent rating measures. Parents rated well children with ill siblings as significantly higher in externalising and internalising behaviour than age and gender matched population norms. Children did not rate their behaviour problems higher than norms but did indicate quite high rates of emotional problems on a projective (drawing) test. Parent-rated behaviours of well children were associated with parental, family and ill child variables, including (high) parental stress (daily hassles),
(low) family income and (high) ill child internalising and externalising behaviours. Relationships between the well child’s perception of having a sibling with a chronic illness or disability and various parent, child and family variables were also explored. Well children who listed more negative (than positive) attributes about having a sibling with a chronic illness were more aggressive and rule breaking in their behaviour. Well children with emotional problems, as assessed by the child family drawings, did not differ significantly from children without emotional problems in any of the parent, child or family variables however both the emotional problems index and the use of scribble drawings were associated with several measures of well child maladjustment. The results were discussed in terms of family systems and resilience theory. Implications for well children and their families including practical applications for existing interventions which target well children, ill siblings and parents were discussed and ideas for future directions for interventions to improve outcomes for well siblings were presented.
Acknowledgements

Of course this research would never have happened without the generosity of the children and families who contributed their time and emotional energy. Families with a chronically ill or disabled child are already stretched the limit of their resources and I am truly grateful to you all for your commitment and enthusiasm. Thanks also to the many individuals in a variety of organisations who helped with the development, piloting and recruitment for the study.

Thanks to my supervisor, Prof Susan Moore, for her endless patience and persistence, for her enthusiasm when mine was waning, and her encouragement when it got tough. I feel fortunate to have worked with her. Thanks also to Katie Wood, my co-supervisor, for her thorough and insightful feedback on my draft.

Thanks to my writing buddy Naomi, for her humour, pragmaticism and tough love. Together we have pushed, cajoled, nagged, sympathised, applauded and dragged each other over the finish line.

Thanks also to my family. I know they wonder why I’m doing this, but they have supported me anyway because they know it matters to me. Thanks to Dad and Marcus for giving me free run of the office when it got too loud at home; to my sisters Eleanor and Leanne, and my mother-in-law Merle who were not just babysitters, but providers of fabulous fun to my girls “while mum gets on with her work”. That made such a difference to all of us. And mostly thanks to my mum, who has mothered my girls when I have not been around, and who has done lots of formatting detail for me so I could take some time to play. Thanks also to all of you for your tolerance all those times I was, in fact, present – but not really “there”

Thank you to my daughters, Claire and Frances, who are too young to remember when Mummy wasn’t working on a thesis, for your patience, understanding and bundles
of cuddles. Mostly thanks to my husband Ian, who simply spread out time before me by handling everything else that makes up our lives. Ian never once hesitated or questioned or complained. I am overwhelmed by his generosity and wonder if I could be so giving in his place.

Finally to my mentor and friend Geoff Kelso, whose tragic death turned my life in this direction - an extraordinary person I was privileged to know. Thank you Geoff.

I could not have done this without all of you.
Declaration of Originality

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, except where due reference is made in the text of the thesis. To the best of my knowledge, this thesis contains no material previously published or written by another person except where due reference is made in the text of the thesis. I further declare that the ethical principles of the Australian Psychological Society in relation to research have been observed.

Meredith Rayner

Date
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Chapter 1: Introduction

1.1 Overview

All children face stresses in the normal developmental progression to adulthood, such as adapting to school, learning to get on with others, coping with hormonal surges of adolescence and dealing generally with the complex set of freedoms and restrictions that form part of becoming a socialised human being. Some children also face chronic or negative event stresses, like parental divorce, family discord, poverty, parental alcoholism, and illness or death occurring in the family. The current study examined the stresses placed on children when they have a sibling with a chronic illness and the impact of these stresses on their adjustment.

Long term stresses such as chronic illness, poverty and parental divorce have long been assessed by social researchers as “risk factors” for poorer outcomes in children. There is a large body of research which shows that children from “at risk” environments are more likely to succumb to either internalising disorders such as anxiety and depression, or externalising problems such as antisocial and aggressive behaviour, or substance use. However some children from highly risky environments do not experience adverse outcomes. They grow up happy, healthy and fully functioning adults. These children have been labelled by psychologists as resilient, they have the capacity to cope with stress and maintain their equilibrium. This study examined resilience and vulnerability in children who have a sibling with a chronic illness or disability.

This first chapter introduces the topic of childhood chronic illness and disability and the pressures placed on families, parents and the well children in the family. In chapter two the literature on resilience in children is reviewed and evidence for the presence of risk and protective factors among children is discussed. Chapter three
describes in more detail the specific risk factor of having a sibling with a chronic illness or disability. The impact of childhood chronic illness on the whole family is considered, including family resources, parent functioning and sibling relationships. Chapter three also contains a review of previous research into the impact of sibling chronic illness on well children in the family and includes aspects such as the well child’s feelings about having an ill sibling and the results of findings in relation to adjustment outcomes for well children. Chapter four provides a foundation for assessing childhood adjustment in the current study by presenting several methodological issues in relation to resilience research. In particular, issues relating to the assessment of adjustment in children such as the importance of using a diversity of types of child adjustment measures as well as more than one informant are discussed.

Chapter five presents the detailed aims and hypotheses, however a brief summary is provided here. The specific focus of this study was well children in families in which there is also a chronically ill or disabled child. The first aim of the current study was to describe social, family and personal characteristics of a group of these well children with siblings who have a chronic illness or disability. The second aim was to explore the impact of a number of family, parent and child factors on the adjustment of well children who have a sibling with a chronic illness or disability. In summary the hypotheses were

- well child behaviour problems would be higher than the population norms;
- well children with authoritative parents would have fewer behaviour problems than well children with parents who did not use an authoritative parenting style or who used it to a lesser degree
- better well child adjustment (using a variety of measures and raters) would be associated with and predicted by child, parent and family factors
well child adjustment, and more positive attitudes on the part of the well child toward their ill siblings would be correlated.

the various measures of well child adjustment used in this study would be related.

Chapter six describes the methodology of the present study. The results are presented over four chapters. Chapter seven presents the descriptive data relating to the parents, well children and ill children, as well as the results of analyses comparing well child adjustment outcomes with population norms. Chapter eight presents the analyses of family, parent and child factors as predictors well child adjustment and chapter nine presents the analyses of the child drawings (another measure of well child adjustment) and child attributions. Chapter ten presents the analyses of relationships between the several different measures of well child adjustment. A summary of the results is provided in chapter eleven.

Finally a discussion of the results in relation to previous research, implications of these findings, limitations of the current study and suggestions for previous research is presented in chapter twelve.

1.2 The Focus of the Present Study

The current study examines adjustment in children and adolescents (7-19 years old) who have a sibling with a chronic illness or disability. This research is designed to contribute to the existing body of literature in several ways. Firstly the current study addresses some methodological problems in previous studies by incorporating several methods of assessing child behaviour and using multiple assessors. Child adjustment is assessed using a standardised behaviour rating scale, but also analyses of the child’s drawings of their family and the child’s comments about their ill sibling are incorporated into the study. In addition both parent ratings and child (self) ratings are
examined. These approaches build on previous research which primarily relies on one rater to provide a well child adjustment score (usually the mother) and one measure of adjustments (usually a behaviour rating scale). More detailed discussion of these methodological issues is presented in chapter four. The current study also adds to the existing body of research, primarily conducted in the US and the UK by providing information on the circumstances for children in Australia. Similar to the work of Strohm (2002) this study is not confined to one type of chronic illness or disability; instead a range of illnesses and disabilities are included. Finally, the current study addresses a gap in previous research exploring the possibilities of positive outcomes as well as negative outcomes for well siblings of ill or disabled children.

1.3 Definitions of Chronic Illness and Disability

Many of the published studies in this area of research do not provide a definition of chronic illness or disability and typically focus on one specific diagnosis such as cancer (Sloper, 2000) or diabetes (Hollidge, 2001). However, in the studies which do provide definitions, the concepts ‘illness’ and ‘disability’ are not mutually exclusive. For example, Mindence (1994) required that a chronic illness cannot be cured and treatment is mostly related to controlling the symptoms and enabling the child to lead as normal a lifestyle as possible. This involves pain control (e.g., sickle cell disease), the reduction of attacks (e.g., asthma), bleeding episodes (e.g., hemophilia) or seizures (e.g., epilepsy). There are similarities between the definition of chronic illness and the definition of disability, which has been described as a long-term reduction in ability to conduct social role activities such as school or play because of a chronic physical or mental condition (Newacheck & Halfon, 1998).

In terms of research into the impact on siblings, the differences between having a sibling who is ill or one who is disabled, appear to be even less clear. For example, in
a large and seminal piece of research into the effects of chronic illness on siblings, Cadman, Boyle and Offord (1988) were very broad in their definition and included chronic illnesses with and without physical limitations. The list of specific illness included in their study contains some conditions which may be considered disabilities under different circumstances such as blindness, visual problems even with glasses, deafness or hearing problems even with aids, absence of speech, persistent moderate or severe pain, asthma, heart problems, epilepsy, kidney disease, arthritis, cerebral palsy, muscular dystrophy, spina bifida, diabetes, cancer, cystic fibrosis and missing limbs. Strohm (2002) provided a much simpler and more inclusive definition in her reports of the impact of chronic illness on siblings by including all children with special needs. The current study also focuses on families in which there are children with either disabilities and chronic illnesses (or both), with the requirement that the condition is ongoing and that the focus of treatment is to reduce the potential negative effects of the condition so as to facilitate the child leading, as much as is possible, an ordinary life.

1.4 Incidence of Children with Chronically Ill or Disabled Siblings

The number of children with chronic illness and disabilities has increased over the past few decades for several reasons. Firstly, there has been a decrease in infectious diseases across the world because of vaccinations, access to medical treatment and improved living conditions. Accordingly the morbidity and mortality in children due to infectious diseases has significantly decreased, so vulnerable children with chronic conditions are likely to live longer (Leventhal & Sabbeth, 1986). Secondly there has been an increase in the prevalence of chronic illness because of improvements in medical care and technology which has lengthened the survival rates of premature babies and children with many previously fatal chronic illnesses such as cystic fibrosis. This brings with it many challenges to families as these children grow older.
Developing independence, moving away from home, finding employment and establishing long term relationships are all major challenges for children with chronic illness and disabilities, and for their families as well.

The most recent large epidemiological study of chronic illness and disability was conducted in the US and included 30,032 children under 18 years of age (Newacheck & Halfon, 1998). The results showed 18% of children had a chronic physical, developmental, behavioural or emotional condition that required health related services beyond what was normally required by children. Leventhal and Sabbeth (1986) estimated that 10-15 percent of children have a chronic problem affecting their physical health and that 1-2 percent of all children have a severe chronic illness.

In Australia, the Australian Institute of Health and Welfare and the Victorian Department of Human Services studied ill health in Victorians. The Victorian study (Victorian Government Department of Human Services, 1999) lists the five most common diseases in children with long term outcomes as asthma, attention deficit disorder, congenital heart disease, low birth weight and autism for boys, and for girls asthma, low birth weight, depression, attention deficit disorder and congenital hearth disease. An Australian study by the Australian Institute of Health and Welfare (Al-Yaman, Bryant & Sargeant, 2002) lists the five most common disabilities as intellectual disability, respiratory diseases, diseases of the ear, diseases of the nervous system and diseases of the eye. The Victorian Government study (Victorian Government Department of Human Services) also provides details on the prevalence of disease (which includes disability) in Victoria and from these data it is possible to estimate (conservatively) that approximately 121,000 children (age 0-14 years) in Victoria can be classified as having a disability or a serious illness. Given that the average number of births per female in Victoria is 1.75 (Australian Bureau of Statistics (ABS), 2002),
around 91,000 might be expected to have brothers or sisters. Victoria’s population is 4.75 million and 20 percent of these are 14 years and under (ABS, 2002) therefore, using these figures, approximately 9.5 percent of Victorian children would have a sibling with a disability or serious illness. This would appear to be consistent with Derioun and Jessie’s (1996) study in which they report around 10 percent of US children grow up with a brother or sister who has a chronic illness. It also compares with the large Ontario Child Health Study (Cadman, Boyle, Szatmari & Offard, 1987), where between 10-20 percent of children were found to suffer from chronic disease. Extrapolating to the national population, around 300,000 Australian children have a sibling with a serious illness.

As modern medicine continues to improve, children with serious illness and disabilities are living longer, and living more and more with their families. It is therefore increasingly important to understand the issues surrounding families of children with serious illness, and in particular the impact on well siblings.

1.5 The Family’s Experience

The birth or diagnosis of a child with a chronic illness or disability can be a devastating event for parents. Strohm (2002) draws on interviews with child and adult siblings to paint a vivid picture of what life is like for families with a chronically ill or disabled child. For these parents the future may feel incredibly uncertain. The hopes and expectations they had for their child may be shattered and they may feel unable to provide protection for their family. When a child is born with a chronic illness or disability all the emotion, stress, and exhaustion of a new baby is intensified, making it hard to remain optimistic. Juggling appointments, activities and care tasks can put considerable strain on family functioning. It can be difficult for family members to
interact positively with each other when exhausted and under pressure, placing all family relationships under pressure (Strohm, 2002).

Parents may experience worry and fear for their child, for themselves and for their family. They worry about the pain of medical procedures, the impact of the illness on their child’s development, and on the rest of the family. They may worry about their care giving role extending indefinitely into the future and doubt their ability to manage the demands placed upon them. They may feel protective, angry, anxious and guilty. They may have to reconsider their working lives, one parent may need to give up work, and medical costs are likely to add considerably to the family’s expenses. The ongoing stress of day-to-day care for a child with a chronic illness or disability can be physically and emotionally overwhelming and negotiating service providers can be confusing and exhausting (Strohm, 2002).

Parents can feel isolated. Often they lose friends because of the demands of caring for the ill child. Participating in social activities is difficult when they also have to manage wheel chairs, medical supplies, special diets and dealing with difficult behaviour. It is often simpler just to stay at home (Strohm, 2002). When there are other children in the family they also need considerable time and energy from parents who have less to share around. It is difficult for adult parents to cope with what is happening to the family, it is even harder for children who are lack adult maturity and understanding. Young children may not be capable of understanding the illness or disability, and may think they might have caused it, or they might catch it. In addition society can encourage well children to feel lucky that they are healthy resulting in feelings of guilt and responsibility. Adult siblings talk about trying to be good and to achieve in life in order to make things right for their parents (Strohm, 2002).
“I felt a huge responsibility to my parents, even more than to myself, to be successful at whatever I did, so they could have a child they could be proud of. Not that they weren’t proud of my brother, but I knew that being the only ‘normal’ child, to a degree all their hopes and dreams for both their children were somehow sitting on my shoulders. I realise all too much that I am the only child who will be able to provide them with the joy of grandchildren” (Strohm, 2002, p. 40).

Strohm (2002) reported that well siblings may believe they are isolated and alone with their feelings and excluded from discussions about their ill brother or sister. They often do not want to upset their parents by asking questions and the reactions of other people can further distance these children.

“I remember the whispers, and hushed conversations of adults out of my parents’ earshot, talking about my brother. I picked up the negativity, secrecy and shame associated with my brother’s disability; I didn’t really understand it on an intellectual level, but rather felt it on an emotional level” (Strohm, 2002, p. 20).

Children may feel overwhelmed by the pressure to succeed in order to make things right for their parents. They may not feel safe to take the normal risks necessary to perfect new skills because failure will disappoint their already overburdened parents (Strohm, 2002).

“I was always the ‘good’ child. I was told I was good every day of my life. Telling a child what a good child they are, what an angel they are, how wonderful they are to their parents and sibling, causes that child some stress in that they (or at least I) became scared to disappoint anyone. I lived my life as the perfect child and boy did that put pressure on me. I used to worry (and occasionally still do) about dying young and then my parents would have no ‘normal’ children. I was this little eight-year-old worrying about dying and leaving my parents and brother alone” (Strohm, 2002, p. 23).
Siblings may feel they are never the centre of attention in the family. The attention of the parents is often focused on the constant and pressing demands of the ill child’s care. The ill child has a greater need for care, and the sibling may resent the extra attention and feel a sense of unfairness. Time alone with one parent is precious, time with both parents is rare. Children may be resentful that parents cannot attend events together the way other parents can. Well siblings can also feel jealous of the different behaviour standards applied to the ill child in the family. The ill child may be allowed to behave in ways which, although appropriate for their disability, are not acceptable in well children, and this can be a source of resentment (Strohm, 2002).

Well siblings may be expected to grow up more quickly than ill children and to help the family with household chores, care for the ill child or at least look after themselves at a young age. If the responsibility is not too great, children say they have gained a sense of competence and that care-giving increased their bond with their ill sibling, developing empathy, understanding and a positive outlook on life and toward their parents. They are likely to miss out on the features of a normal sibling relationship when their sibling has a disability or chronic illness. Experiences such as gaining companionship and support from each other, and learning social skills such as negotiation, co-operation and compromise are often restricted or in the most severe cases not possible at all.

In describing the circumstances for families, Strohm (2002) highlighted the difficulty researchers face in getting children to express their real feelings. Children feel under pressure to present the positive aspects of having a sibling with a chronic illness or disability, however, rewarding experiences for children are not always the case.
“None of the images I saw in the media showed the reality of life in my house – 12 hours straight of my brother’s autistic tantrums, violence, screaming, and then being expected to go to school as if nothing was wrong and never telling anyone at school how much I dreaded going home” (Strohm, 2002, p. 26).

Strohm’s case material suggests the importance of more intensive and systematic study of the impact on children of having a chronically ill or disabled sibling.
Chapter 2: Resilience and Vulnerability

2.1 The Nature of Resilience

As described in the previous chapter, having a seriously ill or disabled child in the family can lead to many stresses and problems for the well child in the family. What factors are associated with better or worse coping with this kind of pressure? In this chapter, general literature regarding resilience in children is reviewed to provide a framework for more detailed discussion of sibling chronic illness/disability as an adversity for children. The chapter includes definitions of resilience and the types of adverse outcomes found in children faced with adversity. The factors which put children at risk of poorer outcomes, and those which protect children from adverse outcomes are presented.

2.2 Resilience Definitions

Adversity is a common occurrence. At some time during the course of a lifetime, all children will face some type of hardship. Some will be lucky enough to face only relatively minor changes, disappointments and hassles such as moving house, changing schools or loss of a pet. Others will face major adversity such as poverty, abuse, parental illness, natural disasters or loss of loved ones. Some even face several of these major traumas during their life, at times simultaneously. Researchers have explored how individuals cope with adversity and found that some succumb to problems such as depression and anxiety, while others cope well, are able to adapt and even thrive (Tedeschi & Calhoun, 1995). Those who cope well and adapt in the face of adversity have been referred to as resilient. Resilience research has flourished over the past few decades and has led to many insights into the factors and processes which lead to successful negotiation of stress and hardship (Luthar, Cicchetti & Becker, 2000).
Resilience is the term used to describe the ability of a person to withstand or recover quickly from difficult conditions. Some definitions of resilience refer only to the process of adaptation and the presence of hardship. Berk (2000) provides the simplest definition of resilience as “the ability to adapt effectively in the face of adversity” (p.10). An often used definition is provided by Luthar, et al. (2000) “resilience is a dynamic process encompassing positive adaptation within the context of significant adversity” (p.543). However, Luthar et al. further expand on the concept of resilience by highlighting two essential aspects implicit in this definition and necessary to meet the criteria for resilience. Firstly, there must be an exposure to a significant event or adversity, and secondly, positive adaptation must be achieved despite the possibilities of detrimental effects. Luthar et al. caution resilience researchers and theorists to ensure both criteria of resilience are met before concluding a resilient outcome, asserting a preference for longitudinal research into resilience to determine adaptation over a period of time. Similarly, Masten and Powell (2003) define resilience as a pattern of behaviour, not a description of a person in totality and at all times. Resilient people should not be expected to be doing well at every minute of the day under every circumstance and in perpetuity. Instead, resilience should be seen as a pattern of adaptation evident in people’s behaviour and life patterns, not a trait that some people have and some do not.

Adding to the understanding of resilience, Rolfe (2004) paints a picture of the characteristics of a resilient child as having a positive attitude and able to remain optimistic and purposeful in times of hardship; able to seek out and find support and comfort when needed; having strong self-respect and high self-esteem. Rolfe sees resilient children as being able to maintain commitment to their path when faced with challenges.
2.3 Historical Context of Resilience Research

Current resilience research stemmed from traditional deficit-based investigations, not of childhood resilience, but of childhood vulnerability. Early researchers were more interested in adverse outcomes resulting from unfavourable situations than the positive aspect of adapting to adversity. For example, studies in the 1940’s and 50’s studied patients with schizophrenia in order to understand the behaviour those patients displayed. In these early studies, the focus was primarily on the disordered patients, the patients who showed more adaptive behaviour were considered atypical and largely ignored. However, in the 1970’s researchers began questioning why patients with the same apparent risk of behaviour problems, displayed marked differences in their coping abilities and health outcomes. According to Masten and Powell (2003) early investigations revealed the schizophrenic patients with the least severe courses of illness had remarkably similar premorbid history of competence at work, social relationships, marriage and capacity to fulfil responsibility. Researchers began to question whether specific factors could be identified which led to a more successful behavioural outcome for patients with schizophrenia - the first suggestion that specific factors may be related to resilience, or more positive outcomes in otherwise unfavourable circumstances.

At the same time, investigators were examining the behavioural and mental health outcomes of children with mentally ill parents and finding these children to be at a higher risk of experiencing adverse outcomes during their lifetime (Garmezy, 1974). However, evidence that many of these children not only survived but flourished despite their adverse circumstances lead to increasing research efforts to understand individual variations in response to adversity. Some children seemed to be able to overcome this adversity and thrive, while others did not, suggesting that some children were more
resilient than others (Garmezy, 1974; 1983; Masten & Powell, 2003). Two areas of investigation followed: identification of the factors which place children at risk of adverse outcomes such as mental health problems, behaviour problems (including criminality and substance abuse) and poor academic achievement; and identification of factors which seem protect some children from negative outcomes.

2.4 Identification of Risk and Protective Factors

Risk factors are circumstances which have been linked to negative psychosocial outcomes in children. Since the first identification of parental mental illness as a risk factor, many studies have identified and explored other risk factors for children including poverty (Garmezy, 1991, 1996; Rutter, 1979, Werner & Smith, 1982, 1993) maltreatment (Cicchetti & Rogosch, 1996) chronic illness (O’Dougherty & Wright, 1990; Wells & Schwebel, 1987) repeated hospital admission (Rutter, 1982) and community violence (Richters & Martinez, 1993). In addition several risk factors for children relate specifically to their family circumstances such as parental divorce, unwanted births particularly to teenage parents, single parent families, large families, parental alcohol abuse and family breakdown (Werner, 1993; Werner & Smith, 1977, 1982; Rutter, 1982; 1985). The current study explores chronic illness and disability in families as a risk factor for adjustment in children. This study will explore adjustment outcomes in children who experience the adversity of having a sibling in the family with a chronic illness or disability.

While early studies of psychosocial risk in children often focused on exploration of one risk factor, it soon became apparent that risk factors rarely occur in isolation. In reality, stressful experiences often occur as a sequence of events or accumulate over a period of time (Fergusson & Horwood, 2003; Masten & Powell, 2003; Rutter, 1979).
The most influential study into the cumulative effect of risk factors in children was a large longitudinal study of 10 year olds conducted on the Isle of Wight. Rutter (1979) identified six specific risk factors among children living in poverty, and found the effects of exposure to risk factors to be cumulative. The presence of one of the six identified risk factors (severe marital discord, low socio economic status, overcrowding/large family size, paternal criminality, maternal psychiatric disorder and foster home placement of children in the family) was found to individually increase the rate of children’s psychiatric disorders by one percent. However Rutter found risk to increase more than additively as the number of risk factors increased. The presence of two risk factors was found to be associated with a five percent increase in psychiatric disorders in children, while four or more risk factors were associated with a 21 percent increase.

Similarly, a comprehensive 21 year longitudinal study of 1265 children in Christchurch, New Zealand explored resilience to childhood adversity. Fergusson and Horwood (2003) found that children exposed to six or more adverse factors during childhood had rates of externalising disorders 2.4 times higher and internalising disorders 1.8 times higher than those with low exposure to adversity.

At the same time, findings have led resilience researchers and theorists to propose the existence of factors which “protect” some at risk children from poor developmental outcomes. Protective factors ameliorate or decrease the negative influences of being at risk. Research into protective factors argues that a focus on protective factors moves away from the traditional deficit approach toward a more positive view of children’s skills and attributes (Fergusson & Horwood, 2003). A number of significant studies have paved the way by identifying protective factors in the lives of children who display resilience.
The biggest and most groundbreaking study of risk and protective factors was undertaken in Hawaii in the 1970’s (Werner, 1993; 1995; 1996; Werner & Smith, 1977; 1982; 1993). This 40 year longitudinal study of 700 children born in Kuaui, Hawaii began as an exploration of the long-term negative effects of risk factors. The study included all the children who were born on Kuaui in 1955 and followed the development of these children at one, two, 10, 18 and 41 years of age. Most of the children (442) were born without complications and grew up in supportive environments. Some, however, grew up in families where they experienced disadvantage and neglect. The researchers set out to explore risk factors, specifically how stressful early experiences impacted on cognitive, emotional and physical development, however, over time they became increasingly interested in the individuals who were identified high risk (having several risk factors including parental mental illness, parental alcohol abuse, family breakdown and poverty) but grew into adults who “loved well, worked well and played well” (Werner, 1989, p.4). Werner et al. examined the characteristics and life experiences of the 33 percent of high-risk children who overcame adversity in this way, compared with those who had developed serious behaviour, mental health or learning problems.

There were several major features identified as common to the children who demonstrated resilience, but absent from the lives of the children with problematic outcomes. First were characteristics of the child such as having an easy-going nature, second were family characteristics such as having a close positive relationship with an adult and finally there were factors external to the family such as support outside the family unit.
2.5  **Resilience from Child Factors**

Werner and Smith’s (1982) Kauai study found resilient children had temperamental characteristics that included being active and social and having a low degree of excitability and distress. They were often described as “easy-going”, “even-tempered” and “affectionate” (Werner & Smith, 1982). Their teachers reported that they were good at concentrating in class and were alert and responsive. They were also physically active and engaged in many sports. Rolfe (2004) described the attributes of resilient children as active, cuddly, responsive and easy going even in infancy. Rolfe suggested the importance of this easy going temperament is the positive responses it elicits from others and thus early positive relationship experiences are facilitated.

Other personal characteristics of resilient children are good reasoning ability and problem solving skills. They are also autonomous, demonstrating the ability to complete tasks on their own. They show signs of psychological androgyny by displaying behaviour which is not gender stereotyped, such as females participating in adventurous activities and males showing the capacity for deep emotional expression. They show high levels of social orientation from an early age, and respond in socially appropriate ways demonstrating sensitivity to the emotions of others (Rutter, 1985).

Resilient children also have an internal locus of control, a belief that they have the power to influence their own destiny (Garmezy, 1983; Werner, 1989; Werner & Smith, 1982). Other studies have found resilient children have a belief in their own effectiveness and a positive sense of themselves (Rutter, 1985). They have confidence in their ability to prevail over obstacles (Werner, 1993) and are able to make effective use of available resources and opportunities by seeking out educational opportunities and choosing supportive friends. They also view hardship as an opportunity to learn from the experience (Werner, 2000). The positive attitude toward life, and ability to
remain optimistic, have been seen as key factors in finding a practical application for resilience theory. The ability to think positively and maintain an optimistic attitude may, if acquired and gradually internalised by children in adverse situations, provide some useful adaptive skills (Alvord & Grados, 2005). The current study explores the relationship between resilience in children, and their attitude (positive or negative) toward their sibling with a chronic illness or disability.

2.6 Resilience from Parent and Family Factors

The second feature common among the resilient children in Kuaui related to aspects of the child’s family or early relationships. The children who demonstrated resilience appeared to have the opportunity to form a close, positive relationship with at least one caregiver – although not necessarily the parent – early in their childhood. This was someone who knew the child well, was committed to that child’s wellbeing and was able to give positive attention during the child’s early years. These nurturing relationships at times came from grandparents, older siblings, aunts and uncles, or even regular babysitters (Werner & Smith, 1982). Rolfe (2004) highlighted the importance of this care-giving relationship as crucial in the development of trust, security and later autonomy and initiative in the child. As the children grew older they appeared to be adept at seeking out support and assistance from adults as “surrogate parents” when their biological parents were unavailable or incapacitated. Similarly, Masten (2001) identified children with connections to competent and caring adults in the family and community as a key characteristic evident in resilient families.

Parental attitudes have a major influence on the psychological well being of the child. Resilient children often come from homes where parenting styles reflect competency and enhances self-esteem by clear setting of limits and consistently enforcing rules (Werner & Smith, 1982). Good supervision and well-balanced
discipline seem to protect children from high-risk environments (Rutter, 1974). Wilson (1974) found children in conditions of extreme poverty benefited more from firm parental supervision than a happy family atmosphere.

Resilient children also share other protective factors found in their family. They were more likely to come from smaller families (Werner, 1995; Werner & Smith, 1982). They received positive attention as infants from at least one caregiver who was not separated from them for a prolonged period of time (Garmezy, 1983; Werner & Smith, 1982; Werner 1989). Resilient girls were more like to have mothers who were employed, providing them with a role model and the responsibility and skills required to take care of younger siblings. Both boys and girls also benefited from sharing a structured routine of household duties. It appears children gain a sense of responsibility from looking after younger siblings and sharing in household tasks (Werner 1989). In the current study, the relationship between child adjustment and several family protective factors were explored. Factors included parental autonomy granting (the extent to which parents are democratic and non coercive in their discipline), parental behavioural control (the extent to which parents had firm consistent rules and supervised their children) and participation in care and household tasks.

2.7 Resilience from Community Factors

Finally, the characteristics of the wider social environment are important. In the Kauai study, resilient children were able to find support outside the family, from classmates, neighbours, teachers and elders within the community. School became a refuge from a chaotic home and many children reported contacting favourite teachers who had supported them in times of crisis (Werner & Smith, 1982). These support networks play a role in encouraging the child and reinforcing feelings of competence.
They assist the resilient children to develop a sense of meaning in their lives and a belief that they have a control over their future (Rolfe, 2004; Werner & Smith, 1982; 1993).

Within the wider community, resilient children are often able to find emotional support with at least one friend and/or a network of relatives, neighbours, peers and elders for counsel and support when they encounter a crisis. Education also plays an important role in resilience in children by helping children bond with their school, teaching leadership and teamwork as well as providing at least one teacher who is a role model, friend and confidant (Werner, 1995). Supportive adults who foster trust and act as mentors, and provide opportunities that become available at key transition times in the child’s life may also foster resilience (Werner, 1993). The current study explored the relationship between adjustment in well children with a chronically ill sibling and factors relating to support (for example parental warmth, access to support and availability of respite care for the ill child).

In summary, an integrative review of the current resilience research, Luthar and Zalazo (2003) concluded that resilience is a dynamic process involving protective and vulnerability forces, plus varying risk contexts and developmental stages. However some fundamentals exist such as good relationships, preferably with at least one supportive adult, usually a primary caregiver. Interpersonal relationships in the early years encourage growth of effective coping skills and utilisation of resources which help children deal with adversity later in life. Relationships outside the family are also important for children. Support systems such as teachers or informal mentors in the community can, over time, compensate for difficult family situations. Additionally, children cannot reach their full potential if their safety and physical survival is in jeopardy (as is the case with some children living in circumstances of poverty, abuse or
warfare). Resilience is more likely if the most basic needs of food, shelter, safety and education are met.
Chapter 3: Chronic Illness and Child Adjustment

3.1 Resilience and Childhood Chronic Illness

Childhood chronic illness has been identified in resilience literature as a risk factor for adverse outcomes in children (Barlow & Ellard, 2006; Bellin & Kovacks, 2006; O’Dougherty & Wright, 1990; Wells & Schwebel, 1987). Although not directly part of the resilience literature, chronic illness in a sibling has also been identified as a risk factor for behaviour problems with children (Cadman, et al., 1988; Houtzager, Grootenhuis, Caron, & Last, 2004; Sharpe & Rossiter, 2002). This chapter presents the literature on well child adjustment in families with a chronically ill child.

There is no doubt that having a child in the family with a chronic illness or disability places the family under additional pressures. As a result, the whole family, including any well children, will be affected in some way. Exactly what the effect will be depends on many circumstances. In their book on families with a disabled child, Powell and Gallagher (1993) describe a continuum of outcomes for siblings, with positive outcomes like new skills and attributes at one end, and negative outcomes such as psychological disturbances at the other. Each child’s position on the continuum depends on a number factors relating to the family, the parents, the child and the other siblings.

In a similar approach, Williams (1997) identifies four general factors influencing adjustment in well children with chronically ill siblings. Williams conducted a comprehensive review of the literature on siblings and paediatric chronic illness and concluded that characteristics of the family, parent, illness and well child are the four key factors impacting on adjustment in well children with a chronically ill sibling. These four categories are used as a framework for discussion in this chapter. This chapter examines family, parenting, well and ill child influences on child development,
as it applies to children in general, and more specifically the circumstances for children with a chronically ill or disabled sibling. The family, parenting and child influences discussed in this chapter include styles of parenting, available resources, stress within the family and the influence of illness factors and well child characteristics. Finally a review of the literature on impact of these influences on psychosocial development of well child is presented.

3.2 Families and Child Adjustment

Family systems theory provides a framework for understanding family impact on adjustment in children. According to family systems theory, relationships among family members are interconnected and disruptions in one relationship may be reflected in difficulties in other relationships (Minuchin, 1974). Research has documented associations between adjustment problems in children and various aspects of family conflict including parent-parent conflict and poor parent-child relationships (Cummings, Keller, & Davies, 2005; Kaczynski, Lindahl, Malik, & Laurenceau, 2006; Low & Stocker, 2005). A comprehensive study (Low & Stocker) of family functioning and child adjustment in families used observational data as well as self report data from 136 mothers, fathers and children. The researchers highlighted the interconnected nature of family relationships on both parent and child adjustment. In the study, increased conflict in parent relationships was related to increased parent-child hostility which in turn was linked with increased child adjustment problems (Low & Stocker). Similarly a recent study of 235 families in Midwestern USA revealed interrelationships between child adjustment problems and several family factors including more depressive symptoms in parents, more conflict in the marriage, insecure marriage attachment and less parental warmth (Cummings, et al., 2005). A theme of research into family conflict and child adjustment problems is the role of parent conflict and its impact on parenting.
Most recently, parenting behaviour has been identified as important in understanding how family conflict relates to child behaviour problems (Kaczynski, et al., 2006). Structural equation modelling with a sample of 226 families found parenting behaviour mediates the relationship between child behaviour problems and family conflict. A number of possible reasons for this relationship are proposed. High levels of marital conflict may drain energy and motivation from parents making it difficult for them to interact effectively with their child. Alternately, children with adjustment problems may increase the strain on parents, leading to marital and parental conflict. Finally, some parents may not manage conflict well, resulting in deterioration in both marital and parental functioning and leading to problem behaviours in children (Kaczynski et al.).

3.3 Family Factors and Chronic Illness

In one of the earliest discussions of the impact of chronic illness in families, Leventhal and Sabbeth (1986) stated that the high level of physical as well as emotional energy required to care for an ill child can be so exhausting that other important family tasks such maintaining the marriage and providing for the individual growth and activities of other family members may be overlooked. Another study (Quittner et al., 1998) employed structured interviews, card sort procedures, and daily diaries to explore role strain, marital satisfaction and maternal mood in 33 couples caring for a child with cystic fibrosis and 33 comparison parents with a healthy child. Higher role strain was found in the parents with an ill child in areas of role conflict, child care tasks and exchange of affection than among the comparison parents. Parents with ill children also spent less time on recreational activities.

Bluebond-Langer (1996) reported role strain and role changes affecting families of seriously ill children. In detailed case studies on 40 families with children diagnosed
with cystic fibrosis, Bluebond-Langer concluded that as the ill child’s health deteriorated, family roles became subject to more change and responsibilities increased. The data was collected through observations and interviews with well children, ill siblings and parents over a period of eighteen months. Bluebond-Langer concluded as ill children needed to spend more time inside the home and required more medical care and attention from their parents, the well children reported perceiving an increase in their responsibility toward the ill child. It appears the well children were picking up on and responding to the role changes of their parents, and assuming changes to their own roles as a result.

Chronic illness or disability can lead to disruption to family routines and restriction of family activities. Sloper (2000), in a study of 94 children who had siblings with cancer, found family disruption an important factor in the adjustment of these children. Eighty percent of siblings of children with cancer reported restrictions in family routine and/or in their own social activities. However, the siblings also reported that when they could understand the reasons for such restrictions they saw them as temporary and justified. Still, over half voiced negative feelings such as resentment, sadness or anger about disruptions to family activities.

There can also be positive changes within the family. Some families report increased closeness as a result of the chronic illness of one of the children in the family (Ferrari, 1983; Mindence, 1994). In a review of the literature on the effects on family members of childhood chronic illness, Mindence suggested that the way families interact, as well as the provision of social and financial support, are important factors for well child adjustment. Similarly Drotar (1997) reviewed 57 studies published between 1975 and 1995 exploring family and parent functioning and adjustment in children with chronic illness. Although these studies did not explore adjustment
problems in well children, they did provide evidence linking poorer family relationships and increased adjustment problems in the ill child. In general, less adaptive family relationships, such as increased conflict and maternal distress, consistently predicted adjustment problems in the ill children and more supportive family relationships (such as higher family cohesion) predicted better adjustment for these children.

Families with high cohesion and high flexibility appear to adapt better, possibly because the closer connections between family members provided more opportunities for support (Cohen, Freidrich, Jaworski, Copeland, & Pendergrass, 1994). A study of families with a child who has cancer revealed that families who were very adaptable had children who scored higher on adjustment measures. Adaptable families provided a better environment for child adjustment by being more flexible in the types of behaviours they viewed as acceptable from their children, and also by demonstrating many different skills when managing the changes brought on by the diagnosis (Cohen, et al.).

In a smaller study of 32 siblings of children with cancer and 32 control sibling pairs, Horwitz and Kazak (1990) found families of children with cancer differed from the normal population distribution in scores of adaptability. Nearly all these families fell into an extreme category, more or less equally into either rigid or chaotic. Only a few families scored in the mid range of these two extremes. About half of the sample were rigid, imposing structure and schedules in order to cope with the challenge of a seemingly uncontrollable event, and the other half were chaotic, extremely flexible in order to care for all family members while facing the fluctuations of disease, treatment and side effects. No relationship was found between adjustment of the well children and level of family cohesion, however, in this study, well child adjustment did not differ from published norms, or from a control group of children with no illness in the family.
either. Another study (Daniels, Moos, Billing & Miller, 1987) of 72 families with a ill child and 72 comparison controls found lower levels of family cohesion and expressiveness were associated with problems for well children in families with an ill child, compared to demographically matched controls. The study suggested that well children do better in families where there is more interfamily support and the opportunity to express feelings and concerns. Higher levels of family cohesion and adaptability have also been found to have a buffering effect against the negative effects and difficult circumstances of families with chronically ill children who have behaviour problems (Ievers, Brown, Lambert, Hsu, & Eckman, 1998).

Families with a chronically ill child also report decreased family satisfaction and decreased family adjustment (Carter, Urey, & Eid, 1992; Gayton, Friedman, Tavormina, & Tucker, 1977). Researchers have identified several factors associated with these findings. In a review of research on families with a child with cystic fibrosis, Carter et al. concluded that complex and time consuming daily treatment regimes required for children with cystic fibrosis resulted in increased social isolation for mothers, potentially leading to less satisfaction and more feelings of depression. The authors also drew attention to extensive impact of financial stress associated with caring for a child with cystic fibrosis. Many interrelated issues were raised by families in relation to financial pressure including increased medical costs, reduced employment opportunities due to care requirements and the expense of relocation to (often) more costly accommodation closer to medical services. Financial pressure was also related to breakdown in communication, family sacrifices, supplementary employment to meet financial commitments and disrupted work patterns to keep medical appointments. Research has identified families of children with chronic illness or disability as at significantly increased risk of adverse socio economic circumstances (Emerson, Hatton,
Llewellyn, Blacker & Graham, 2006) suggesting these pressures experienced from financial hardship are likely to be the norm rather than the exception to the rule.

Higher socio economic status has a positive effect on parent’s ability to cope with a disabled child and on the overall functioning of the family. A study of 80 two parent families (Gavidia-Payne & Stoneman, 1997) found more financial resources and higher education levels were associated with more maternal involvement in programs for their disabled child, less stress, better coping skills and better use of social support in mothers of disabled children. Mothers with more financial security had access to more resources which enhanced their interactions with their family and increased their levels of satisfaction.

Utilisation of respite and in-home care services by families with a chronically ill child has been found to have positive effects on the family. A controlled longitudinal study of outcomes for families using respite found increased optimism in caring for the child at home and reduced stress in parents (Bruns & Burchard, 2000). However, the benefits to the family provided by respite are often short term. Mothers utilising respite summer camps for their chronically ill children report reduced anxiety, depression and distress, but the effects lasted for only one month after the camp finished (Meltzer & Johnson, 2004). A comprehensive review of respite literature also found the benefits of respite to be short-term and highlighted several problems which prohibit longer term benefits. One such problem is guilt and worry about the ill child while they are in respite; another is difficulty for parents in resuming social networks during the short periods of respite (McNally, Ben-Shlomo, & Newman, 1999). Family members also reported feelings of discomfort with carers intruding into their home environment in in-home respite services (Valkenier, Hayes, & McElheran, 2002). Research has also found inequities in the provision of respite services to families such as a bias in uptake of
services by articulate middle class families and exclusion from respite of children with challenging behaviours (McGill, Papachristoforou & Cooper., 2006).

An early review of the literature previously referred to (Leventhal & Sabbeth, 1986) reported similar findings from the US where chronic illness can restrict family’s social activities outside the home, and limit job mobility because of the necessity to stay near centres of medical care.

Marital conflict is common in families with a chronically ill child (Quittner et al., 1998). Higher rates of single parent families have been found amongst children with intellectual disabilities (Emerson et al., 2006), but separation and divorce is not inevitable. A review of 34 published papers concluded divorce rates in families with chronic illness were not substantially higher than control families (Sabbeth & Leventhal, 1984). Although divorce rates are not necessarily elevated in families with a chronically ill child, these families are at significant risk of marital distress (Hauenstein, 1990; Sheeran, Marvin & Pianta, 1997). Epidemiological studies have also found a relationship between single parent families and childhood chronic illness or disability. In a US epidemiologic study of 30,032 children under 18 years of age, Newacheck & Halfon (1998) found children from single parent families were 40% more likely to have special health needs than children from two parent families.

Recent research indicated marital satisfaction is lower when parents perceive the child’s illness is more severe and the impact on the family is greater, regardless of medical and objective measures (Berge, Patterson, & Rueter, 2006; Berant, Mikulincer, & Florian, 2003) suggesting the link between severity of illness and impact on the marriage or the family is not a simple one. The parent’s perception of the impact of the illness appears to be just as important as the actual time required for medical treatment and care.
In addition to perception, attitude of parents and use of support systems to enhance parental well being also appears to be important for well child adjustment. In a study of well child behaviour problems and maternal wellbeing in 170 mothers and siblings of children with cancer, and 170 matched controls, mothers who felt better emotionally and physically, and who found the resources and support systems they used were more helpful, had children who adapted better. In contrast, children’s adjustment was worst where mothers felt more emotionally and physically vulnerable and did not access support systems or did not find the support they accessed helpful (Sahler et al., 1997).

Little information is available in Australia about the circumstances for families with chronically ill or disabled children. Anecdotal evidence from Australian support workers and advocacy groups suggest these families have higher rates of marital separation and lower financial resources. In addition, field workers report families have little access to social support or family recreation due to poor availability and utilisation of respite. The current study will examine family structure and social support of a sample of Australian families with an ill or disabled child, focusing on outcomes for the well child in the family.

3.4 Parents and Child Adjustment

A considerable body of research links aspects of parenting to a number of child outcome variables. Longitudinal research shows that some qualities of parenting have many positive outcomes for children such as increased academic achievement and better social and psychological adjustment. A three year study of parenting behaviours and child adjustment in middle school aged children, revealed children with supportive and aware parents had better academic, social and psychological adjustment, and their adjustment improved over time. In contrast, children with inattentive and harsh parents
had poorer adjustment outcomes which declined over the three year period (Bronstein et al., 1996). Similarly warm and supportive parenting predicted behavioural adjustment, social skills and academic performance in children, and mitigated the adverse affects of family adversity in a seven year longitudinal (Petit, Bates, & Dodge, 1997). Evidence of further support of the impact of parenting practices on childhood outcomes can be found in interventions to improve parenting practices which have been found to result in improvements to outcomes for children. Randomised participation in a parenting program improved parenting practices in divorcing mothers of primary school children by reducing coerciveness and increasing positive involvement. The children of the parents who had participated in the program showed improvements in teacher-reported school adjustment, child-reported maladjustment and mother-reported maladjustment ( Forgath & DeGarmo, 1999).

Theorists have presented several models of parenting style but the most frequently cited is based on Baumrind’s (1967, 1991) three-fold model. This model assesses methods of parenting on amount of warm affection and acceptance demonstrated by parents, and the level of control exercised by parents. Three parenting dimensions result: authoritative parenting, where parents express high levels of warmth and involvement and maintain reasonable levels of control over their child; authoritarian parenting where parents exercise high levels of control but provide lower levels of warmth and acceptance, and permissive parenting where parents exercise low levels of control over their children. More recently, Maccoby and Martin (1983) revised the three fold model by proposing that the permissive parenting style be split into two separate dimensions: indulgent parenting where parents exercise little control but provide high warmth and involvement, and neglectful parenting where parents provide low control and little warmth and involvement.
A further extension of the model of parenting style includes a refining of the concept of behavioural control. Control over a child’s behaviour is viewed as a positive and necessary aspect of parenting behaviour which promotes maturity and prevents injury or harm. On the other hand, Barber, Olsen and Shagle (1994) highlighted the need for the inclusion of psychological autonomy granting in parental behaviour when imposing discipline on children. Psychological autonomy granting involves promoting democratic principles in parenting, encouraging participation in decision-making and explaining reasons for parental decisions at a level appropriate to the child’s age. For parental control to have positive effects, the child’s behaviour must be controlled in a socially acceptable way and promote psychological independence. When parents exercise control over the child’s psychological world by intimidation and psychological manipulation the effects on children can be negative and harmful (Barber, 1996). High levels of psychological control are predictive of internalising problems in children (Barber et al., Steinberg, 1990). Some research linking parenting styles to outcomes for children has incorporated the concept of psychological autonomy granting as well as behavioural control in the definitions of authoritative, authoritarian, indulgent and neglectful parenting styles.

Research has consistently found the most adaptive and successful of the parenting styles is authoritative parenting which comprises high levels of acceptance and involvement, as well as moderate levels of behavioural control and autonomy granting (Lamborn, Mounts, Steinberg, & Dornbusch, 1991). Authoritative parents express warmth and affection and are attentive to their child’s needs and involved in their lives. They make reasonable demands for maturity, set limits and give reasons for their decision-making. They are aware of where their children are and with whom they are involved. They also encourage autonomy at an appropriate age, listen to the child
and encourage participation in decision-making. Authoritative parents have clear ideas about rules and discipline but are willing to discuss the rules and explain decisions to children and adapt as circumstances change. Research has found authoritative parenting to be associated with many aspects of competence in children (Baumrind, 1991; Bronstein et al., 1996; Steinberg, Darling, & Fletcher, 1995). In a comprehensive series of studies exploring the effects of authoritative, authoritarian, indulgent and neglectful parenting styles on 2300 children, children of authoritative parents had the highest levels of psychosocial competence and were lowest on measures of psychological and behavioural dysfunction. They also had better school performance and stronger school engagement. These differences were maintained or increased over time (Lamborn et al., 1991; Steinberg, Lamborn, Darling, Mounts, & Dornbusch, 1994; Steinberg, Lamborn, Dornbusch, & Darling, 1992).

Another large study of 1230 mothers of primary aged children found authoritativeness in parents was a strong and significant predictor of children’s adjustment. Authoritative parenting was associated with fewer emotional and behavioural problems in children compared to authoritarian parenting, and also with healthy adjustment in children when gender, age, ethnicity and income were controlled (Kaufmann, et al., 2000). Similarly, Strage and Brandt (1999) surveyed 236 US college students and found the authoritative parenting characteristics predictive of academic success, confidence, persistence, task involvement and rapport with teachers. The pattern of influence appears to continue amongst populations with more serious behaviour problems. A large recent study of 1,355 juvenile offenders found those who described their parents as more authoritative were more psychosocially mature, more academically competent and less prone to anxiety, depression and aggression than those
who described their parents as neglectful (Steinberg, Blatt-Eisengart, & Cauffman, 2006).

The relationship between authoritative parenting style and positive adjustment in children can be seen clearly with an exploration of the coping and achievement strategies used (Aunola, Stattin, & Nurmi, 2000). When faced with challenges, children from authoritative families apply more adaptive, task-oriented strategies and have higher expectations of success. They also report more frequent use of self-enhancing attributions which help them maintain a more positive perspective and attitude. The encouragement, support and autonomy granting of authoritative parents promotes self-belief, independence and self-regulation in children. At the same time, authoritative parenting provides an opportunity for children to learn skills and strategies in an accepting environment, enhancing their ability and tendency to apply adaptive strategies when faced with problems (Aunola, Stattin, & Nurmi).

In contrast, authoritarian parenting combines high levels of control together with lower levels of both acceptance/involvement, and autonomy granting (Lamborn et al., 1991). Authoritarian parents have strict rules and ideas about discipline which are not open to negotiation. They set rules for their child, do not explain the reasons, and expect obedience. They may appear cold and rejecting, and do not allow the child to participate in decision making, resorting to force or punishment if the child expresses dissent. Several studies have identified relationships between authoritarian parenting and outcomes problems for children including increased anxiety, unhappiness, lower self-esteem and self-reliance, and a tendency to act with hostility when frustrated (Lamborn et al.). A four year study of 277 families found more authoritarian parenting in mothers predicted children’s aggressive and defiant behaviour at school (Nix et al., 1999). Similarly, a longitudinal study from a large British population sample showed a
clear relationship between authoritarian parenting and subsequent conduct problems in children at five years of age and later at age ten (Thompson, Hollis, & Richards, 2003). A series of studies on parenting styles and child outcomes also indicated problems for children with authoritarian parents increased over time (Steinberg et al., 1992). In a large national survey involving over 3000 parents and children and adolescents, harsh punishment and low levels of support by parents were associated with poor child adjustment, poor school performance and more behaviour problems (Amato & Fowler, 2000). Children of authoritarian parents were not doing well compared to their peers with authoritative parents.

Research suggests problems for children of authoritarian parents may stem from the employment of maladaptive coping strategies which resemble learned helplessness (Aunola, et al. 2000). These children have been found to employ passive behaviour and show less use of self-enhancing attributions possibly as a result of the excessive control and criticism demonstrated by authoritarian parents undermining the motivation of children to attempt and practice strategies for dealing with problems. The children seem to become convinced that they are unable to solve problems themselves and lack the belief they can impact on their circumstances (Aunola, et al.).

Similarly, children from indulgent or permissive parents do not manage as well as those with authoritative parents. Indulgent parenting involves high levels of acceptance and involvement with low levels of control and inappropriate autonomy granting. Indulgent parents are warm and accepting of their children but exercise little control over them, making few demands and setting few limits. They allow their children to make decisions for themselves at an age when they are not yet capable of doing so (Lamborn et al., 1991). Children of indulgent parents report the use of self-enhancing attributions when faced with problems, but also engage in maladaptive
strategies such passivity and task irrelevant behaviours (Aunola et al., 2000). The lack of control exercised by parents and autonomy granting at an inappropriate age appears to limit the child’s exposure to adaptive problem solving strategies as well as the opportunities for experimenting and mastering skills. Children from indulgent families have been found to be more impulsive, disobedient and rebellious and to show less persistence at tasks (Baumrind, 1991). Lamborn et al. (1991) found children with indulgent parents have a strong sense of self-confidence but report higher frequency of substance abuse and school misconduct and are less engaged in school, effects which increase over time (Steinberg et al., 1994).

Children from uninvolved or neglectful parents tend to have the poorest outcomes (Baumrind, 1991). Lamborn et al. (1991) found these children scored lowest on measures of psychosocial competence and highest on psychological and behavioural dysfunction when they came from neglectful families. Neglectful parents demonstrate low levels of acceptance and involvement, as well as little control or autonomy granting. Uninvolved parents make few demands, set few limits and are emotionally detached and unresponsive to the child’s needs (Lamborn et al.). In extreme cases, uninvolved parenting is neglectful and is likely to be characterised by depressed parents with many stresses in their lives such as marital conflict, little or no social support and poverty (Smith, Cowie, & Blades, 2003). Children of uninvolved parents display many problems such as poor psychosocial development, low academic success, higher anxiety and depression and increased conduct problems compared to children from other parenting styles (Lamborn et al.). When faced with challenges these children use the most maladaptive strategies of avoidance, passivity as well as engaging in behaviour irrelevant to solving the problem (Aunola et al., 2002). They report little use of self-enhancing attributions and have internal attributions for their failures and external
attributions for their successes. It appears the family environment which provides no encouragement, support or parental involvement, fosters doubts in children about their own abilities and exposes them to the use of task avoidant and other ineffectual problem solving strategies as well as negative attributions.

This study examines parenting styles in families with a child with a chronic illness or disability. The intention is to assess how the relationship between parenting styles and well child functioning is expressed in families with the particular stress of an ill child. In these families the more ideal form of authoritative parenting may be more difficult to sustain when the many stresses related to having a chronically ill or disabled child are present.

In considering the impact of parenting on child development, Belsky (1984) notes that many factors impact on the quality of parenting. He proposes a model of parental functioning that distinguishes three main influences on the quality of parenting in the following order of importance. First and most important are the quality of internal resources available to the parent such as psychological resources and mental health. In support of this are many studies indicating that parental mental health problems such as neuroticism, depression and schizophrenia are related to poor child outcomes (Belsky, Crnic, & Woodworth, 1995; Cummings, et al., 2005). Positive resources, such as maternal education, also have in impact on the quality of parenting. Low maternal education has been consistently linked to poorer outcomes for children such as poorer cognitive development and problem behaviours (Duncan, Brooks-Gunn, & Klebanov, 1994; Fantuzzo, Rouse, McDermott, & Sekino, 2005).

Secondly, sources of support such as partners, social networks and friends as well as practical sources of support such as employment and financial circumstances can impact on a parent’s ability to function and the quality of their parenting actions.
According to Belsky (1984), lack of practical support such as parental unemployment and financial difficulties, and lack of social support are sources of parental stress which directly affect the quality parenting by impacting on the parent’s psychological well-being. Research has found a lack of these support factors places children at high risk of adverse outcomes, and that the risk increases exponentially as families have fewer supports available (Appleyard, England, Van Dulmen, & Sroufe, 2005).

Finally Belsky (1984) proposed the personal characteristics of the child, such as easy or difficult temperament, impact on parental functioning, suggesting the characteristics of the child can make them more or less difficult to parent, shaping the quality and quantity of the parental care they receive. In support of this model, subsequent research has found mothers of children with difficult temperaments respond more negatively to the infant and interact with them less frequently than mothers of children with easygoing temperaments (Belsky et al., 1995). Although not specifically discussed by Belsky, there are other characteristics specific to children with a chronic illness or disability, which may make these children more or less difficult to parent. Children with a chronic illness or disability present parenting difficulties such as; increased need for supervision and care, presence of distress and pain, and the need for ongoing medical treatments. In addition many chronic illnesses, such as autism and fragile x syndrome, bring with them specific and difficult problem behaviour which presents parents with further challenges. The challenge is not just in managing the ill child’s behaviour but in managing the application of different standards of behaviour to well children in the family at the same time as accommodating the special needs and abilities of the ill child.

This study examined parenting factors in relation to families with a chronic illness or disability. One intention is to explore the relationship between well child
outcomes and the factors which influence the ability to parent including parent education, income, social support and ill child characteristics. In families with a child with a chronic illness or disability it may be more difficult to maintain a high quality of parenting due to impacts on internal parental resources, availability of support and characteristics of the child as described in Belsky’s (1984) model.

In addition to the factors described in Belsky’s model, stress in the family has been found to have detrimental effects on the well being of parents, children and parent child relationships, especially stress which is consistently present such as child illness. In particular, stress specifically related to the parenting role is more closely associated with poor child outcomes than other forms of stress experienced by parents such as work stress or stress in the martial relationship, presumably because it occurs closer to parent child interactions (Deater-Deckard, Smith, Ivy, & Petril, 2005). High levels of parental stress have been related to poor child adjustment outcomes such as behaviour problems and poor social competence (Creasey & Reese, 1996; Crnic & Greenberg, 1990) and poorer child wellbeing (Crnic & Low, 2002). Pett, Vaughncole and Wampold (1994) found mothers with high levels of parental stress reported more problem behaviours in their children than non stressed mothers. Using observations as well as parent ratings to assess child behaviour problems, Crnic, Gaze and Hoffman (2005) found high parenting stress related to increased child negativity, accounting for 15 percent of the variance in child behaviour problems. Similarly, in a study of 211 parents and their adolescent children, Compas, Howell, Phares, Williams and Ledoux (1989) found higher levels of parental stress related to increased levels of psychological symptoms in children.

Parental stress can also have detrimental effects on the parent child relationship. Parents with higher levels of stress tend to use more authoritarian approaches to
parenting and be more negative and less involved in their interactions with their children (Belsky et al., 1996, Bolger, DeLongis, Kesler & Schilling, 1989; Crnic & Low, 2002; Deater-Deckard & Scarr, 1996; Deater-Deckard, 1998; Pett et al., 1994). Woofson & Grant (2006) found parents of young children with developmental disabilities scored higher on all measures of stress and used more authoritative parenting styles than parents of typically developing children, however use of authoritative parenting style decreased with child age. The authors suggest the challenges involved in using authoritative parenting on children with disabilities such as ongoing stress, the amount of repetition required and the limited success achieved wears the parents down over time.

High parental stress also results in less parent-child pleasure and more parent-child conflict (Crnic et al., 2005) and has been linked to failure to engage in services, decisions to seek out of home care for disabled children and higher rates of adjustment problems and antisocial behaviour in children (Emerson et al., 2006). High parental stress has also been associated with well child reports of less satisfaction with the sibling relationship as well as more negative behaviours and fewer positive behaviours toward siblings with autism (Rivers & Stoneman, 2003).

Researchers investigating the impact of parent stress on children have further explored the differences between minor daily hassles, such as constantly cleaning up mess, and being nagged at or whined to by children, and single major life events, such as divorce or job loss. Crnic et al. (2005) suggest different processes are involved in minor daily hassles compared to major life events, resulting in different impacts on the parent–child relationship. Stress created from minor everyday problems causes irritation and annoyance, depressing positivity and enjoyment in parents and children, while major stressful life events involve a single difficult circumstance and the presence
of distress in the parent, which increases conflict between parents and children (Crnic et al.).

Current research suggests daily hassles are a better measure of the impact of parent stress than single major life events. Parenting daily hassles are more closely related to psychological symptoms in children (Compas et al., 1989) and have been found to be substantially better at predicting psychological wellbeing and mental health than life events (Chamberlain & Zika, 1990; Kanner, Coyne, Schaefer, & Lazarus, 1981). Longitudinal research reveals the effects of stressful life events are less constant than the cumulative and consistent effects of stress caused by the daily hassles of parenting. Minor daily hassles appear to exert a cumulative effect on parental stress over time, which present a greater risk to children’s adjustment than single stressful events which may be present for one period but not another. A three year study of parental stress in 125 mothers and their children found cumulative parenting stress affects parenting behaviour and puts pressure on the parent child relationship, placing the children at increased risk of poor adjustment outcomes (Crnic et al., 2005). The same study found parents who were stressed tended to remain stressed. Parents reporting stress when their child was aged three were likely to report higher stress levels at age five and maintained stability in their stress scores over that period. Stress from daily hassles was slightly more stable than for major life events suggesting that although parenting tasks change as children age, the experience is no less stressful to some parents (Crnic et al.).

Finally there appears to be little difference in the overall level of parenting stress reported by fathers and mothers in the same families. Where there is stress, both parents appear to experience it (Crnic & Booth, 1991). However, parental support from
family and friends as well as broader social support, appears to moderate the adverse impact of stress (Crnic & Booth).

Stress is a constant problem for parents of a child with a chronic illness or disability. Not only are there pressures relating to the care and wellbeing of the ill child but also financial pressures, reduced employment opportunities, worry about other children in the family, and restrictions in employment opportunities and social life (Mindence, 1984). A more recent study (Smith, Matthew, Oliver, & Innocenti, 2001) of families of children with disabilities found factors such as low income, lack of time available for interaction with the child and lack of social support, all increase parenting stress more than child functioning variables such as motor or cognitive abilities. The parental stress caused by the presence of problem behaviours in children also appears to be higher in families with childhood chronic illness. Mothers of children with Duchenne Muscular Dystrophy were more stressed by problem behaviours in their children than mothers of the normative group (Nereo, Fee, & Hinton, 2003).

Ongoing parental stress is particularly relevant to children with a chronically ill sibling due to the pervasive nature of parental stress. Children’s exposure the chronic parental irritation and stress has negative effects even when the negative behaviour is not directed toward them (Crnic et al., 2005) suggesting children with a chronically ill or disabled sibling are likely to be negatively affected by their parents’ chronic and ongoing stress despite best efforts to shield the children.

Parental stress has been related to child adjustment outcomes in families with a chronically ill or disabled child. In a study comparing families of children with spina bifida and an able-bodied control group. High parental stress and low marital satisfaction both predicted aggression and rule breaking behaviour in children at aged eight or nine years, and again two years later (Friedman, Holmbeck, Jandasek,
Zukerman, & Abad, 2004). The authors concluded that the process by which parental functioning predicts child adjustment was similar across the spina bifida group and the healthy control group, however parents in the spina bifida group experienced greater stress in the parenting role, placing the children of the chronic illness group at greater risk for adjustment problems.

The current study will examine parenting stress in families with a child with a chronic illness or disability. The intention is to assess how parenting stress impacts on well child functioning in families with the increased pressures of a chronically ill or disabled child.

3.5 Parenting Factors and Chronic Illness

Available evidence suggests that chronic illness changes the way parents operate in selective ways. In a review of available literature on the influence of chronic illness on family process, Warmbolt and Warmbolt (2000) concluded that parents of ill children do not change their general practices or overall philosophy of child-rearing compared to families of well children, however many families become more structured as they struggle to manage the stress, burdens and demands of a chronically ill child. The necessary increase in organisation and planning to meet the needs of the ill child may come at the cost of warmth and spontaneity and families have less time for affection and less flexibility for impulsive activities.

The impact of parent factors on well child adjustment has been highlighted in a study of 22 siblings of children with diagnoses of cancer, cystic fibrosis, diabetes and spina bifida (Williams et al., 1999). Mothers who had a more positive mood had families who functioned better, resulting in a more positive outcome for the well child. In addition, children perceived they had more social support and reported higher self-esteem when their mothers had a more positive mood.
The importance of parental mental health and internal resources on parenting quality and child outcomes is of significant concern in families with a chronically ill child where parents have a high prevalence of emotional problems, depression and other mental health issues (Houtzager et al., 2004; Quittner et al., 1998). A study previously referred to, Mindence (1984) found even when more severe psychological problems such as depression are not present, many parents still suffer from high levels of ongoing stress related to issues including increased caretaking, anxiety, and feelings of guilt about the cause of the chronic illness and restrictions in social life.

Another element of parental impact on child adjustment is the child’s personal experience of parenting behaviour. Several studies have explored the well child’s own experience of aspects of parental behaviour and identified several factors the child experiences as stressful. A number of parent factors were identified as stressors by 10 well children with a chronically ill sibling using semi structured interviews (Gardner, 1998). Gardner acknowledges the sample size is too small for statistical analysis but the interviews revealed useful information. The children identified several parent related factors which exacerbated their stresses including parent preoccupation with the ill sibling, perceived unfair treatment in relation to the sibling, parental distress over the ill sibling and parent blaming of the well child. The main parental factor identified was ‘poor’ parental responses to the well child’s concerns. Children described their parents as responding in unhelpful ways such as reprimanding the well child for being selfish, suggesting they think about how the ill child feels, or telling them to ignore their own feelings. Experiencing affection, having time with parents, and having questions answered adequately were all reported as helpful ways that parents relieve the stresses of the well children.
Children also reported stress from increased separation from parents. Parents of chronically ill children need to meet the physical and medical demands of the ill child and siblings report feeling lack of attention, and a perception that the focus of the family is on the ill child. Physical or emotional separation from parents can be particularly difficult at a time when siblings are worried about the ill child, adding to the feelings of rejection and loneliness (Sloper, 2000). Several studies report children experiencing negative feelings about themselves and toward the family, resulting from their perception of reduced status within the family (Drotar & Crawford, 1985; Sargent et al., 1995). In a study described earlier, Sloper found real or perceived distance from the parents a key stressor for well children. In interviews with these children, Sloper found over half the well children reported loss of attention such as emotional unavailability of a parent because of the parent’s own distress, or concentration on the ill child to the perceived exclusion of the well child. As a consequence well children reported struggling to come to terms with feelings of resentment or anger.

Another area of parental behaviour presented in the literature on childhood chronic illness and disability is parental expectation of children’s contribution to housework and care tasks. For families with a chronically ill or disabled child, under pressure to meet the demands of the ill child as well as maintain the rest of the family, the need for a contribution from children to maintain the household and care for the family is likely to be high. Differences in parental expectation of the child’s participation in care and household tasks has been explored, as has the relationship between well children’s contribution to the family’s child care or household tasks and well child adjustment. Girls with chronically ill or disabled siblings appear to have more responsibility for family care tasks compared with boys, although boys still appear to have more responsibility for childcare than their peers without a disabled sibling
In an early study of 24 preschool children with a disabled sibling, and 22 comparison children matched for family size, family income, sibling age, birth order, sex, age spacing and marital status of parents, Lobato, Barbour and Hall (1987) found parents of children with a disabled sibling had different expectations of their well children than comparison parents. Girls with disabled siblings had the greatest degree of responsibility for child-care and household tasks compared to boys with disabled siblings or children in the control group (with healthy siblings). Girls also had fewer privileges and more restrictions than their brothers or the control group. Similarly, a study of 100 siblings of children with chronic illness in the Philippines (Williams, Lorenzo, & Borja, 1993) found the well children’s housekeeping chores and caretaking activities increased significantly after the ill child’s diagnosis and girls were found to have more household activities delegated to them when compared to boys.

In contrast, a more recent Australian study (Cuskelly, Chant, & Hayes, 1998) found no differences in the level of participation in household tasks (including care tasks for their ill siblings) between 45 children with a sibling with Down syndrome and 88 comparison children with healthy siblings. However, where children did participate in household tasks, a significant relationship between level of participation and problem behaviours was identified. For boys, more participation in household tasks was related to fewer internalising and externalising problem behaviours, and for girls, more participation in household tasks was related to fewer externalising behaviours but also to more internalising behaviours. These findings suggest benefit may be derived from participating on household tasks, possibly from the increased responsibility, but in some cases there may also be a cost.
Stoneman, et al. (1988) suggests the type of care tasks may have a different effect on the adjustment outcomes for the well child and on the sibling relationships. Increased care demands, for example, appear to place stress on older siblings of mentally retarded children, creating dissension and resentment, while more participation in household tasks was related to less conflict in the sibling relationship. In families with disabled children, often the younger sibling takes on a childcare role for a disabled older sibling, reversing the usual roles for responsibility and maturity in a family. Younger children who assume childcare roles for their older disabled siblings have been found to have less conflicted interactions with their brothers and sisters (Stoneman, Brody, Davis, Crapps & Malone, 1991) although it is possible parents only assign childcare responsibilities in cases where the sibling relationship is good. It is not likely a parent would leave a disabled child in the care of a younger sibling who was unkind or uncaring toward them.

Although it is clear that caring for an ill child is extremely demanding, Boling (2005) suggests the rewards and satisfactions of providing care for chronically ill children are still evident. Boling asked 100 parents of children with cystic fibrosis to rate statements about their quality of life, placing them in order from most important to least important. The third most important statement was “I have more of a positive outlook on life since my loved one’s diagnosis”. This statement was only preceded in importance by distress over their child’s health and fear over the death of their child suggesting parents placed a high degree of importance on the positives gained from their child’s chronic illness.

3.6 Child Factors and Chronic Illness

Little research has been reported about possible relationship between the characteristics of the well child and adjustment. Stawski, Auerbach, Barasch, Lerner
and Zimm (1997) tested for age effects in sibling adjustment and found no difference in problem behaviour scores, or any of the externalising behaviour subscales for younger children compared with older children. However older well children did have more internalising problems than younger well children suggesting as well children get older they may become more anxious and depressed. This may be a reflection of a desire to hide their worries and fears from their already overburdened parents, or the increased pressure well children feel to be ‘perfect’ and successful at everything to compensate their parents for the worry, sorrow and regret over the ill child in the family. Ferarri (1983) found younger children were more negatively affected by their sibling’s condition than older ones. Younger siblings displayed more externalising problem behaviours than older siblings, possibly a reflection of the developmental stage of younger children who are not able to express feelings of anger in frustration in a more appropriate way.

Similarly there is little published data on gender differences in well child adjustment. Lobato et al. (1987) found boys with disabled siblings to be more depressed and aggressive than girls. The author’s suggest this finding relates to the amount of participation in care and household tasks in that (as previously discussed) the increased caretaking responsibilities at an early age may have some protective effect for the girls with a disabled sibling (Lobato et al., 1987).

Sahler et al. (1994) found the combination of age and gender to be important as a predictor of adjustment problems in well children. In a sample of 224 well siblings of children with cancer, younger boys and older girls were identified as the two most vulnerable subgroups. Younger boys (11 years or younger) were at risk of more problem behaviours and older girls were more susceptible to distress. The authors suggest the higher levels of behaviour problems in younger boys reflects their relative
immaturity compared to girls at that age, and the propensity for early adolescent boys to express their problems in aggressive ways. In relation to older girls, the authors raise the possibility of a relationship between increased care-giving responsibilities, decreased time for social contact and higher levels of distress. However a more comprehensive review of the household tasks literature (as presented earlier) suggests the relationship between age, gender, responsibility for care tasks and well child adjustment is more complex that proposed by Sahler et al., and Lobato et al (1987).

In addition to individual characteristics of well children, the interactions and relationships between the children in a family also need to be considered in relation to development of healthy levels of child adjustment. The importance of the sibling relationship cannot be underestimated. The sibling relationship is one of the longest most people experience. Few relationships compare for longevity, beginning at birth and continuing throughout your lifetime to death. Siblings share with their family many of the vital elements of life, genetic material, family history, early life experiences, and immediate and extended family relationships. Such an intimate and enduring relationship has a profound impact on our early development. In childhood, we spend more time with our siblings than with anyone else and they play a vital role in the development of crucial social skills such as language, teaching and care giving, perspective taking, establishing and maintaining friendships, and conflict resolution. Siblings form the basis of our first personal experiences, and, in many cases, are still with us when our life comes to an end. A substantial percentage of the groundwork for later intimate relationships is laid during early life interactions with our siblings. Siblings affect us from early childhood onwards in a myriad of ways. By sharing in the relationships and the space within a family, siblings teach each other how to interact with others and how to master critical social skills (Merrell, 1995).
The most often referred to relationship between siblings is rivalry, either for parental attention or material resources, however, longitudinal research has shown sibling relationships develop and change over time. A new baby takes much of the parents' time, rivalry and jealousy by older siblings are commonly evident at this time, but so are expressions of affection and concern for the new baby. As the siblings grow they begin to spend time together, sharing toys, imitating and expressing friendliness as well as anger and ambivalence. Older sibling can also be powerful agents for socialisation (Dunn & Kendrick, 1982). As the siblings continue to grow, socialisation becomes more complex and the skills contribute to perspective taking, moral maturity and competence in relation to other children. Positive sibling ties predict favourable adjustment even among hostile children at risk for social difficulties (Dunn, Slomkowsk, & Beardsall, 1994; Stormshak, Bellanti, & Bierman, 1996).

Sibling relationships leave a lasting impact on our ability to develop intimate relationships and are particularly important to the advancement of self-esteem and self concept (Merrell, 1995). Positive sibling relationships facilitate the capacity to socialise and co-operate with peers while negative sibling relationships can have a damaging effect on our ability to initiate and maintain social links (Bank & Kahn, 1982).

When a child has a sibling with a chronic illness or disability many of the normal developmental relationships may not be possible. The longevity, which characterises sibling relationships, is not present if the chronic illness is life threatening or life limiting. Sibling interactions are likely to be impacted by bouts of illness, hospitalisation or by the nature of the illness itself. The normal elements of sibling relationships, sharing, confiding, arguing, compromising can be interfered with and there may be little reciprocity in the relationship. Competition for parental attention, sibling rivalry and jealousy can be exaggerated. The normal development of sibling
relationships as children mature together is altered. The impact of having a sibling with a chronic illness or disability can be complex and far reaching (Powell & Gallagher, 1993).

Chronic illness and disability researchers have explored the impact on the sibling relationship through the well child’s perception of the experience. In one of the earliest studies of well child attributions, Menke (1987) explored the needs and concerns of 72 well children with a sibling with a cystic fibrosis or cancer. The children were asked the most difficult thing about having a sibling with a chronic illness, and most children reported worry about their chronically ill sibling as the biggest difficulty. Menke reported that some children found it difficult to put their feelings into words in the interview situation and stressed the importance of more expressive research methods to provide a vehicle for the children to express their feelings. In the current study, well siblings were given the opportunity to express their feelings about their ill sibling by open ended questioning.

A previously reported study (Sloper, 2000) also explored well children’s perceptions of their lives as a result of their sibling’s diagnosis of cancer. Immediately following diagnosis, 98 percent of siblings reported at least one negative effect such as loss of attention or status, loss of their own and family routines, loss of certainty and security, and loss of companionship of the ill sibling. In follow-up interviews 18 months later, changes to the number negative events were minimal with some children reporting fewer negative events, but some reporting more had appeared. Some gains were also reported with 60 percent of well children reporting gains immediately following diagnosis and 72 percent reporting gains 18 months after diagnosis. Gains included closer family relationships, increased independence and maturity, more
understanding and compassion and increases in family and social activities as families decided to make the most of life and available opportunities.

A recent study explored quality of life and sibling expectations regarding the illness and found maintaining positive expectations of illness outcomes predicted positive quality of life in 83 well children with a sibling diagnosed with cancer (Houtzager et al., 2005). Similarly, Williams et al. (2002) in a study of 252 children, found that well children who expressed positive feelings regarding their ill sibling and positive attitude toward the illness recorded fewer adjustment problems as assessed by mood, self-esteem and beliefs about social support.

In a smaller study (Derouin & Jessee, 1996) involving interviews with 15 well children regarding their perceptions of the impact of their sibling’s illness, a number of positive and negative outcomes were revealed. Positive outcomes included strengthening of family relationships, achieving more personal independence and experiencing satisfaction in seeing improvement in the ill child. Negative outcomes included worrying about the ill sibling’s illness, being jealous of the attention paid to the ill child and restriction of family events.

Another study (Tritt & Esses, 1988) enabled children to express their feelings through semi-structured interviews. The study involved 27 children with ill siblings and 27 children from healthy families. The children with ill siblings reported themselves as the unhappiest person in the family because of sibling’s illness. The reasons given for their unhappiness were their worry, sense of exclusion and loss. Children also reported feeling resentment over increased chores and responsibilities as a result of the illness and most reported decreased attention to themselves and increased special treatment to their ill siblings. However despite a high number of children reporting numerous negative effects of having a sibling with a chronic illness, less than half of the children
reported any feelings of jealousy. Possibly social desirability influences the reports of negative emotions when a sibling is ill. Strohm (2002) reports that siblings of children with a chronic illness or disability may feel the need to hide their negative feelings from their family and from the wider community. This may be partly to save their parents from additional worry, and partly because it is seen as undesirable to express jealousy or resentment toward any sibling, let alone one with a chronic illness.

Interviews with siblings have proposed similar sources of distress for children with an ill sibling. Well children indicated distress about family separations and disruptions, lack of attention from parents and focus of family on the ill child. Well children also reported feeling distress about their own feelings. When they experienced negative feelings about themselves and other family members they felt upset and guilty (Drotar & Crawford, 1985; Menke, 1987; Sargent et al., 1995).

Sloper (2000) reported siblings expressing stress over a perceived loss of status, where siblings felt that they no longer occupied the same place and importance in the family as before the diagnosis. However, interviews 18 months after diagnosis showed that two thirds of well children felt that their parents no longer treated them differently from the ill child. Also, where the well child understood any differential treatment related to the limitations of the chronic illness, they were generally accepting of the situation. These findings suggest that over time, the well child’s perception of the illness and the consequent changes to family roles and routines may play a role in the acceptance of differential treatment, potentially reducing stress for the well child and enhancing their ability to cope with any necessary changes. It is possible this positive outlook may lead to better adjustment outcomes for well children as they adjust more easily to the increased demands on themselves and their parents, and the increase in pressure on the family unit. In the current study, the role of these positive and negative
feelings about ill brothers and sisters was explored in relation to the psychosocial health of the well child.

Research has also explored the impact of the behaviour of the ill child on the well siblings. Gardner (1998), in a study already reported, identified several factors relating to the ill child as exacerbating the stress in the well children, such as seeing the ill child in pain or in hospital, knowledge of the possible death of the ill child and lack of knowledge about the illness. Similar findings are evident in other studies (Drotar & Crawford, 1985; Menke, 1987; Sargent et al., 1995). Worry about the sibling and lack of knowledge about the illness appear to be related. Sloper (2000) found that children worried about their ill sibling largely because they did not want to place additional worry on the parents.

Weiss, Schiaffino and Ilowite (2001) compared the sibling relationships between 20 well siblings of children with juvenile chronic arthritis and 20 siblings in a comparison control group. The sibling relationships of the arthritis sibling groups and the healthy control group did not differ significantly in terms of authority over each other, positive feelings, conflict, or perceived parental favouritism. It is possible the diagnosis of arthritis may have resulted in some sibling pairs becoming closer and helping each other more. In fact it was the severity of the symptoms which related to more or less sibling conflict, in that more conflict was reported by siblings of children with the most severe arthritis symptoms, suggesting severity of illness has a negative impact on sibling relationships. The authors suggested that sibling conflict increases as severity of symptoms increase because siblings may have less in common and find it more difficult to relate to each other. Similarly, in a meta-analysis of 51 published studies, Sharpe and Rossiter, (2002) concluded more intense daily treatment requirements have a negative impact on well children in the family. Siblings of
children with a chronic illness, which affects day-to-day functioning (e.g., bowel
disease) are more negatively affected than siblings requiring less daily assistance (e.g.,
craniofacial abnormalities) suggesting a relationship between the level of care-giving
required by the parent and well child adjustment (Sharpe & Rossiter).

Ill child behaviour has also been identified as impacting adversely on the well
children in the family, with healthy children’s distress levels found to be positively
associated with problem behaviour in their ill siblings (Gardner, 1998; Treiber, Mabe, &
Wilson, 1987). The relationship between ill child behaviour and well child behaviour
was explored more closely in a recent study (Stawski et al., 1997) of ill children, closest
in age siblings and well children and psychiatrically referred children. Well siblings
were not found to have any more behaviour problems than the control group of healthy
children. However, where behaviour problems were found, they were associated with
behaviour problems in ill children, so in families where ill children displayed problem
behaviours, the well children did too. The authors suggest that ill child behaviour plays
a role in shaping the development of aggressive and rule breaking behaviour in well
siblings possibly in an overt way in that the well child observes what is acceptable by
observing their ill sibling behave and the consequences. Another possibility is that the
influence is less direct where parents who are already under stress find it difficult to
maintain two separate standards of behaviour, one for the child with a chronic illness
and one for the well children with the result that behaviour standards are lowered for all
the children in the family.

The current study assessed the impact of factors relating to the ill child on well
child adjustment. Previous research has found many ill child factors such as severity of
symptoms, parental attention required and ill child behaviour are related to well child
adjustment problems. These factors vary within diagnoses and illness classifications.
For example, one child with cystic fibrosis may have mild symptoms which are controlled well with medication and require limited daily treatment; another may have severe symptoms and require intensive supervision and care. A strength of the current study is that the chronic illness or disability is not categorised by diagnosis (e.g., cancer or cystic fibrosis). Several different methods are employed to assess ill child variables including characteristics of the illness, amount of care required, ill child behaviour and well child participation in care activities.

3.7 Psychosocial Outcomes for Siblings

Research into psychosocial outcomes for children with a chronically ill or disabled sibling has produced contradictory findings. A recent review of the literature concluded that the impact of an ill child on siblings remains unclear (Barlow & Ellard, 2006). Various researchers have reported children with chronically ill siblings are worse off, better off and no different to their peers in terms of psychosocial adjustment problems.

3.7.1 Studies Reporting Meta Analyses

A comprehensive meta-analysis conducted by Sharpe and Rossiter (2002) has already been referred to. Fifty studies published between 1976 and 2000 were collected from computer searches of PSYCHLIT and MEDLINE. Case studies and non-empirical studies were excluded, as were studies without controls or published norms and studies exploring sibling deaths and adult siblings. Effect sizes were calculated by subtracting mean score for comparison participants from mean score for siblings with a chronic illness and dividing by the standard deviation. The analysis found a statistically significant effect size for adjustment problems in children with chronically ill siblings. The well children were found to have more adjustment problems then their peers with healthy siblings. Internalising behaviours such as anxiety and depression were
associated with larger negative effects than externalising behaviours such as aggression and rule breaking behaviour. The authors suggested the well children in the family may find expressing any frustration and worry through externalising behaviours to be more difficult in families with already overburdened parents. As a result, in these studies more internalising behaviours were presented in the well children with a sibling with a chronic illness.

The most recent meta analysis (Del Rosario & Keefe, 2003) was conducted on 48 studies of children with a range of disabilities. The results found children with a disabled sibling were at greater risk of negative effects including low psychological well being and more problem behaviours. A number of positive effects were also reported including increased empathy, compassion, understanding and kindness.

These findings are consistent with an earlier meta-analysis into the psychosocial outcomes of chronic illness on children (Lavigne & Faier-Routman, 1992), conducted on studies published between 1928 and 1989. Chronically ill children were found to be at increased risk of psychological adjustment problems, although with a smaller effect size than attributed to siblings of chronically ill children by Sharpe and Rossier (2002).

A review of the literature by Williams (1997) analysed 43 studies published between 1970 and 1995. The review counted the number of outcomes for well children with a chronically ill sibling and reported the results in three categories: increased negative risk for well children; both positive and negative outcomes reported for well children; and no reported no difference between adjustment of well children and population norms or control groups. Williams found 60 percent (n=26) of studies reported well children to be at higher risk of adjustment problems such as increased anxiety, depression, and aggression and decreased social competence and self-esteem. Five of these studies were found to report well child problem behaviours in the clinical
range using standardised data collection tools. Thirty percent (n=12) of studies reviewed found no differences in social or emotional adjustment between children with a chronically ill sibling and their peers in the general population. The remaining 10 percent (n=5) found both positive and negative effects for well children such as enhanced family closeness at the same time as low levels of self-esteem.

In a recent review of the literature, Bellin and Kovacs (2006) caution researchers against focusing on the production of either assets or problems as a result of having a sibling with a chronic illness, but to consider both. Children may demonstrate difficulties in one area of emotional or social development, but may simultaneously reveal positive outcomes in other aspects of their functioning. These writers underscore the importance of using multiple methods of assessing child adjustment, as is the case in the current study. More detailed discussion and justification of assessment methods is in chapter 4. In the following sections (3.7.2 – 3.7.4) further details of individual studies showing negative, positive and no effects of having a sibling with a chronic illness or disability are described, elaborating on the previous general discussion of trends.

3.7.2 Studies Indicating Negative Effects

As indicated previously, several studies have found children with a chronically ill sibling to have higher rates of adjustment problems including depression, anxiety and aggression more emotional problems and lower self concept than either control groups or population norms (Breslau & Prabucki, 1987; Cohen et al. 1994; Cowen et al. 1986; Ferrari, 1987; Giallo & Gavidia-Payne, 2006; Treiber et al. 1987; Tritt & Esses, 1988; Wood, et al., 1988).

One very large study, The Ontario Child Health Study (Cadman, et al., 1988) measured adjustment in 2330 siblings of children with a chronic illness or disability.
The study collected adjustment data from parents, the children and the children’s teachers using behaviour rating scales, and structured interviews. Adjustment scores were converted to a diagnostic category and children were classified as having an adjustment problem if two or more reports generated a score at or above the threshold. The well children were found to have twice the risk of emotional disorders including depression, anxiety, and obsessive compulsive disorder than children without a seriously ill child in the family. The study also found a 1.6 fold increase in risk of poor peer relationships in children with a seriously ill sibling.

In a comprehensive study of children with spinal muscular atrophy, well siblings and healthy controls, well children with a chronically ill sibling had the highest rate of behaviour problems (Laufersweiler-Plass et al., 2003). The ill children and well controls scored lower on externalising and internalising behaviour scores than the well siblings, and 20 percent of well siblings scored in the clinical range for adjustment problems compared to 11.7 percent for well controls and 11.5 percent of patients. Rates of behaviour problems were two to three times higher in well children than peers with healthy siblings. Silver and Frohlinger-Graham (2000) matched well siblings and a control group for sibling age, gender, birth order and age spacing. The results showed higher levels of anxiety, depression, interpersonal sensitivity and hostility in well girls with a chronically ill sibling compared to well children with healthy siblings.

Well children have also reported lower quality of life than their peers with healthy siblings (Houtzager, et al. 2005). A previously reported longitudinal study investigated quality of life in 83 well children with a sibling diagnosed with cancer, at one month and again at two years after diagnosis. At one month after diagnosis well children reported lower quality of life in the form of more emotional and cognitive problems than their peers. About half were experiencing emotional difficulties at rates
twice as high as the reference group. At two years after diagnosis, well children were still experiencing lower quality of life, and in addition 26 percent of older children (aged 12-18) scored higher on measures of internalising problems such as anxiety than population norms suggesting problems for well children continue beyond the diagnosis of their sibling’s illness.

A recent Australian study found well children with disabled siblings had significantly higher emotional and behavioural functioning compared to normative populations (Giallo & Gavidia-Payne, 2006). Similarly, higher levels of emotional problems have been reported in siblings of children with a chronic physical disorder such as spina bifida and cancer (Taylor, Fuggle, & Charman, 2001). Emotional adjustment in well siblings was related to recency of acute illness episode in that well siblings were less adjusted when the ill child had experienced a severe episode of illness within the past six months. Emotional adjustment in the well child was also related to maternal awareness of the child’s attitudes about the illness; well siblings who were better emotionally adjusted had mothers who were more aware of their perceptions and attitudes about the illness. In this study the link between parental awareness of well child perceptions is raised as an important factor as there was significant variation in the level of agreement across the mother-child pairs in this study. Overall, mothers demonstrated a tendency to overrate the well child’s concerns, rating the well children as having more negative attitudes and perceptions about the physical disorder than reported by siblings themselves. On a more detailed level, the agreement between mothers and well children was higher on issues relating to the physical disorder (e.g., worries about catching the brother/sister’s illness) and lower on issues relating to family functioning. For example, one sibling reported feeling disappointment in her family’s interactions since the illness began “my parents give him too much attention, because
they’re worried he’ll be ill again”, in contrast to the parent’s comments “when we try to talk to her she says ‘don’t worry, I’m OK, I understand’ and we just leave it” (Taylor et al., 2001, p. 960).

Some research has explored well child adjustment problems by looking more closely at the well child’s feelings about the effects of having a sibling with a chronic illness or disability. Interviews have revealed some of the possible factors behind the findings of problem outcomes for siblings. Hollidge (2001) assessed 28 well siblings on a number of psychological scales and found well siblings at risk of several psychological stressors. The siblings demonstrated significant anxiety, low self concept and depressive affect, although did not display significant levels of behaviour problems. Hollidge found the well siblings experienced shame and anxiety when they felt they could not live up to the high standards they set for themselves to provide emotional and physical care for their sick brother or sister. The result was lowered self concept and an increase in depressive symptoms. The siblings also demonstrated significant difficulty in communicating their problems to parents and friends, which compounded their problems. Children with seriously ill siblings have also reported feeling as though they are the most unhappy members of the family, and feeling that no one cared about them (Derouin & Jessee, 1996).

3.7.3 Studies Indicating Positive Outcomes

A number of studies highlight potentially positive outcomes for children growing up with a sibling with a serious illness. Effects include increased sensitivity, compassion, empathy, maturity, family closeness and social competence (Faux, 1991; Ferrari, 1983; Horwitz & Kazak, 1990; Kramer, 1994; Menke, 1987). Sloper (2000) found increased independence, maturity and compassion in well siblings. Sloper suggested these skills are developed as the children are exposed to increased
responsibility at home. Siblings also reported increases in social activities and that their families had decided to make the most of every available opportunity. Similarly, Kiburz (1994) conducted interviews with children aged 7 to 12 years who had siblings with spina bifida and collected survey data from their mothers. The study revealed well children had high levels of empathy and concern for their brothers and sisters and low levels of embarrassment and avoidance regarding their sibling’s disability.

More responsibility and less attention from parents has also been linked to a higher incidence of proactive coping methods amongst children with siblings with a disability or chronic illness. Children with ill siblings were more likely to suggest positive, action oriented ways to solve problems and less likely to ask for suggestions, internalise the problem, or do nothing (Cox, Marshall, Mandleco, & Olsen, 2003).

In structured interviews with 254 siblings of children with cancer, Saregent et al. (1995) explored the thoughts and feelings about the effects of their sibling’s cancer on themselves and their family. The well children reported positive outcomes including becoming more compassionate and benefiting from experiences they would otherwise not have had. The children also reported families becoming closer when their sibling was diagnosed with cancer. Some distressful experiences were also reported including disruptions to the family, lack of attention from their parents, the family being focussed on the ill child and fear about the cancer treatments and possible death of their sibling. Older children were more likely to report positive effects than young children suggesting maturity may lessen the feelings of distress when a sibling is diagnosed with cancer. Tritt and Esses (1988) found some of the older siblings in their study felt they were more patient, understanding and sensitive to the ill child in the family and more aware of how to deal with someone who is sick.
In a study previously referred to, Horwitz and Kazak (1990) found the siblings of ill children had fewer behavioural problems than the control group and showed significantly higher levels of a number of positive behaviours such as helping with household chores, gift giving, praising and giving compliments, sharing toys and showing affection.

Although it may first appear that these findings of positive outcomes contradict previous research findings of increased adverse outcomes for well children, it is possible both findings in fact complement each other. The existing body of literature appears to be focused on the presence of either negative outcomes such as anxiety, depression or aggressive behaviour, or positive outcomes such as empathy, compassion and maturity. A possibility is that children can experience some positive as well as some negative outcomes at the same time. Evidence for this is provided by Hollidge (2001) who found siblings of children with diabetes were vulnerable to anxiety and low self concept, but also demonstrated high levels of behavioural competence suggesting researchers could benefit from exploring both positive and negative outcomes for well children in their studies (Bellin & Korvacs, 2006).

3.7.4 Studies Indicating No Differences

Finally, a few studies have found no differences in adjustment between children with a chronically ill sibling and their peers. Noll, et al. (1995) explored peer and teacher ratings of social competence in children who had siblings with sickle cell anaemia and found no difference between these children and a comparison group of children with well siblings. Further, the chronic illness group and the control comparison group showed no difference in their perception of their own peer relationships.
Thompson, Curtner and O’Rear (1994) found no differences in psychosocial adjustment of healthy siblings of ill children compared to healthy siblings of well children, although the study was small (19 siblings of chronically ill children and 19 siblings of healthy children). A relationship was found however, between parent’s marital status and well child adjustment in that well children residing in single parent families had poorer adjustment outcomes than well children in dual parent families. Similarly a study of ill children, closest in age siblings, healthy children and psychiatrically referred children, well siblings did not score higher on any measures of problem behaviours than the comparison group of normal children (Stawski et al. 1997).

Another study found no significant difference between behaviour problems in well children compared to matched controls, but did find trends toward higher levels of depression and anxiety and significantly lower self-esteem. The well children also reported more problems in their relationships with peers than the control group, including inferiority, social insecurity and withdrawal (Engstrom, 1992).

One possible reason for the apparent contradictory findings into well child adjustment is the difficulty in comparing results with such a diverse range of methodologies. In the body of literature, poor adjustment outcomes include a wide variety of indicators including behavioural problems, emotional problems, peer relationship problems, self-esteem, insecurity and quality of life. Positive outcomes are similarly broad. In addition, as previously discussed, positive and negative outcomes, although rarely assessed at the same time, are not necessarily mutually exclusive. As well, most studies have relied on one assessor of child adjustment (parent, teacher or child) and most do not compare outcome data with any normative data or control groups. These methodological issues are discussed in more detail in chapter 4.
3.8 Relation to Current Study

Psychosocial adjustment of children with a chronically ill or disabled sibling is the focus of this study. The study, based on the literature examined in these and the two previous chapters, examines the relationships between adjustment of well children and several family factors (family size, family income, access to and utilisation of respite) parent factors (daily hassles, autonomy granting, warm involvement, behavioural control, maternal education, parental access to support) and factors relating to the individual children (ill child behaviour, care time required, participation in social support activities, well child age and time well child spends caring for ill child).
Chapter 4: Methodological Issues

4.1 Control Groups and Normative Comparisons

When reviewing the chronic illness and disability literature for well child outcomes some important methodological issues become apparent. One problem with studies of this nature relates to how judgements are made about whether well children with ill siblings are faring better or worse than children in healthy families. One type of comparison can be made using a control group of children with healthy siblings, matched on ‘key’ variables. Another possibility is to compare well child outcomes with normative data, using standard testing instruments. Sharpe and Rossiter (2002) found well children were less likely to differ from control group children in behaviour comparisons than they were to differ from published normative data (when control group studies were compared to normative comparison studies). The authors suggested the discrepancy in findings may be influenced by the complex matching which is evident in many studies using control groups (e.g., age, gender, birth order and age spacing), but there was no evidence for the accuracy of one method over another.

One problem for researchers is that large amounts of time and resources are required to obtain data from matched control groups as well as from the chronic illness sample. Families with a child with a chronic illness are difficult and time-consuming to recruit. These families have limited time and resources available, many already participate in medical and other scientific research relating to their ill child. They may understandably lack the resources or motivation to explore any potential problems with the well child in the family. Recruitment of these families may absorb the resources of the researchers unless there is excellent funding available.

Additionally it is not clear which are the key variables to be matched in the control sample. The more detailed the matching criteria, the more difficult it becomes
to recruit the control group. When matching criteria are reduced, matching ‘errors’ may be averaged out if samples are large, but of course this too is difficult to achieve. Use of measures for which there is good quality normative data appears a viable alternative to the use of a control groups, although it is clear from the Sharpe and Rossiter study that cautious interpretation of differences is in order.

4.2 Use of Multiple Informants

Another problem relates to methods of measurement of child outcomes and studies vary widely in the way these are assessed. Most common are parent reports of child behaviours; less common are child self reports, occasionally studies have used teacher reports, observational data and interviews. In a review of methodological issues in assessing adjustment in siblings of children with a disability, Cuskelly (1999) points to the prevalence of maternal reports, lack of child self reports and absence of any paternal reports as a problem with the published research. There is some evidence that parent reports produce different outcomes from child self reports. In their comprehensive meta-analysis, Sharpe and Rossiter (2002) found parent reports of well child behaviour were more negative than reports provided by the well children themselves. This may be a reflection of the child’s inability to perceive problems in their own behaviour, or denial that problems exist. Alternatively it may reflect overprotective parents who are concerned about every aspect of their children’s development, or hyper vigilance and oversensitivity to problems with their children.

Another study (Houtzager et al., 2005) previously reported, found little correspondence between parent and well child ratings of adjustment problems. Well children reported more physical, motor and behavioural problems and fewer positive emotions than reported by their parents. Similarly Guite, Lobato, Kato, and Plante (2004) found differences in parent and child ratings of adjustment problems. Parents
reported more well child adjustment problems than well children reported. Rivers and Stoneman (2003) reported similar findings in a study of sibling relationships of children with autism. Parents and well children from 50 families reported on the quality of the relationship between the child with autism and the well sibling. Parent reports and well child report of the sibling relationship was highly correlated, however well children reported being happier and more satisfied with the relationship than the parent did. The authors suggest the discrepancy may be due to parents being more aware of difficulties between children and more focused on the interactions which are difficult. These studies highlight the importance of using multiple informants in studies of well child adjustment.

4.3 Assessment Methods

Another methodological issue in studies of resilience in well children with a chronically ill sibling is conceptualisation of adjustment outcomes and selecting an appropriate method of assessing adjustment. Traditionally, indicators of behavioural competence have been used as outcome measures such as include social skills, social adjustment and lack of overt behaviour problems. Resilience theorists Masten and Coatsworth (1998) described competent children as demonstrating a pattern of effective adaptation, and proposed social competence with peers and socially appropriate conduct as indicators of competence. Other measures of areas of adjustment include emotions, physical health and academic/vocational achievement (Staudinger, Marsiske, & Baltes, 1993), as well as lack of mental health problems and absence of physical health problems such as migraines (Luthar, 1993).

In the current study, resilience in well children with a chronically ill sibling, was conceptualised as the absence of any adjustment problems such as depression, anxiety or aggressive behaviours. Children with more adjustment problems were considered to
be less resilient, and more vulnerable to the stresses placed on them by having a chronically ill or disabled sibling. Methods of assessing child adjustment are reviewed providing a background for the choice of outcomes measures used in the current study.


4.3.1 Direct Behavioural Observation

Direct behavioural observation involves observing and recording the child’s behaviour as it occurs. This approach allows the observer to gather information not just on the behaviour of the child, but on contextual and situational factors such as the physical environment, interactions with others, preceding and antecedent behaviours and consequences. Methods include naturalistic observation, where an observer watches the child in their natural environment such as home or school; analogue observation where the conditions are reproduced in a controlled environment such as a clinic or a laboratory, and self-monitoring where the child is trained to observe and record their own behaviours. A variety of standardized coding systems exist to interpret the observations, such as the Child Behavior Checklist – Direct Observation Form (Achenbach, 1987).

The advantage of direct behavioural observation is that it can be used to identify antecedent events and consequences as well as the behaviour itself. Accuracy though, relies on highly skilled observers. Observer bias can be a problem and the presence of an observer can influence the behaviour of the child and any other people in the environment (Merrell, 1999). In addition, Kazdin (1982) reported that some behaviour may be situation-specific. For example, children may behave differently in two different classrooms with two different teachers. Behavioural observations are also mostly
unstandardised making them unsuitable for comparing data from one participant to another. For research purposes, direct behavioural observation can be a time consuming and expensive way to gather large amounts of behavioural information, although it can be a rich source of data for hypotheses generation.

4.3.2 Behaviour Rating Scales

Behaviour ratings scales are questionnaires, which assess a child’s behavioural, emotional and social functioning by presenting a series of standardized questions about how the child behaves. The scales can be designed to be completed by children, parents, teachers or other adults who know the child well (Merrell, 1999). The scales are a less direct method of data collection than behavioural observations because they measure someone’s perceptions of a child’s behaviour rather than the event itself, however these scales have objective components built in (for example standardised instructions), and can be highly statistically valid and reliable depending on the scale selected.

Behaviour scales usually take the form of a checklist (“yes” or “no” answers) or a rating scale (“0 = never”, “1 = sometimes” or “2 = always”) in response to a statement such as “(The child)… is noticeably sad or depressed”. Response bias can be a problem where clients may consciously fake their responses so they appear good (or bad) or they may rate a child positively or negatively because they possess other positive or negative qualities (the halo effect). They may also tend to avoid the endpoints by selecting “sometimes” frequently. Social desirability is also a potential problem where respondents feel pressure to respond as they think they should, rather than the reality. Some scales are structured in a way to detect bias in responses in order to minimise these effects (Edelmann, 1996; Martin, Hooper & Snow, 1986; Shaughnessy, Zechmeister, & Sechmeister, 2003).
Reliability and validity are critical elements of behavioural rating scales. A reliable measure is one that yields consistent results each time it is taken and a valid measure is one which measures what it purports to measure (e.g., anxiety). Measures of reliability and validity are usually indicated in scale manuals or research reports (Gravetter & Wallnau, 1992).

Assuming the measure selected has acceptable levels of validity and reliability, behaviour ratings scales have many advantages, hence their widespread popularity. They are less expensive and time consuming than behavioural observation or interviewing and are often more valid and reliable than interviews and projective techniques (Martin et al. 1986). Rating scales are also more objective in their scoring so minimise the amount of subjective interference from the assessor. Also they can identify rarely occurring but important behaviours that might not be seen in a few observation sessions or revealed in an interview by taking advantage of observations over a period of time in a child’s natural environment by people who know them well and can be considered expert informants (Edelmann, 1996; Martin et al. 1986, Merrell, 1999; Shaughnessy et al., 2003).

4.3.3 Interviewing

Interviewing is a structured communication, mainly verbal but with elements of the non-verbal as well. It differs from general conversation in that it is structured, is led or controlled by the interviewer, and has a goal or objective (Martin, et al., 1986). Interviews can be very loose in structure such as stream-of-consciousness monologues, or highly structured schedules focussing on specific issues. Clinical interviewing of children requires highly skilled clinicians with expertise in developing interpersonal relationships and a knowledge of developmental issues to inform their interviewing
technique. The interpersonal skills of the interviewer are cited as the most important aspect of interviewing technique (Merrell, 1999).

An advantage of clinical interviewing is the flexibility it allows. The clinician has the opportunity to shorten or lengthen the interview, to change directions or focus on specific areas as they arise and the client can give, in their own words, a detailed commentary of their own circumstances. This is rarely possible with other techniques of assessment. However, the non-standardised nature of the interview, which enables this flexibility, is also criticized for producing potential unreliability and inconsistency over time and between interviewers. Bias is also a problem; the client may under-report negative behaviours and/or over-report positive behaviours. The usefulness of interview data depends not only on the accuracy of the report from the client, but also on the accuracy of the interpretation placed on the information by the clinician or researcher. Another advantage of interviews is the possibility of assessing behavioural, emotional and social skills in a structured environment. Insight, defensiveness, willingness to cooperate can all be observed and assessed by the clinician throughout the course of the interview. Other problem issues relate to distortion and bias by clinicians or the interview subject, such as selective or faulty recall on the part of the child (Gregory, 2004).

The most commonly discussed problem with clinical interviewing is variation across interviewers because the interview, more than any other assessment technique, relies on the skill of the interviewer for its success. Several barriers exist which impede the use of clinical interviews for research purposes. Successful interviews require interviewers with extensive skills, experience and expertise; they are time consuming to conduct and it is time consuming and difficult to convert comparable data for research purposes. These disadvantages mean clinical interviews are more commonly used for
clinical diagnostic applications than research purposes (Endelmann, 1996; Gregory, 2004; Merrell, 1999; Shaughnessy et al., 2003).

4.3.4 Projective Expressive Techniques

Projective expressive techniques are methods which use ambiguous stimuli to elicit responses from individuals. The theoretical basis is that unconscious responses to the stimuli presented reflect the needs, motives and conflicts of the individual. Various types of projective expressive techniques encourage the individual to explain an image, produce a drawing, tell a story or complete a sentence. The assessor evaluates data (drawings, statements, key words) for the purpose of deciphering underlying personality processes and psychological functioning (Gregory, 2004). Projective and expressive assessments are controversial amongst the professional community with two main points of contention. First, many psychologists simply do not believe the fundamental principle of projective techniques - that responses to ambiguous stimuli reveal important information about the self. Second, projective expressive assessment is not as well supported by psychometric data, as is the case with direct and objective assessment (Gregory, 2004; Merrell, 1999). Despite the controversy surrounding the use of project expressive techniques they remain widely used. The most popular projective assessments for children are thematic approaches, drawing techniques and sentence completion tasks (Merrell, 1999).

In thematic approaches an individual is presented with a series of drawings or pictures showing ambiguous characters and situations and asked to tell a story about each picture. According to Merrell (1999) the most popular example is the Thematic Apperception Test in which 31 black and white picture cards are presented and the child is requested to tell the story of what is happening in the picture. Obzrut and Boliek (1986) stated that there is substantial reliability and evidence of validity for thematic
approaches, however Gregory (2004) is less supportive stating that reliability and validity of thematic approaches is untested and unknown.

Drawing techniques like the Draw-A-Person test require the child to draw a person for analysis by a standardized method such as that developed by Koppitz (1968). The scoring system is detailed and complex and has been found to be consistent between raters. Cummings (1986) integrated the results of 13 inter-rater reliability studies and found a high correlation in the agreement of raters between studies (ranging from .75 to .95). Contradictory evidence has been provided as to whether drawings are able to distinguish between children with behavioural, social or emotional problems and children with normal adjustment (Cummings).

In sentence completion tasks, the clinician presents a sentence stem and the individual provides a written or oral response by completing the sentence, for example “I wish ….”. Sentence completion tasks are interpreted in two ways: a subjective or intuitive analysis of the underlying motivations, or a more objective analysis by assigning scores to the completed sentences (Gregory, 2004). Although sentence completion tasks are commonly used with adolescents, a problem with the use of these tasks with children is that in the preoperational stage (most children under age 13), concrete factual responses tend to be the norm, possibly defeating the purpose of the expressive intent of the task. Gregory (2004) reports that most sentence completion tasks used for children are non-standardised and not commercially published or widely available. In addition, clinical use and research application of sentence completion tasks has waned in recent years (Merrell, 1999).

Projective and expressive techniques have several advantages and can be useful when used in addition to other more objective tests. One advantage is their use in establishing rapport with children. Children find the projective expressive techniques
safer and less threatening, often even fun and enjoyable, so the use of these techniques can help establish a positive relationship with the child and help the child to relax and enjoy the assessment experience. Another advantage is their usefulness with extremely shy or reluctant children, as well as young children not yet verbally sophisticated enough to engage in an interview. Finally projective expressive techniques can assist the clinician to understand the world from the child’s personal perspective (Gregory, 2004; Merrell, 1999).

4.4 Relation to Current Study

The current study assessed child adjustment using both parent and child informants. Direct and objective methods of assessment (behaviour rating scales), projective/ expressive methods (child family drawings) were used. Open ended statements were used to explore children’s attitudes toward their ill sibling. Detailed information relating to family structure, parenting styles, parenting stress and the chronic illness or disability of the child was collected using published scales and researcher developed items. Child adjustment scores from both parent rated and child rated measures were compared to age-and gender-specific published normative data rather than control group data.
Chapter 5: Aims and Hypotheses

The current study had two major research aims. The first was to describe social, family and personal characteristics of a group of well children with siblings who have a chronic illness or disability. The second was to test a series of hypotheses about these well siblings.

The rationale for the study was the large body of literature on resilience in children, suggesting some children who have a sibling with a chronic illness or disability, may adapt and thrive, while others may succumb to psychosocial problems (see Chapter 3). There is a body large body of research which shows that children from adverse environments (such as those characterised by poverty, violence or illness), are more likely to succumb to either internalising disorders (such as anxiety and depression) or externalising behaviour problems (such as antisocial and aggressive behaviour). However some children from highly risky environments are resilient, they do not experience adverse outcomes but grow up happy, healthy and fully functioning adults. Research has explored the factors that contribute to resilience in children. The current study looks specifically at the risk factor of chronic illness in the family, the stresses placed on a child when a sibling in the family has a chronic illness and the relationships between psychosocial outcomes for these children and several family, parental and individual child characteristics (see Chapter 3).

The study hypotheses concerned:

1) Adjustment of the well children

The first hypothesis related to previous studies (Lavigne & Faier-Routman, 1992; Sharpe & Rossier, 2002; Williams, 1997) suggesting deficits in adjustment among well children with ill siblings.
Specifically it was predicted that well child behaviour problems, when rated by parents and also when self rated by well children, would be higher than the population norms for children of a similar age and gender. This set of hypotheses was tested using a series of dependent t-tests. The measures of child behaviour used to test these hypotheses were confined to measures for which, there was appropriate normative data. The behaviour problems assessed were:

- parent rated well child behaviour; specifically well child internalising behaviour (comprising anxious/depressed, withdrawn/depressed and somatic complaints); externalising behaviour (comprising aggressive behaviour and rule breaking behaviour); and well child attention problems, social problems and thought problems

- child (self) rated behaviour, specifically child rated anxiety (comprising physiological anxiety, worry/oversensitivity and social concerns). Child rated aggression was not used to test this hypothesis, as comparable normative data was not available for the modified scale used.

2) Relationships between parenting style and well child adjustment

The second hypothesis related to previous studies (Kaufmann, et al., 2000; Lamborn et al., 1991; Steinberg et al., 2006; Steinberg et al., 1994; Steinberg et al., 1992; Strage & Brandt, 1999) suggesting that a more authoritative parenting style was related to better child adjustment than a less authoritative parenting style, or than parenting styles that were authoritarian, indulgent or neglectful.

- Specifically, it was predicted that well children with authoritative parents would have fewer behaviour problems than well children with parents
who did not use an authoritative parenting style or who used it to a lesser degree. These hypotheses were tested with MANOVAS, using the categories of parenting style as the independent variable, and measuring it in two different ways. In the first, authoritative parenting style was compared with authoritarian, indulgent and neglectful styles; in the second, highly authoritative parenting styles were compared with styles that were moderately, somewhat and not at all authoritative (see section 6.2.2.4). The dependent variables in these analyses were the four major measures of child adjustment (parent rated and child rated internalising and externalising).

3) Prediction of well child adjustment from ill child, family and parenting variables

Relationships between well child adjustment and several key individual child variables (ill child behaviour, care time required, ill child participation in social activities, well child age, well child participation in social activities and well child time spent caring for ill child), parent variables (daily hassles, parenting style, maternal education and parental access to support) and family variables (family size, family income and utilisation of respite) were assessed using correlation and regression techniques. The measures of well child adjustment used in this set of hypotheses included parent rated well child internalising, externalising, attention problems, social problems and thought problems as well as well child (self) rated aggression and anxiety.

- Specifically, it was predicted that better adjustment in the well child, as measured by parents and the well child, using behaviour rating scales would be associated with, and predicted by
Individual child variables (a) lower levels of externalising and internalising behaviour in the ill child, (b) less seriousness of the ill child’s illness as assessed by care time required for the ill child (c) more participation in social activities by the ill child (d) older well child age (e) greater access to social support for the well child, that is more well child participation in social activities and (f) more time the well child spent caring for the ill child rated by parents and children (based on the findings of Lobato et al. (1987) and Cuskelly et al. (1998) that increased participation in household and caretaking tasks may be a protective factor for children with disabled siblings)

- Parent variables (a) less parental stress as assessed by frequency and intensity of parental daily hassles (b) better (more authoritative) parenting styles that is greater psychological autonomy granting, warm involvement and behavioural control (c) higher maternal education and (d) more parental access to social support

- Family variables (a) fewer children in the family, (b) higher family income, (c) higher utilisation of respite by the family, that is more hours of respite per week and more respite options for the family.

4) **Relationships between well child adjustment and the child’s attitude toward his/her ill siblings**

The fourth hypothesis related to previous studies (section 3.7.3) suggesting that a well child’s positive attitude toward their ill sibling will impact on the positive adjustment of well children in the family, therefore a more positive attitude would be associated with fewer adjustment problems. This hypothesis was tested using correlations.
• Specifically, it was predicted that well child adjustment, and more
positives attitude on the part of the well child toward their ill siblings,
would be correlated.

5) Relationships between well child adjustment as measured by drawing techniques
and the previously listed family, parent and ill child variables

Drawings were assessed based on the number of emotional indicators as defined
by Koppitz (1969, 1983, 1984). Drawings with two or more emotional
indicators were categorised as indicative of emotional problems and drawings
with one or no emotional indicators were categorised as reflecting no emotional
problems. This hypothesis was tested using MANOVAs: the independent
variable was emotional problems (yes or no) and the dependent variables were
the same child, family and parent variables listed in hypotheses 3.

• Specifically, it was predicted that well child adjustment, as measured by
the presence of two or more emotional indicators, would have the same
associations with the parent, family and child variables as listed in
hypothesis 3 for other indicators of well child adjustment.

6) Relationships between several different kinds of measures of well child
adjustment

• Specifically, it was hypothesised that (a) parent rated measures of well
child adjustment using behaviour rating scales, (b) well child self rated
measures of well child adjustment using behaviour rating scales and (c)
projective/expressive measures of well child adjustment in the form of
family drawings would be related. Relationship strength was assessed
using:
- correlations for continuous variables: parent and child rated adjustment using behaviour rating scales

- a MANOVA comparing the categorical independent variable: emotional problems assessed by two or more emotional indicators (yes or no), and the dependent variables: parent rated adjustment and child rated adjustment.
Chapter 6: Methodology

6.1 Participants

Participants were 102 well children, each of whom had a sibling with a chronic illness or disability. These children were from 77 families. One parent from each family (n=77) also participated. In 14 families more than one well child from the same family participated in the study.

The selection criteria for participation were that the well child be aged between 7 and 19 years and have a sibling with a chronic illness or disability. The final sample of well children (51 males and 51 females) had a mean age of 12.3 years (SD=2.7 years). Most children were either first born (51%) or second born (27%).

The parents (69 mothers and 8 fathers) were aged between 30 and 52 years (M=36 years, SD=5.3 years). Most of the parents were well educated with 46% holding a tertiary qualification and 35% having completed secondary education or a trade or a TAFE qualification.

Family size ranged from two to nine children (M=3, SD=2). The majority of families (86%) had 3 children or fewer. Ninety percent of families had both parents living at home, and family income was generally high with 56% having an income of more than $55,000 per annum.

The children with a chronic illness or disability (n = 77) did not participate directly in the research, but were a key aspect of the study. There were 28 females and 49 males, ranging in age from 2-23 years (M=9.9, SD=3.7). All the illnesses and disabilities were chronic (long term) and serious (life threatening and/ or requiring continuous monitoring and care). A wide range of illnesses and disabilities were present in the families and in many cases more than one aspect of the child’s functioning was affected and several, sometimes many, diagnoses were described.
Detail about the nature and severity of the illnesses and disabilities are described in the results section but include cystic fibrosis, diabetes, asthma, epilepsy, cerebral palsy, Duchene’s muscular dystrophy, cancer, Autism spectrum disorders (Aspergers and Autism), Rett syndrome, Wolf Hirschhorn syndrome, Prader-Willi syndrome and Down syndrome.

6.2 Measures

Parents completed three questionnaires: the first contained demographic data and information on family structure and illness characteristics; a second questionnaire was a measure of well child and ill child adjustment (Child Behavior Checklist, Achenbach & Rescorla, 2001); and the final questionnaire was a parent stress measure (Parenting Daily Hassles Scale: Crnic & Greenberg, 1990). The well children completed four measures: firstly a drawing of the family; then a questionnaire containing demographic data and information about their ill sibling, followed by a self rating of adjustment (Revised Children’s Manifest Anxiety Scale: Reynolds & Richmond, 1985 and a modified version of the Child Behavior Checklist – Youth Self Report: Achenbach & Rescorla, 2001) and finally a parenting style measure (Parenting Styles Questionnaire: Lamborn, et. al.). All scales, with the exception of the CBCL (a readily available published test) are included in Appendix A.

6.2.1 Parent Measures

6.2.1.1 Demographic information. Demographic information was obtained using a researcher- designed questionnaire. Information was collected about the whole family (both parents and all children) as well as family access to support and respite and details about the diagnosis and care for the child with a chronic illness or disability.

Parents were asked their age, gender, occupation and their relationship to the ill child (parent, guardian, other). Parents were also asked to identify whether they had
other adult support in the home (single parent/only adult in the home; dual parent/living with a spouse or partner; or living with other adults/relatives, friends or others). Other questions concerned occupation of both parents, the main language spoken at home and postcode of the family residence. Annual family income was indicated by selecting an option ranging from “Up to $15,000” to ”$55,000 and above”. Level of education for mother and father was selected from an option ranging from “primary” to “post graduate qualification”. Information on the structure of the family was provided by questions about the age, gender and living arrangements (living with parents) of all their children, as well as identifying which of the children were participating in the study, and which had a chronic illness or disability.

The parent demographic questionnaire also included several questions about access of the family to support. Parents were asked to describe who they turned to when in need of support or assistance and in which group activities or support programs their well children and ill children participated. Questions about respite included type (e.g., inside or outside the home; regular or occasional care), amount of respite available, frequency used, type of respite providers (e.g., family, friends, charities, support groups, government agencies, etc.) as well as any difficulties associated with accessing or utilising respite.

Parents were also asked to report the amount of time per day the well child spent participating in care activities for the ill child as well as the type of care tasks performed (e.g., getting food or drinks, calming their sibling down when they are upset). In addition, parents were asked whether there had been any major change or events the well child may have been experiencing which might cause significant stress or anxiety (e.g., parent separation, recent bereavement). Questions relating to the chronic illness or disability of the ill child included name and description of condition, age of onset
(e.g., from birth) and whether the ill child attended a school during the day or was cared for at home. Parent’s estimate of the amount of time needed to care for the ill child per day (care time required), was indicated by selecting an option ranging from “less than 1 hour” to “continuous care”.

6.2.1.2 Well child and ill child adjustment. Well child and ill child adjustment were measured by the Child Behavior Checklist (CBCL: Achenbach & Rescorla, 2001). The CBCL is a measure of behavioural maladjustment designed to be completed by a parent, about their child or adolescent aged 6-19 years. It is widely used in research settings because of its demonstrated reliability and validity, ease of administration and applicability in clinical, non clinical and cross cultural populations, and because there is age and gender specific normative data available which enables normative comparisons (Dutra, Campbell, & Western, 2004). The CBCL was used to measure adjustment in both the well child and the ill child by asking the parent to rate the degree to which 113 items described these children now or within the past 6 months. Ratings are made on a 3 point scale, where 0 = “not true as far as you know”; 1 = “somewhat or sometimes true”; and 2 = “very true or often true”. Items describe various behaviours e.g., “Demands a lot of attention” and “Too shy or timid”. Responses are added to provide total scores in eight subscales Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule Breaking Behaviour and Aggressive Behaviour. Achenbach and Rescorla state that the title of each scale summarises the types of problems measured by that subscale. These eight subscales can be further grouped into two domains: Internalising and Externalising Behaviour Problems. Internalising Problems are problems of overcontrol and can be considered more covert. The Internalising Behaviour Scales includes the Anxious/Depressed, Withdrawn/Depressed and Somatic
Complaints subscales. Externalising Problems are more overtly displayed in behaviour and usually involve conflicts with others. Externalising behaviour includes the Rule Breaking Behaviour and Aggressive Behaviour subscales. The three remaining subscales, Social Problems, Thought Problems and Attention Problems, are not grouped into any domain. Population norms are provided for both Internalising and Externalising Behaviours and for each of eight subscales. The problem scales of the CBCL have good internal consistency with Cronbach alpha coefficients ranging between .78 and .97 (Achenbach & Rescorla, 2001). In this study the Cronbach alpha coefficients were satisfactory, ranging from .72 to .90.

6.2.1.3 Parent stress. Parent stress was measured by the Parenting Daily Hassles Scale (PDHS:Crnic & Greenberg, 1990). The PDHS measures routine minor stressors associated with parenting based on the theoretical premise that daily hassles are a more significant predictor of stress than significant life events. The PDHS indicates how frequently and intensely the parent is affected by 20 hassles relating to parenting, using statements describing events that routinely occur in families with young children e.g., “Continually cleaning up messes of toys or food”. Parents are asked to consider each event and rate the frequency (how often it has happened) and intensity (how much of a hassle it felt) over the past few weeks. In rating the frequency and intensity the parents are asked to consider all the children in their family. The intensity scale is rated on a 5 point scale where 1 = “no hassle”; 2 = “small hassle”, 3 = “medium hassle”, 4 = “large hassle”, 5 = “extreme hassle”. An intensity score is produced by adding all the intensity ratings. Possible scores range from 20-100 with low scores indicating the event causes little hassle and a high score indicating a large impact. The frequency scale was adapted from the original PDHS after pilot testing revealed parents required a “never” option (the original ratings range from ‘rarely’ to
constant’). This addition also had the benefit of making the scoring of both the frequency and intensity scales consistent in that both had five options. In this study score ratings for the frequency items ranged from 1 = “never” to 5 = “constantly”. A frequency score was produced by adding all the frequency ratings. Possible scores range from 20-100 with low scores indicating the hassle rarely occurs and high scores indicating frequent occurrence. Internal consistency alphas for the frequency scale range from .80-.89 and for the intensity scale range from .89-.93 (Crnic & Greenberg, 1990). For this study the Cronbach alpha for the frequency scale was .87, and for the intensity scale was .89.

6.2.2 Child Measures

6.2.2.1 Draw a family. Children were presented blank paper and an assortment of pencils and were asked to draw a picture of their family. The instructions were “Here are some pencils and paper. I would like you to draw me a picture of your family. Please draw everyone who is part of your family. Please name them all so I know who they are. For example if you draw your mum in the picture, write “mum” next to your drawing of her.”

The family drawing was administered for several reasons. The first objective was to provide a familiar initial task, which is easy and enjoyable in order to build the child’s confidence in their ability to participate in the study, and to encourage the children to relax and feel more comfortable. The second objective was to provide a vehicle for understanding the children’s perspective of the family structure by allowing the children to draw whoever they considered part of their family, and omit people as they chose. The final objective was to provide another method of assessing children’s adjustment using an adaptation of Koppitz’s method for psychological evaluation of children’s human figure drawings (Koppitz 1968; 1984). The method of assessment is
suitable for children aged between 5 to 14 years of age (81% of the current sample). Koppitz lists 30 emotional indicators which occur frequently in drawings of children with emotional problems when compared to children with no emotional problems. Koppitz found the indicators were not related to age. The 30 emotional indicators are described in relation to five emotional problem areas for children: anxiety, aggression, impulsiveness, insecurity and timidity. The emotional indicators are not considered to be mutually exclusive; one attitude can be expressed in several emotional indicators, so a total score is not produced. A tally of two or more emotional indicators in a drawing is considered to be highly suggestive of emotional problems and unsatisfactory interpersonal relationships. A checklist was developed to assess the number of emotional indicators on each drawing and identify drawings with two or more emotional indicators (Appendix B). In addition to the Koppitz method of child drawing assessment, the drawings were analysed for any unusual themes such as distance between family members and absence of family members. Chapter 9 includes the details of the method used to analyse the drawings, several examples of the drawings and the results of the drawing analyses. This structure is intended to eliminate the need to refer back to the method section for detailed information regarding the drawing assessment.

At the time of the drawing task the children were given a packet of coloured pencils to keep as a thank-you gift for participating in the study. A separate and larger range of coloured pencils, grey-lead pencils and erasers were also provided for use if the children preferred, ensuring the choice of drawing tools was not limited to the gift packet.

6.2.2.2 Demographic information. Demographic information was obtained from children using a questionnaire designed by the researcher. Children were
first asked to report their gender and age. Two questions required information about the
types of activities and amount of time the children spent caring for their ill sibling.
These questions were the same as those included in the parent questionnaire to enable
comparison of child and parent perceptions about well child participation in care.
Children were asked to list the type of things they do to help care for their ill sibling.
Some examples were provided to assist the children understand the requirements (e.g.,
“getting food or drink”). The children were also asked how much time they spent each
day performing these tasks. Options were “None” “Less than one hour”, “1-2 hours”,
“2-3 hours” or “more than 3 hours”. Finally the children were asked to describe the
positive and negative things about having a sibling with a chronic illness, using the
following statement: “Having a sick brother or sister can be difficult, but it can be
special too. What has it been like for you? (What is good and what is bad?)”. A copy
of the child demographic questionnaire is in Appendix A.

6.2.2.3 Well child (self) rated adjustment. Well child (self) rated adjustment,
was measured by the Revised Children’s Manifest Anxiety Scale (RCMAS: Reynolds &
Richmond, 1985) (Appendix A) and a modified Youth Self Report (CBCL YSR:
Achenbach & Rescorla, 2001). The RCMAS is a 37 item instrument designed to assess
anxiety in children and adolescents aged between 6 and 19 years. It was used in this
study as a self rated measure of internalising behaviour. The RCMAS is one of the
most widely used self report inventories of anxiety in children and adolescents (Dadds,
Perrin, & Yule, 1998). Items consist of generally descriptive statements, 28 relate to
anxiety (e.g., “I worry a lot”) and nine relate to social desirability (e.g., “I am always
kind”). Respondents are asked to determine if the item describes them and then to circle
“Yes” (yes = 1) or “No” (no = 0) accordingly. The “Yes” responses are added to provide
a total anxiety score. Scores can also be calculated for three anxiety subscales:
physiological anxiety; worry/oversensitivity and social concerns/concentration.

Physiological anxiety is a measure of the child’s expression of the physical manifestation of anxiety (e.g., “often I feel sick in the stomach”) worry/oversensitivity measures degree to which the child is afraid, nervous or oversensitive to environmental pressures (e.g., “I worry a lot of the time”); social concerns/concentration measures concern in relation to other people or difficulty in concentrating (e.g., “others seem to do things easier than I can”). High scores on the anxiety scale or subscales indicate high levels of anxiety. The Lie subscale is used to determine the effects of social desirability biases on the child in rating their own behaviours (e.g., “I am always good”). High scores on the Lie scale indicates that the child is more likely to be answering according to social desirability biases. The RCMAS has good internal consistency with an alpha coefficient of .83 (Reynolds & Richmond, 1985). In this study the alpha coefficients was .82 for total anxiety and ranged from.65 to .79 for the subscales. The social desirability subscale produced an alpha of .71.

A child rated measure of externalising behaviour was adapted from the YSR (Achenbach & Rescorla, 2001). The complete YSR is designed to assess adaptive functioning in adolescents aged between 11 and 18 years using self report. The YSR consisted of too many items for the comprehension and concentration limitations of the younger children, given the number of other items they were asked to complete. In addition, as the measure was being completed by some children under 11 years of age, some of the aggression items were considered too confrontational for the purposes of this research (e.g., “I threaten to hurt people”). To shorten the questionnaire, six items were chosen based on the factor loadings provided in the manual from data on 2,581 adolescents. The six items with the highest factor analysis were considered too confrontational so the next six items with the highest factor loadings on aggression were
chosen. The six acceptable items with the highest factors loadings, and the six rejected and factor loadings are presented in Appendix C. The six aggression questions were randomly placed amongst the 37 RCMAS questions making a final child behaviour questionnaire of 43 questions. The YSR is normally scored on a 3 point scale where 0 = “not true as far as you know”; 1 = “somewhat or sometimes true” and 2 = “very true or often true”, however to ensure the questionnaire was simple for children and the aggression questions were not obviously different, the scoring system for the RCMAS (“yes” or “no”) was applied to the YSR aggression questions. For scoring purposes a “yes” response for an aggression question was scored according to the YSR “1” response (“very often or often true”) and a response of “no” was scored as 0 (“not true as far as you know”). The YSR aggression scale has good internal consistency with an alpha coefficient of .95 (Achenbach & Rescorla, 2001). In this study the alpha for the aggressive behaviour scale was lower, but satisfactory for research purposes, at .64.

6.2.2.4 Parenting Style. Parenting Style was measured using an unpublished, scaled-down version of the Parenting Styles Questionnaire (PSQ: Lamborn, et al.). The PSQ is a child rated measure of parenting style based the model of parenting style originally proposed by Baumrind (1971) and further developed by Maccoby and Martin (1983). The original PSQ, and the unpublished scaled-down version, both measure levels of warm involvement, psychological autonomy granting and behavioural control displayed by parents as perceived by children. A comparison of the original PSQ and the unpublished version used in this study reveals several improvements in the unpublished version for the purposes of this research. The unpublished version is more suitable to the reading age of younger children; the number of items is reduced by replacing questions specific for ‘mother” and “father” with a general term ‘parents’, the wording has changed from a mix of statements and questions in the original to all
statements in the unpublished version, and the response options have been standardised making responding easier and expectations clearer for the respondent. The differences in the two versions of the scale are presented in Appendix D.

The PSQ consists of 26 items and children are asked to relate the items to the parent(s) with whom they live. If they live between more than one home, they are asked to answer in relation to the parent they spend most time with. The first 18 questions comprise the warm involvement and psychological autonomy granting scales scored on a four point Likert scale where 4 = “strongly agree”, 3 = “somewhat agree”, 2 = “somewhat disagree” and 1 = “strongly disagree”. The nine even numbered items comprise the Warm Involvement scale which measures the degree to which the child perceives their parent(s) as loving, responsive and involved (e.g., “I can count on my parents to help me out if I have some kind of problem”). The nine odd numbered items comprise the Psychological Autonomy Granting Subscale which measures the extent to which the child perceives parents as democratic and non-coercive in their discipline. Eight of the nine items are reverse scored (e.g., “My parents tell me that their ideas are correct and that I should not question them”). High scores indicate parents who are perceived as democratic and encouraging of the child to express individuality within the family. The remaining eight items comprise the behavioural control scale. This scale measures the amount of parental monitoring and supervision. The scale consists of four questions: two items require the child to identify how late they are allowed to stay out at nights, rated on a 7-point scale and two items relate to the child’s perception of how much the parents TRY to know, and how much they DO know, what their children do. Children are asked to identify how much their parents try to know a) where they go to at night, b) what they do with their free time and c) where they are, most afternoons after school. Response are rated on a 3 point scale “Don’t try”, “Try a little” and “Try a
lot”. Children are then asked to rate how much their parents really do know about the same three events (a) where they go to at night, b) what they do with their free time and c) where they are most afternoons after school. Responses are rated on a 3 point scale “Don’t know” “Know a little” and “Know a lot”. The original parenting styles questionnaire reported alpha coefficients of .72 for warm involvement, .82 for psychological autonomy granting and .71 for behavioural control (Steinberg, Darling & Fletcher, 1995). For this study, warm involvement alpha = .64, psychological autonomy granting alpha = .60 and behavioural control alpha = .37. Due to the unacceptably low alpha for the behavioural control scale, analyses using this scale must be treated with caution.

Steinberg et al. (1994) provides two methods of categorising parenting style from scores on the PSQ. The first method uses only the warm involvement and behavioural control scales by dividing scores at median to form four groups: authoritarian (low warm involvement and high behavioural control), authoritative (high warm involvement and high behavioural control), neglectful (low warm involvement and low behavioural control) and indulgent (high warm involvement and low behavioural control).

In the second method, all three subscales are divided at their respective medians (Steinberg, 1992). A score of “1” is assigned to low scores, and “2” is assigned to high scores. Parents with three high scores are categorised as most authoritative, two high scores are categorised as moderately authoritative, one high score is categorised as somewhat authoritative, and no high scores are not at all authoritative. These four groups are different, but overlap, with the four categories produced using method one. Both methods for determining parenting style were used in this research. Table 1 presents a summary description of the all the instruments used in this study.
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<thead>
<tr>
<th>Variable</th>
<th>Instrument</th>
<th>Description</th>
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<td><strong>Child variables</strong></td>
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<tr>
<td>Well child demographics</td>
<td>Researcher generated</td>
<td>Well child age, Well child participation in social activities, Parent rating and well child rating of time well child spends caring for ill child, amount of time required to care for ill child, ill child participation in social activities</td>
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<tr>
<td>Illness/Disability Factors</td>
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<td><strong>Parent variables</strong></td>
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<td>Parenting Stress</td>
<td>Parenting Daily Hassles Scale (Crnic &amp; Greenberg, 1990).</td>
<td>Intensity and frequency of parenting daily hassles specifically related to child behaviours and parenting tasks.</td>
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<td>Parenting Style</td>
<td>Parenting Styles Questionnaire (unpublished version of the PSQ: Lamborn, Mounts, Steinberg, &amp; Dornbusch, 1991)</td>
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<td>Parent factors</td>
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<td><strong>Family Variables</strong></td>
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<tr>
<td>Family Factors</td>
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<tr>
<td>Child Attribution</td>
<td>Researcher generated open ended question</td>
<td>Children described the positive and negative aspects of having a sibling with a chronic illness, in response to an open ended question. Total perceived consequences score was calculated by subtracting the negative responses from the positive responses.</td>
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Approval to conduct this research was granted by the Swinburne University of Technology Human Research Ethics Committee. The research was funded by a grant from the Australian Research Council with initial assistance in the first year from Carenet, a Victorian organisation providing support to siblings of children with a chronic illness.

6.3 Procedure

A consultation phase was undertaken prior to recruitment. The aim of the consultation phase was to understand the issues for siblings of children with chronic illness and disabilities in Australia, and identify what type of information would be useful to children, families and service providers. The consultation phase involved conferring with Victorian experts and service providers in the areas of chronic illness, disability issues and sibling support services. The organisations participating in the consultation phase were Siblings Australia Inc (www.siblingsaustralia.org.au), Association for Children with a Disability (www.acd.org.au) and Very Special Kids (www.vsk.org.au)

The information gathered from the consultation phase was used to inform development of the questionnaires. Pilot administrations were conducted to trial the procedure, the relevance of the questions for children. Results of the pilot phase were presented to the consultation groups for review before the main study commenced.

It became clear during the consultation phase that it would be difficult to obtain participation from families with an ill child, as these families are already pressured in terms of time as well as emotionally and financially. To ensure maximum possibility of obtaining a large and broad sample while still meeting ethical and privacy considerations, participants were recruited by engaging a variety of organisations and encouraging them to take an active role in recruiting for the study. Organisations were
contacted by phone and in most cases an appointment was made for a personal visit to explain the project and gain support. Where possible, organisations were asked to contact their clients and collect a list of volunteers. Where this was not possible, organisations mailed out information about the project, or advertised in newsletters or on websites. Potential participants could then contact the researcher directly, or indicate to their organisation that they were prepared to be involved and provide a phone number to the researcher. Child friendly flyers, developed in conjunction with the Association for Children with a Disability, were provided to organisations to distribute to families (Appendix E).

When names and contact numbers of potential volunteer participants were provided, the researcher contacted each family and arranged participation either by personal visit or mail. Personal visits were encouraged wherever possible, especially in cases where the well child to be assessed was younger than 10 years. Where parents were not comfortable with (or did not require) a personal visit, or where geographical distance was prohibitive, the questionnaires were mailed out. In these cases, telephone support for filling out the questionnaires was available from the researcher, if required.

For a personal visit ($n=26$) a personalized letter was provided containing details of the study (Appendix E). The researcher explained and discussed the contents of the letter with parents and children and consent forms were signed prior to administering the questionnaire. To reduce any parental influence on children’s responses, parents were asked to complete the questionnaires in a separate room from the children. Children were instructed to read the first few questions aloud and answer the questions to ascertain their reading and comprehension ability. The children were then instructed to continue answering all the questions and ask for assistance if they encountered problems. Where reading ability was clearly not adequate, the researcher read the
questions to the child and ensured they marked the response relevant to their verbal answer.

For mail administration ($n=76$) a personalized letter containing details of the study, consent forms, questionnaires, coloured pencils and a checklist for documents to return was mailed along with a postage paid self addressed envelope for return to the researcher (Appendix E). Explanations were provided to parents about the importance of not influencing, directly or indirectly, the responses of their children and parents were requested to remove themselves from the room when the child was completing their questionnaires in order to minimise possible parental influence. Parents were also requested to respect the confidentiality of the child’s responses by not reading the completed questionnaires and to discuss these safeguards with their children prior to completing the questionnaires. Contact details of the researcher were provided and participants were encouraged to contact the researcher if assistance was required by either the child or the parent. Participants were assured of confidentiality and that none of their individual details would be identifiable, only group data would be reported.

At 12 months after the first wave of data collection a letter was sent to all the children who had already participated. The purpose was to provide some information on the progress of the project, to remind participants who had not already done so to return completed questionnaires by a nominated closing date, and to request families to pass on information to friends in an effort to recruit more families (Appendix E). On completion of the study, a summary of findings was sent to all participants and organizations involved in the project (Appendix E).

A total of 112 organisations were approached to recruit participants for the study (33 advocacy or support groups for chronic illness and disabilities and 79 Victorian special developmental schools). Response rates were as follows.
Thirty three chronic illness or disability organisations were approached to recruit participants. A total of 17 (52%) agreed to participate in a variety of different ways.

Four organisations agreed to personally invite participants through the organisation support workers. This was the most effective method of recruitment, with 28 families recruited. Thirteen organisations agreed to advertise the project either in newsletters, via the organisation website or by making the project flyers available to families. Three families were recruited using this method. Reasons for organizations refusing to participate included being too busy and not wanting to impose on families.

All 79 Victorian special developmental schools listed on the Victorian Department of Education and Training website were approached. Thirteen participated in the project (16%) by advertising the project to parents in the school newsletter. A total of 24 families responded, of these 20 returned completed forms.

A further 24 families contacted the researcher directly via email or phone and did not indicate how they were informed about the project. Three families were personally known to the researcher and two families were informed by friends who had already participated. Individual details of the contact organisations and response rates are provided in Appendix F.

Response rates from some sources such as websites and newsletter advertisements could not be ascertained. From the sources for which data was available it is possible to say that of the 99 families who agreed to respond, 77 actually returned completed questionnaires (78%).

6.4 Analyses

The following analyses were conducted to test the aims and hypotheses. First descriptive data was analysed using means, standard deviations and frequencies. These data provide a description of the social, family and personal characteristics of the well
children and their families including well child participation in care for the ill child, family access to social support and access to, and use of respite facilities. Included in the initial descriptive investigation was an analysis of the data relating to well child adjustment in comparison to age and gender specific population norms. For this analysis, assessment of child adjustment was restricted to measures with published population norms (CBCL for parent rated child adjustment and RCMAS for child rated adjustment). Ill child adjustment was also compared to population norms although this did not form part of any hypotheses. The descriptive data, including comparison to norms, are presented in Chapter 7.

Next, an analysis of the associations and predictions of well child adjustment from family, parent and child variables were explored. Correlations and regressions were used for the continuous measures of well child adjustment (parent rated and child rated behaviour scales). A MANOVA was used for the child family drawing data, it being a categorical measure of well child adjustment (emotional problems, or no emotional problems). Child variables included parent rated measures of ill child behaviour, amount of care time required, ill child participation in social activities, parent and well child ratings of the amount of time the well child spent caring for the ill child, well child age and well child participation in social activities. Parent variables were parenting stress (intensity and frequency), parenting style (psychological autonomy granting and warm involvement as continuous measures), mother’s education and parental access to support. Parenting style was also analysed using two methods of categorising the styles, as described previously. Family variables were number of children in family, family income, respite hours utilised per week and number of respite options available. Associations and predictions for the parent and child rated
behaviour ratings scale measures are presented in Chapter 8, and for the projective/expressive measures of child adjustment, Chapter 9.

A correlation was used to analyse the relationships between the well child’s attitude to their sibling with a chronic illness or disability, and well child adjustment (parent and child rated behaviour problems). These analyses are also presented in Chapter 9.

Finally the relationships between all three measures of well child adjustment were examined. Correlations were used to analyse the continuous measures (parent rated and child rated behaviour scales) and a MANOVA was used for the child family drawing data. The comparisons of the different measures of well child adjustment are presented in Chapter 10. A brief summary of the results is presented in Chapter 11.
Chapter 7: Description of Social, Family and Child Characteristics

7.1 Overview

This chapter presents the results of the descriptive data relating to the social, family and personal characteristics of a group of well children with siblings who have a chronic illness or disability including comparisons of well child adjustment with population norms. Relationships and predictions of well child adjustment from ill child, family and parenting variables are reported in Chapter 8. Results from the projective/expressive measures of well child adjustment (child family drawings) are presented in chapter 9, along with relationships between the well child’s adjustment, and their attitude toward their ill sibling. SPSS version 13 was used to analyse the data. Data were examined for accuracy of data entry, and examined for missing values.

7.2 Missing Values

Overall there were very few missing values with the exception of the following items. In the demographic questionnaires, the only missing variables were parent age (n=26) and family income (n = 2) where some participants had elected not to provide that information. Missing data for family income was replaced with the mid rating (3.5). Missing values for parent age were not replaced. In the CBCL, there were two cases where parents had not completed the behaviour questionnaires for the sibling with a chronic illness or disability. These cases were excluded from analysis of ill-child behaviour subscales.

In the child self report questionnaire, some children appeared to find it difficult to respond to the dichotomous “yes” or “no” question and added their own response “sometimes”. This response was recoded into a “yes” or “no” response according to the wording of the question. e.g., a response of “sometimes” to the question “I am always kind” was recoded to “no”, because if a child describes themselves as “sometimes”
kind, they are only kind sometimes, not always. A response of “sometimes” to the question “I worry about what my parents will say to me” was recoded to a “yes” because even worrying sometimes is worrying.

7.3 Management of Data

Reliability of scales and sub-scales was assessed using Cronbach’s alpha. All scales produced adequate reliability indices of >.60, except behavioural control which was subsequently used as the basis for a categorical variable (high and low behavioural control). Each scale met the assumptions for skewness and kurtosis (less than ±3) with the exception of the Rule Breaking Behaviour subscale of the CBCL. This was the case for both the well child (kurtosis = 13.3), and the ill child (kurtosis = 21.8). The Rule Breaking Behaviour variable was examined for extreme outliers. For the well child, two extreme outliers (15 and 24) were pegged back to the highest non-outlying score (8) and for the ill child one extreme outlier (23) was pegged back to the highest non-outlying score (10). These procedures reduced the kurtosis of these scales to .6 and .3 respectively. The means, standard deviations, and alphas for all scale variables are presented in Tables 14 and 15. The skew and kurtosis for these variables are shown in Appendix G.

7.4 Descriptive Data

7.4.1 Summary of Participants

Table 2 gives a summary of the number of participant parents and well children, as well as the number of families with more than one ill child and more than one well child.
Table 2

Summary of the number of participant families, parents and well children

<table>
<thead>
<tr>
<th></th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well children participating</td>
<td>102</td>
</tr>
<tr>
<td>Parents</td>
<td>77</td>
</tr>
<tr>
<td>Families</td>
<td>77</td>
</tr>
<tr>
<td>Ill children</td>
<td>77</td>
</tr>
<tr>
<td>Families where more than 1 well child participated</td>
<td>14</td>
</tr>
</tbody>
</table>

7.4.2 Demographics of Well Children

Well children comprised 102 children (51 females and 51 males) who had a sibling with a chronic illness or disability. The well children ages ranged from 7 – 19 years ($M=12.3$, $SD=2.7$). Seventy-nine percent of well children were younger than the ill child in the family.

7.4.3 Demographics of Children With a Chronic Illness or Disability

Data were also collected on the ill children in the family. These were 77 children (28 females and 49 males) with a chronic illness or disability. As these children did not participate directly in the research this data was collected from the parents. The ill children ages ranged from 2-23 years ($M=9.9$, $SD=3.7$). The age range of ill children is greater than for the well children because there were no participation criteria limiting the possible age of the ill children.

There were 10 families who had more than 1 child with a chronic illness or disability (nine families had two ill children and one family had three). In these cases, data were collected for all children and the child with most severe illness or disability (according to illness/disability information collected from parents) was included in the analysis.

7.4.4 Demographics and Socio-Economic Status of Family

Table 3 shows the demographic and socio-economic information collected from the 77 families who participated in the study. Mothers’ ages ranged from 31-50 years.
(\(M=41.4, SD=4.3\)). Fathers’ ages ranged from 30-66 years (\(M=42.7, SD=6.1\)). In most cases it was the mother who participated although this was not stipulated by the selection criteria.

The education level of both parents in this sample was very high; more than half of the mothers and fathers indicated they had completed secondary or tertiary education. Family income was also relatively high in this sample; most families having a combined income of over $55,000 per annum. A low percentage (10\%) of single parent families participated in the research (N=8).

Table 3

Demographic information for parents

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents participating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers</td>
<td>90</td>
<td>69</td>
</tr>
<tr>
<td>Fathers</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Mother Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete secondary</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Complete secondary/trade/TAFE</td>
<td>35</td>
<td>27</td>
</tr>
<tr>
<td>Tertiary</td>
<td>48</td>
<td>37</td>
</tr>
<tr>
<td>Father Education*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete secondary</td>
<td>22</td>
<td>15</td>
</tr>
<tr>
<td>Complete secondary/trade/TAFE</td>
<td>35</td>
<td>24</td>
</tr>
<tr>
<td>Tertiary</td>
<td>43</td>
<td>30</td>
</tr>
<tr>
<td>Family Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dual parent families</td>
<td>90</td>
<td>69</td>
</tr>
<tr>
<td>Single parent families</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Primary Language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English primary language</td>
<td>99</td>
<td>76</td>
</tr>
<tr>
<td>Family Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$15,000 per annum</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>$15,000-$35,000 per annum</td>
<td>17.3</td>
<td>13</td>
</tr>
<tr>
<td>$35,000-$55,000 per annum</td>
<td>20</td>
<td>15</td>
</tr>
<tr>
<td>&gt;$55,000 per annum</td>
<td>56</td>
<td>42</td>
</tr>
</tbody>
</table>

N=77

NOTE: *n= 69 for father data because in 8 cases there was no father in the family unit
7.4.5 Medical Diagnoses and Functionality of Ill Children

Parents provided detailed information on the illness and disability conditions. A wide range of illness and disabilities were present in the families and in many cases more than one aspect of the child’s functioning was affected and several, sometimes many, diagnoses were described. Illnesses and disabilities were categorised according to the aspect of functioning affected. Table 4 shows the types of chronic illness or disabilities categorised by aspect of functioning affected.

Table 4
Classification of illness types for children with a chronic illness or disability

<table>
<thead>
<tr>
<th>Chronic illness / disability manifestations</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical impediment</td>
<td>15.6</td>
<td>12</td>
</tr>
<tr>
<td>Intellectual disability /developmental delay</td>
<td>64.9</td>
<td>50</td>
</tr>
<tr>
<td>Physical condition and intellectual disability/developmental delay</td>
<td>19.5</td>
<td>15</td>
</tr>
</tbody>
</table>

N=77

The physical impediment category included those illnesses and disabilities where physical symptoms were evident but there was no apparent reduction in intellectual development such as cystic fibrosis, diabetes, asthma, epilepsy (where there is no other associated diagnoses such as cerebral palsy), Duchenne’s muscular dystrophy and cancer.

The intellectual disability/developmental delay category included those illness and disabilities where intellectual functioning was impeded, but there was no impact on the child’s physical development such as Autism spectrum disorders (Aspergers and Autism), and non-specific intellectual disabilities.

The physical disability combined with intellectual disability/developmental delay category included cases where both intellectual and physical development was
impeded such as cerebral palsy, Rett syndrome, Wolf Hirschhorn syndrome, Prader-Willi syndrome and Down syndrome. More ill children had a chronic illness or disability that resulted in an intellectual disability only (no impact on physical development) than the other categories.

7.4.6 Care Implications for Chronic Illness and Disabilities

Parents provided information on the age of onset of illness, amount of care time required and daily activity for the children with a chronic illness or disability. Table 5 shows these data. All illnesses were long term, required significant care and could not be permanently cured by current medical treatment.

<table>
<thead>
<tr>
<th>Illness characteristics of children with a chronic illness or disability</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of onset</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 year old or younger</td>
<td>96</td>
<td>74</td>
</tr>
<tr>
<td>Older than 1 year</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td><strong>Care time required per day</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 hour</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>1-3 hours</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>3-5 hours</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>&gt;5 hours</td>
<td>70</td>
<td>53</td>
</tr>
<tr>
<td><strong>Daily activity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>School</td>
<td>86</td>
<td>66</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>5</td>
</tr>
</tbody>
</table>

N=77

Nearly all of the children had an age of onset of less than one year (96%). Two children with diabetes had been diagnosed at aged five and seven, and one child with asthma was diagnosed at age two. Most children required more than five hours care per day (70%) and most attended school (86%). Activities for the 6% of ill children who were reported as participating in “other” activities (i.e., doing something other than school or home through the day) either attended preschool, or facilities appropriate for
young adults past school age. All of the children at home during the day were of preschool age or younger.

7.4.7 Well Child Participation in Care for Ill Child

Data were collected on the amount of time the well child spent caring for their ill sibling, and the type of care activities performed by the well child. Parents and well children were both asked to rate the well child’s care time and type of care activity. This allowed for comparison of the parents’ and well children’s perception of how much time the well child spends, and what the well child does to care for their ill sibling. Table 6 shows parent ratings and well child self ratings of the amount of time the well child spent caring.

Table 6

Parent ratings and well child self ratings of the amount of time per day the well child spent caring for ill child

<table>
<thead>
<tr>
<th></th>
<th>Parent rating</th>
<th>Well child rating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Less than 1 hour</td>
<td>53.9</td>
<td>55</td>
</tr>
<tr>
<td>1-3 hours</td>
<td>38.2</td>
<td>39</td>
</tr>
<tr>
<td>3-5 hours</td>
<td>7.8</td>
<td>8</td>
</tr>
</tbody>
</table>

N=102

NOTE: N=102 well children; n= 77 parent ratings of all 102 well children

Parents generally rated their well children as spending more time caring for the ill child compared to the amount of time the well children reported spending on care tasks. The most frequently reported care time category was less than one hour, this was the same for both parents ratings and well children ratings. However, a number of parents reported well children spending up to 5 hours per day, while no well children reported spending more than 3 hours per day in care tasks for their ill sibling.
7.4.8 Type of Care Tasks Performed by Well Children

Both the well children and the parents were asked to give examples of the types of tasks performed to assist in the care of their sibling with a chronic illness or disability. The task descriptions were evaluated and categorised into the following categories. “Personal or medical needs” describes tasks which provide for the personal needs of the ill child. Examples include “getting food or drink, dressing, bathing, brushing hair and teeth or getting medicine”. “Calming” includes actions to console the ill child such as “Calm him down when upset, when ... is crying I ask her what is wrong, I help .... stop crying.” “Housework” includes tasks to help with domestic chores and ease the work load on the parents, for example “helping to make the bed”, “fold up rugs”, “cleaning their room”, and “helping to vacuum”. “Supervise, Entertain or Play” includes activities which occupy the ill child such as “keeping an eye on her, do music for her, read stories, helping him with colouring activities, games or puzzles”. “Teaching” involves instructing the ill child such as “teaching him to do things, try to teach her new games and educational things”. “Being adaptable” includes actions that make things easier for the parents by not causing a fuss such as “fitting in with daily routines, shares property (even if he does not want to), has to miss out on time sometimes when we have to watch”.

The number of well children and parents who described tasks in each category was counted and percentages calculated. Table 7 displays the number and percent of parents and well children who described care tasks in each category.
Table 7

Frequency of parent and well child descriptions of well child participation in care task categories

<table>
<thead>
<tr>
<th></th>
<th>Well child self ratings</th>
<th>Parent ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Personal or medical needs</td>
<td>84.3</td>
<td>86</td>
</tr>
<tr>
<td>Calming</td>
<td>47</td>
<td>48</td>
</tr>
<tr>
<td>Housework</td>
<td>21.6</td>
<td>22</td>
</tr>
<tr>
<td>Supervise, Entertain or Play</td>
<td>91.2</td>
<td>93</td>
</tr>
<tr>
<td>Teaching</td>
<td>42.2</td>
<td>43</td>
</tr>
<tr>
<td>Being adaptable</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Nothing</td>
<td>2.9</td>
<td>3</td>
</tr>
</tbody>
</table>

N=102

NOTE: 102 well children self rated and 77 parents rated all 102 well children

Nearly all well children reported assisting in the care of their sibling with a chronic illness or disability by either supervising, entertaining or playing. Attending to personal or medical needs was also very commonly described. A few children stated they did nothing to assist.

The most common care tasks parents reported their well children performing were attending to medical or personal needs or supervising the child with a chronic illness or disability. Some parents mentioned tasks that fitted into the category of being adaptable such as “my child with the disability is moody and aggressive. My daughter did whatever he wanted to do. Played games he wanted and didn’t complain about him hitting her and she never fought back”. Parents considered this type of behaviour as assisting in the care of the child with a chronic illness or disability. In contrast, the well children did not indicate this type of behaviour as one they engaged in. All the activities reported by children were practical and task oriented. No child reported an activity that could be classified as being adaptable when reporting tasks that assisted in the care of their ill sibling.
7.4.9 Respite Access and Utilisation

Parents were asked to provide information on the amount of respite the families were able to access, who provided the respite and any problems associated with using respite services. Table 8 shows the amount of respite utilised by families.

Table 8
Respite utilised by families

<table>
<thead>
<tr>
<th>Access to respite</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular access to respite</td>
<td>75</td>
<td>58</td>
</tr>
<tr>
<td>Occasional access to respite</td>
<td>71</td>
<td>55</td>
</tr>
<tr>
<td>Number of respite options available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td>57</td>
<td>44</td>
</tr>
<tr>
<td>2</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>3 or 4</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>Amount of respite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours respite per week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respite</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>1-2 hours</td>
<td>60</td>
<td>46</td>
</tr>
<tr>
<td>3-6 hours</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td>more than 6 hours</td>
<td>9</td>
<td>7</td>
</tr>
</tbody>
</table>

n=77

Families reported having between zero and four respite options \(M=1.3, \ SD=0.9\) available to them and using between zero and 14 hours respite \(M=2.6, \ SD=3.2\) per week. It was most common for families to have only one respite option, and to use it for two hours per week or less.

Parents were asked to describe any problems with respite. Twenty one parents did not respond and 12 parents reported benefit from respite for example “It’s a lifesaver. I really appreciate it”.

Respite problems were categorised into three groups. “Guilt and worry” relates to problems with the experience of guilt at leaving the child in respite, or worry about
how the child would cope for example, “Can they care for her as well as we do? Because she is non verbal will they understand the signs?” This category also included problems where the ill child experienced worry over respite, for example, “child with a disability doesn’t like separating and not good staying overnight”.

“Quality or consistency of care” relates to problems with the previous experience of poor quality or inconsistent care in the past, for example, “I have problems with my child coming home sick from respite house over some weekends, also the lack of understanding of my child from some carers”.

“Availability” refers to problems with the lack of availability, suitable times or funding to utilise resources for example “CRU is 45 mins away therefore I travel 3 hours to drop off and pick up for 48 hours break. I do this to get her used to CRU life for future. Cost subsidized but still an added expense”. Table 9 displays the respite problems described by the parents (n=56) who reported these.

Table 9
Percentages of parents who reported experiencing problems with respite in categorised into three types

<table>
<thead>
<tr>
<th>Category</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt and Worry</td>
<td>15.6</td>
<td>12</td>
</tr>
<tr>
<td>Quality and Consistency of Care</td>
<td>19.5</td>
<td>15</td>
</tr>
<tr>
<td>Availability</td>
<td>36.3</td>
<td>28</td>
</tr>
<tr>
<td>No Problems</td>
<td>15.6</td>
<td>12</td>
</tr>
<tr>
<td>Did not respond</td>
<td>13</td>
<td>10</td>
</tr>
</tbody>
</table>

n=77

Availability was the main problem with respite reported. Some described exploring several options and still not being able to find respite that met the exceptional needs of the family “govt (sic) agencies do not cater for her very high medical needs. Council just cut all flexible respite. Interchange family unable to care due to high needs.
following surgery”. Many expressed concerns about availability when their child reaches 18 years “Just not enough. Worried about what happens when child turns 18”.

7.4.10 Social Support for Parents

Types of social support reported by parents were categorised into family, friends, support groups, medical and specialist support (including doctors, case workers and counsellors) and other. Table 10 reports number of social supports used by parents.

Table 10

Reported number of social supports used by parents

<table>
<thead>
<tr>
<th>Number of supports used by parents</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3.9</td>
<td>3</td>
</tr>
<tr>
<td>1</td>
<td>14.3</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>28.6</td>
<td>22</td>
</tr>
<tr>
<td>3</td>
<td>33.8</td>
<td>26</td>
</tr>
<tr>
<td>4</td>
<td>5.2</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>3.9</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>10.4</td>
<td>8</td>
</tr>
</tbody>
</table>

n=77

Parents reported using between zero and six social supports ($M=2.8, SD=1.5$).

Most parents reported using three types of social support (33.8%) and three parents reported receiving no support at all. The most commonly utilised type of support was friends. Table 11 shows frequencies of social support in each category.
Table 11

*Frequencies for utilisation of social support by parents.*

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friends</td>
<td>79.2</td>
<td>61</td>
</tr>
<tr>
<td>Family</td>
<td>50.7</td>
<td>39</td>
</tr>
<tr>
<td>Support groups</td>
<td>29.9</td>
<td>23</td>
</tr>
<tr>
<td>Medical services</td>
<td>42.9</td>
<td>33</td>
</tr>
<tr>
<td>Support from other</td>
<td>18.2</td>
<td>14</td>
</tr>
</tbody>
</table>

n=77

Note: (most parents reported using more than one support, so percentages do not add up to 100)

7.4.11 *Social Outlets and Support Networks for Ill and Well Children*

Parents reported the number and type of social outlets for each of the ill and well children. Parents reported well children used between zero and six social supports ($M=1.5$, $SD=1.5$). There were 33 children (32.4%) who had no social supports and 30 children (30.4%) had only one support. Parents reported ill children using between zero and five social supports ($M=0.9$, $SD=1.1$) with 36% of ill children having no social outlets. Table 12 presents the number of social outlets used by well and ill children.

Table 12

*Reported number of social outlets used by well and ill children*

| Number of supports | Ill children | | Well children | |
|--------------------|--------------| |---------------|------|
| 0                  | 49.3 38      | | 32.4 33      | |
| 1                  | 23.4 18      | | 30.4 31      | |
| 2                  | 18.2 14      | | 12.7 13      | |
| 3                  | 6.5 5        | | 12.7 13      | |
| 4                  | 1.3 1        | | 7.8 8        | |
| 5                  | 1.3 1        | | 2.9 3        | |
| 6                  | 0 0          | | 1.0 1        | |

**NOTE: N=102 well children and 77 ill children**

Types of social outlet were sorted into five categories: sporting activities, social clubs (e.g., Scouts and Guides), art (e.g., music/drama/dance) activities, other activities and circumstance-specific support groups. Circumstance-specific groups included all groups that only related to illness. For the ill children, this category included activities
such as speech therapy groups or respite in group settings. For the well children this included activities specifically for children with an ill sibling such as sibling groups (regular activities specifically for siblings of ill children) or sibling camps. The most common types of support used by ill children and by well children were illness specific activities. Ill children mostly attended groups related to their illness and well children most commonly attended sibling specific groups. Table 13 presents the type of social outlets used by well and ill children.

<table>
<thead>
<tr>
<th></th>
<th>Ill children</th>
<th></th>
<th>Well children</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Circumstance specific *</td>
<td>26</td>
<td>20</td>
<td>36.3</td>
<td>37</td>
</tr>
<tr>
<td>Sport groups</td>
<td>18.2</td>
<td>14</td>
<td>35.3</td>
<td>36</td>
</tr>
<tr>
<td>Art groups</td>
<td>0</td>
<td>0</td>
<td>19.6</td>
<td>20</td>
</tr>
<tr>
<td>Social groups</td>
<td>24.7</td>
<td>19</td>
<td>12.7</td>
<td>13</td>
</tr>
<tr>
<td>Other groups</td>
<td>0</td>
<td>0</td>
<td>3.0</td>
<td>3</td>
</tr>
<tr>
<td>No groups</td>
<td>49.3</td>
<td>38</td>
<td>32.4</td>
<td>33</td>
</tr>
</tbody>
</table>

Note: N=102 well children and 77 ill children (some children attended more than one activity)
* circumstance specific category includes sibling groups or illness specific groups

7.5 Parent Rated Well and Ill Child Adjustment

Parents completed adjustment measures for their well child and for their ill child. These results were analysed in several ways as follows. Parent rated ill child and well child adjustment were rated using the CBCL (Achenbach & Rescorla, 2001). Norms for each of the eight child behaviour subscales from the CBCL (Aggressive Behaviour, Rule Breaking Behaviour, Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Attention Problems, Social Problems and Thought Problems), specific for age and gender, were compared with the scores from the parent rated data. The CBCL also provides age and gender specific norms for two syndrome scales
Externalising Behaviour (comprising the Aggressive Behaviour and Rule Breaking Behaviour subscales) and Internalising Behaviour (comprising the Anxious/Depressed, Withdrawn/Depressed and Somatic Complaints subscales). Parent rated scores and population norms were also compared for both of these syndrome scales. Twelve of the ill children were outside the age range and normative data was not available. Data from these children were omitted from the comparison with norms. The 18 year old norms were applied to the children who were aged over 18 years (n=4). One family submitted an incomplete CBCL for the ill child and these data were also omitted. A total of 100 well children and 62 ill children were included in the normative comparisons of parent rated measures of adjustment. Table 14 presents the means, standard deviations and alpha reliability for the key parent rated well and ill child adjustment variables compared to the population norms.

7.6 Well Child (Self) Rated Adjustment

Well child self rated adjustment was measured using the RCMAS (Reynolds & Richmond, 2000) and selected aggression items from the YSR (Achenbach & Rescorla, 2001). The RCMAS provided a measure of anxiety (internalising) behaviour. Age and gender specific norms are provided for each of the three subscales physiological anxiety, worry/oversensitivity and social concerns as well as the total anxiety score and a social desirability (lie) score. All of the well children were within the age range for the RCMAS (5-19 years). As only six selected aggression items from the YSR were used, and the scoring scale was adjusted to suit the current study, comparison with population norms was not possible. Table 15 presents the means, standard deviations and alpha reliability for the well child self rated adjustment variables from the RCMAS compared to the population norms.
Table 14

*Alpha Reliability, Means, Standard Deviations of Parent Rated Well Child and Parent Rated Ill Child Adjustment Variables Compared With Population Means and Standard Deviations*

<table>
<thead>
<tr>
<th></th>
<th>Current Study</th>
<th>Population Norm1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Range</td>
</tr>
<tr>
<td>Parent report of well child adjustment (CBCL)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aggressive Behaviour</td>
<td>6.0</td>
<td>0-28</td>
</tr>
<tr>
<td>Rule Breaking Behaviour</td>
<td>2.2</td>
<td>0-8</td>
</tr>
<tr>
<td>Total Externalising Behaviour</td>
<td>8.3</td>
<td>0-36</td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>4.7</td>
<td>0-16</td>
</tr>
<tr>
<td>Withdrawn/Depressed</td>
<td>2.2</td>
<td>0-19</td>
</tr>
<tr>
<td>Somatic Complaints</td>
<td>3.1</td>
<td>0-12</td>
</tr>
<tr>
<td>Total Internalising Behaviour</td>
<td>10.0</td>
<td>0-29</td>
</tr>
<tr>
<td>Attention Problems</td>
<td>3.4</td>
<td>0-14</td>
</tr>
<tr>
<td>Social Problems</td>
<td>3.4</td>
<td>0-17</td>
</tr>
<tr>
<td>Thought Problems</td>
<td>3.2</td>
<td>0-18</td>
</tr>
<tr>
<td>N=102</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Parent report of ill child adjustment (CBCL) |      |       |      |       |      |     |
| Aggressive Behaviour             | 9.3  | 0-26 | 6.9  | .90   | 4.6  | .1  |
| Rule Breaking Behaviour          | 2.8  | 0-10 | 2.6  | .76   | 2.0  | .4  |
| Total Externalising Behaviour    | 12.1 | 0-31 | 8.9  | .90   | 6.6  | .4  |
| Anxious/Depressed                | 4.0  | 0-18 | 3.8  | .79   | 2.9  | .2  |
| Withdrawn/Depressed              | 3.6  | 0-14 | 3.5  | .80   | 1.4  | .3  |
| Somatic Complaints               | 3.9  | 0-18 | 3.9  | .79   | 1.2  | .1  |
| Total Internalising Behaviour    | 11.5 | 0-42 | 8.6  | .87   | 5.6  | .5  |
| Attention Problems               | 9.2  | 0-19 | 5.4  | .85   | 3.5  | .5  |
| Social Problems                  | 6.2  | 0-21 | 4.1  | .74   | 2.3  | .3  |
| Thought Problems                 | 7.3  | 0-9  | 5.5  | .80   | 1.6  | .1  |
| N=77                             |      |       |      |       |      |     |

1 Population norms from Child Behavior Checklist (Achenbach & Rescorla, 2001)
Table 15

Alpha Reliability, Means, Standard Deviations of Well Child (Self) Rated Adjustment Variables Compared With Age and Gender Specific Population Means and Standard Deviations

<table>
<thead>
<tr>
<th>Child self report of anxiety (RCMAS)</th>
<th>Current Study</th>
<th>Population Norm¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Range</td>
</tr>
<tr>
<td>Total Anxiety</td>
<td>10.2</td>
<td>0-28</td>
</tr>
<tr>
<td>Physiological Anxiety</td>
<td>3.6</td>
<td>0-10</td>
</tr>
<tr>
<td>Worry/Oversensitivity</td>
<td>4.0</td>
<td>0-11</td>
</tr>
<tr>
<td>Social Concerns/Concerns</td>
<td>2.6</td>
<td>0-7</td>
</tr>
<tr>
<td>Lie</td>
<td>3.5</td>
<td>0-8</td>
</tr>
</tbody>
</table>

N=102

¹ Population norms from RCMAS (Reynolds & Richmond, 1985)

7.7. Parent Rated Well and Ill Child Adjustment Compared with Norms

Dependent t-tests were conducted to compare parent ratings of well child and ill child adjustment to population norms. Paired samples are justified because there are variances on both the scale variables and the norms (which vary across age and gender), and other assumptions of the t-test have not been violated (Heiman, 1996). Table 16 presents the t-test results of comparison between parent rated well child adjustment and population norms.
Parents’ reports of well child internalising and externalising problem behaviour scores were significantly higher than population norms. Parents also reported significantly higher scores for well children on several the individual subscales of maladaptive behaviour compared to norms. Well children were rated as more aggressive, more anxious and depressed, and more likely to have somatic complaints, social problems and thought problems than population norms. There were no differences between parent ratings of well child behaviour and norms for rule breaking behaviour, withdrawn and depressed behaviour or attention problems. Table 17 presents the t-test results of parent rated ill child adjustment and population norms.
Ill children were rated by their parents have having significantly higher scores in externalising and internalising behaviour problems than the population. Ill children were also rated as having significantly more aggressive, rule breaking, anxious/depressed, withdrawn/depressed behaviour, somatic complaints, social problems attention problems, and thought problems than a population of similar age and gender.

### 7.8. Well Child (Self) Rated Adjustment Compared with Norms

Dependent t-tests were conducted to compare well child (self) rated internalising variables (physiological anxiety, worry/oversensitivity, social concerns and total anxiety) compared to age and gender specific population norms. A sub-scale measuring social desirability (lie) was also compared to normative data. Table 18 presents the t-test statistics for well child (self) rated adjustment compared to norms.

<table>
<thead>
<tr>
<th></th>
<th>Sample Mean</th>
<th>Population Mean</th>
<th>T statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggressive Behaviour</td>
<td>9.7</td>
<td>4.6</td>
<td>5.78***</td>
</tr>
<tr>
<td>Rule Breaking Behaviour</td>
<td>2.9</td>
<td>2.0</td>
<td>2.94**</td>
</tr>
<tr>
<td>Total Externalising Behaviour</td>
<td>12.2</td>
<td>6.6</td>
<td>5.40***</td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>4.2</td>
<td>2.9</td>
<td>2.51*</td>
</tr>
<tr>
<td>Withdrawn/Depressed</td>
<td>4.0</td>
<td>1.4</td>
<td>5.81***</td>
</tr>
<tr>
<td>Somatic Complaints</td>
<td>4.0</td>
<td>1.2</td>
<td>5.78***</td>
</tr>
<tr>
<td>Total Internalising Behaviour</td>
<td>12.6</td>
<td>5.6</td>
<td>6.06***</td>
</tr>
<tr>
<td>Attention Problems</td>
<td>9.6</td>
<td>3.5</td>
<td>9.20***</td>
</tr>
<tr>
<td>Social Problems</td>
<td>6.6</td>
<td>2.3</td>
<td>8.45***</td>
</tr>
<tr>
<td>Thought Problems</td>
<td>7.8</td>
<td>1.6</td>
<td>8.75***</td>
</tr>
</tbody>
</table>

n=64 (13 children omitted - 12 children below age range for norms, one child incomplete data)

Note: ***p < .001; **p < .01; *p < .05
Table 18

Comparison in mean scores of self rating adjustment variables (RCMAS) for well children compared to population norms adjusted for age and gender

<table>
<thead>
<tr>
<th></th>
<th>Sample Mean</th>
<th>Population Mean</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Internalising Behaviour</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiological Anxiety</td>
<td>3.6</td>
<td>3.7</td>
<td>-.49</td>
</tr>
<tr>
<td>Worry/Oversensitivity</td>
<td>4.0</td>
<td>4.5</td>
<td>-1.53</td>
</tr>
<tr>
<td>Social Concerns/Concentration</td>
<td>2.6</td>
<td>2.7</td>
<td>-.63</td>
</tr>
<tr>
<td>Total Anxiety</td>
<td>10.2</td>
<td>10.5</td>
<td>-.49</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Desirability</td>
<td>3.5</td>
<td>2.3</td>
<td>4.61***</td>
</tr>
</tbody>
</table>

N=102

Note: ***p < .001; **p < .01; *p < .05

Well children scored significantly higher on the measure of social desirability than the population norms, but did not differ from population norms in their self ratings of internalising behaviour.

7.9 Well Child Age, Gender and Birth Order and Measures of Well Child Adjustment

The relationships between well child age, gender and birth order and measures of well child adjustment were assessed. Well child age was found to negatively correlate with four of the eight parent ratings of well child adjustment: Aggression ($r = -.26; p < .01$); Anxious/Depressed ($r = -.23; p < .05$), Attention Problems ($r = -.30; p < .01$) and Social Problems ($r = -.24; p < .05$). Older children were rated by parents as more adjusted on each of these variables. Well child age thus became a covariate in analyses relating to parent rated adjustment.

A MANOVA examined parent rating of well child adjustment with well child birth order (well child younger or older than child with a chronic illness or disability) and gender (male or female) as the independent variables. The dependent variables in this analysis were parent rated well child aggression, rule breaking behaviour, externalising behaviour, anxious/depressed, withdrawn/depressed, somatic complaints,
internalising behaviour, attention problems, social problems and thought problems. Age was entered as a covariate. The multivariate Fs for birth order and gender were not significant [birth order $F(2,96)=1.24, p > .05$ and gender $F(2,96)=1.33, p > .05$]. As expected age was found to be a significant covariate $F(2,96)=3.13; p < .05$. There was no significant interaction between gender and birth order $F(2,96)=.69; p > .05$

Well child age was found to negatively correlate with two of the four well child self rating measures of adjustment; Social Concerns ($r = -.23; p < .05$) and Aggression ($r = -.22; p < .05$). Older children rated themselves as more adjusted than younger children on these variables. Well child age became a covariate in the analyses relating to self rated adjustment.

A MANOVA examined well child self rating of adjustment with well child birth order (well child younger or older than child with a chronic illness or disability) and gender (male or female) as independent variables. Dependent variables in the analysis were well child (self) rated aggression, physiological anxiety, worry/oversensitivity, social concerns/concentration and total anxiety. Well child age was entered as a covariate.

The multivariate Fs for birth order and gender were not significant [birth order $F(2,96)=1.27, p > .05$ and gender $F(2,96)=2.17, p > .05$]. Age was found to be a significant covariate $F(2,96)=3.71; p < .05$. There was no significant interaction between gender and birth order $F(2,96)=1.8; p > .05$.

No significant differences were found between boys and girls or between children who were older or younger than the ill child on parent or child ratings of well child adjustment. Thus in further analyses of well child adjustment, gender and birth order groups were not separated.
7.10 Summary

Families in the current study were relatively affluent, had high levels of parent education and were predominately two parent families. Most of the ill children had both physical disabilities and developmental delays and required more than five hours care per day. Parents rated well children as having more internalising and externalising problems, and as more anxious and depressed, having more somatic complains and more thought and social problems than the normative data. They rated their ill children as having more externalising and internalising behaviour problems and more aggressive, rule breaking, anxious/depressed and withdrawn/depressed in their behaviour, as having more somatic complaints, social problems, attention problems, and thought problems compared with the population norms. For child rated data, well children scored higher than the norms on the social desirability scale but not on self ratings of internalising behaviour. Thus different informants gave somewhat different pictures of the adjustment of well children.
Chapter 8: Predictors of Well Child Adjustment

This chapter presents the results of analyses for associations and predictions of well child adjustment, using the behaviour ratings scale measures of well child adjustment (parent rated and well child rated adjustment). The analyses of the relationship between well child attributions toward the ill sibling and well child adjustment, and the projective/expressive measures of adjustment (child family drawing) are presented in Chapter 9.

8.1 Parenting Style and Well Child Adjustment

The relationship between parenting style and well child adjustment was assessed using MANOVAs. As there are two methods of categorising parenting style (style type and degree of authoritativeness) from the PSQ (see section 6.2.1) one MANOVA was performed for each method. Well child age was a covariate in these analyses (see section 7.7.1)

MANOVA one used the first method of categorising parenting style into four types (authoritative, authoritarian, permissive and neglectful). Four dependent variables were chosen to capture the major parent- and child-rated measures of child behaviour. They were parent rated internalising behaviour, parent rated externalising behaviour (measured using the CBCL), child rated internalising behaviour (total anxiety, measured using the RCMAS) and child rated externalising (agression, measured using the adapted YSR) behaviour. The means and standard deviations are presented in Table 19. There were no significant differences in well child adjustment for authoritative, authoritarian, indulgent or neglectful parenting (multivariate $F(12,213) = .64, p > .05$).
Table 19

*Mean (SD) well child adjustment scores for parenting style categories*

<table>
<thead>
<tr>
<th>Parenting Style</th>
<th>Parent rated internalising</th>
<th>Parent rated externalising</th>
<th>Child rated internalising</th>
<th>Child rated externalising</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authoritative</td>
<td>11.77 (8.1)</td>
<td>8.92 (7.3)</td>
<td>9.46 (7.4)</td>
<td>1.54 (1.4)</td>
</tr>
<tr>
<td>Authoritarian</td>
<td>9.75 (6.0)</td>
<td>8.50 (8.2)</td>
<td>9.42 (4.0)</td>
<td>1.02 (1.0)</td>
</tr>
<tr>
<td>Indulgent</td>
<td>11.52 (7.7)</td>
<td>8.67 (5.3)</td>
<td>12.43 (7.4)</td>
<td>1.90 (1.4)</td>
</tr>
<tr>
<td>Neglectful</td>
<td>12.32 (8.0)</td>
<td>9.79 (6.4)</td>
<td>10.89 (6.5)</td>
<td>1.63 (1.5)</td>
</tr>
</tbody>
</table>

n=77

MANOVA two used the second method of categorising parenting style, degree of authoritativeness (see section 6.2.1). The independent variable was level of authoritative parenting (most authoritative, moderately authoritative, somewhat authoritative, and not at all authoritative). The four dependent variables were, as before, parent rated internalising behaviour, parent rated externalising behaviour, child rated internalising behaviour and child rated externalising behaviour. The means and standard deviations are presented in Table 20. There was no significant difference in well child adjustment for degrees of authoritativeness in parenting (multivariate $F(12,213) = .83, p > .05$).

Table 20

*Mean (SD) well child adjustment scores for parenting style categories*

<table>
<thead>
<tr>
<th>Parenting Style</th>
<th>Parent rated internalising</th>
<th>Parent rated externalising</th>
<th>Child rated internalising</th>
<th>Child rated externalising</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most Authoritative</td>
<td>12.63 (8.1)</td>
<td>7.88 (5.7)</td>
<td>6.00 (5.2)</td>
<td>1.38 (1.3)</td>
</tr>
<tr>
<td>Moderately Authoritative</td>
<td>10.69 (6.5)</td>
<td>8.45 (8.08)</td>
<td>10.90 (6.1)</td>
<td>1.41 (1.4)</td>
</tr>
<tr>
<td>Somewhat Authoritative</td>
<td>11.08 (8.1)</td>
<td>9.88 (6.4)</td>
<td>11.84 (6.5)</td>
<td>1.64 (1.4)</td>
</tr>
<tr>
<td>Not at all Authoritative</td>
<td>11.67 (7.4)</td>
<td>8.87 (5.5)</td>
<td>10.47 (6.3)</td>
<td>1.50 (1.4)</td>
</tr>
</tbody>
</table>

n=77
8.2 Interrelations of Potential Correlates for Well Child Adjustment

Interrelationships between independent variables to be used in subsequent analyses as predictors of well child adjustment were explored to check multicollinearity. These potential correlates/predictors of well child adjustment included three sets of variables – those relating to the child, those relating to parental behaviour and those relating to the family. Child variables included parent rated measures of ill child behaviour, amount of care time required, ill child participation in social activities, parent and well child ratings of the amount of time the well child spent caring for the ill child, well child age and well child participation in social activities. Parent variables were parenting stress (intensity and frequency), parenting style (psychological autonomy granting and warm involvement), mother’s education and parental access to support. Family variables were number of children in family, family income, respite hours utilised per week and number of respite options available. Table 21 presents means, standard deviations and theoretical ranges for all child, parent and family variables. Note that the Parenting Daily Hassles Scale was completed by the parent participants (n=77) and the Parenting Styles Questionnaire was completed by the well child participants (N=102). Table 22 presents the correlations between the ill child, parent and family variables.

For the following analyses (those which involve analyses of parent, family, ill child with well child data) a manipulation of the data set was required. In some families (n=14) there were several well children participating in the study because no children who expressed a desire to participate were refused. This resulted in 102 separate well child contributions, and 102 ratings of each well child (by the 77 parents), but only 77 parent ratings of several other measures (such as ill child variables, parent stress, family demographics). For the following analyses, which include these variables with only 77 parent scores, one well child was randomly chosen from each family and the other well
child data excluded from analyses. For these analyses there are 77 well children from 77 families.

Table 21
Alpha Reliability, Means, Standard Deviations of Parenting Stress and Parenting Styles Variables

<table>
<thead>
<tr>
<th>Child Variables</th>
<th>Mean</th>
<th>SD</th>
<th>Theoretical Range</th>
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<td>Ill Child Internalising behaviour*</td>
<td>11.5</td>
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<td>12.1</td>
<td>8.9</td>
<td>0-96</td>
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<td>3.5</td>
<td>.9</td>
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<tr>
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<td>1.5</td>
<td>.6</td>
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<td>1.1</td>
<td>.4</td>
<td>1-4</td>
</tr>
<tr>
<td>Ill child participation in social activities*</td>
<td>.9</td>
<td>1.1</td>
<td>0-5</td>
</tr>
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<td>Well child age+</td>
<td>11.7</td>
<td>2.5</td>
<td>7-19</td>
</tr>
<tr>
<td>Well child Participation in social activities+</td>
<td>1.7</td>
<td>1.5</td>
<td>0-6</td>
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<table>
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<td>9-36</td>
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<td>4.6</td>
<td>9-36</td>
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<td>Mother’s education*</td>
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<td>.7</td>
<td>1-3</td>
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<tr>
<td>Access to support*</td>
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<td>1.6</td>
<td>0-6</td>
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</table>

<table>
<thead>
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<th>Family Variables</th>
<th>Mean</th>
<th>SD</th>
<th>Theoretical Range</th>
</tr>
</thead>
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<tr>
<td>No of children in family*</td>
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<td>1.2</td>
<td>2-9</td>
</tr>
<tr>
<td>Family Income*</td>
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<td>1.0</td>
<td>1-4</td>
</tr>
<tr>
<td>Respite hours per week*</td>
<td>2.6</td>
<td>3.1</td>
<td>0-14</td>
</tr>
<tr>
<td>No of respite options*</td>
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<td>.9</td>
<td>0-4</td>
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NOTE: *n=77; +N=102
Table 22

Correlations between ill child, parent and family variables

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<td>7.</td>
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<td>-.08</td>
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<td>-.10</td>
<td>-.06</td>
<td>-.07</td>
<td>-.05</td>
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</table>

| 9.  | .29* | .42** | .28* | .15 | .01 | -.16 | -.01 | .00 |    |    |    |    |    |    |    |    |
| 10. | .21 | .42** | .30** | .05 | -.07 | -.23* | -.01 | .01 | .84** |    |    |    |    |    |    |    |
| 11. | .04 | .02 | -.13 | -.21 | -.14 | .10 | .25* | .07 | .01 | -.01 |    |    |    |    |    |    |
| 12. | .12 | -.03 | -.16 | .05 | -.03 | -.01 | -.29* | .09 | -.12 | -.13 | .14 |    |    |    |    |    |
| 13. | -.60 | -.11 | -.36** | -.09 | -.02 | -.18 | -.04 | .32** | -.06 | -.05 | .18 | .00 |    |    |    |    |
| 14. | .02 | -.08 | -.10 | .03 | .06 | -.03 | .06 | .40* | -.08 | .05 | -.03 | .11 | .24* |    |    |    |

| 15. | .10 | .10 | -.01 | .07 | .00 | -.20 | .05 | -.06 | .09 | .00 | .00 | -.11 | .05 | -.12 |    |    |
| 16. | -.05 | -.06 | -.21 | .04 | -.05 | -.07 | .02 | .06 | -.09 | -.11 | .05 | .11 | .37** | .27* | .06 |    |
| 17. | -.11 | -.04 | .16 | -.02 | .12 | .12 | .01 | .12 | .00 | .05 | .13 | -.25* | -.11 | -.07 | -.02 | .07 |
| 18. | .08 | .20 | -.08 | -.04 | .01 | .06 | .16 | .15 | -.03 | .02 | -.02 | -.15 | .06 | .26* | -.13 | .05 | .31** |

n=77

Note: *p <.05; **p <.01

**Child Variables**
1. Ill Child Internalising behaviour
2. Ill Child Externalising behaviour
3. Care time required
4. Parent rating/ well child time caring
5. Child rating/ well child time caring
6. Ill child participation in social activities
7. Well child age
8. Well child participation in social activities

**Parent Variables**
9. Daily Hassles Frequency
10. Daily Hassles Intensity
11. Psych Autonomy Granting
12. Warm Involvement
13. Mother’s education
14. Access to support

**Family Variables**
15. No children in family
16. Family Income
17. Respite hours per week
18. No of respite options
The only variables found to be highly intercorrelated were the two subscales of the Daily Hassles Scale (Frequency and Intensity; $r = .84, p < .01$). The Frequency subscale was selected for the subsequent regression analysis because it correlated with more of the child adjustment outcome variables (parent rated internalising, externalising, attention, thought and social problems) than the Intensity subscale (parent rated externalising, attention, thought and social problems).

Ill child externalising behaviour and internalising behaviour were moderately related. Parents who rated their ill children as more aggressive and rule breaking also rated them as more anxious, withdrawn and depressed. High frequency of daily hassles was related to more internalising and externalising behaviour in the ill child as well as more care time required. Well child age was related to both parenting style variables (psychological autonomy granting and warm involvement). Younger children reported their parents as being warmer and more involved, older children reported their parents as higher in autonomy granting.

### 8.3 Predicting Well Child Adjustment

Prior to performing the regression analyses, correlations were conducted to test the relationships between the outcome variables (well child adjustment) and (a) child variables (ill child internalising and externalising behaviour, amount of care time required, parent and well child rating of well child time spent caring, ill child participation in social activities, well child age, well child participation in social activities), (b) parent variables (daily hassles frequency, psychological autonomy granting and warm involvement, mother’s education, parental access to support) and (c) family variables (number of children in the family, family income, respite hours per week, number of respite options).
Tables 23 and 24 present the results of the correlations between the ill child, parent and family variables with parent rated well child adjustment variables and well child (self) rated adjustment variables respectively.

8.4 Correlates of Parent Rated Well Child Adjustment

All five aspects of parent rated well child adjustment (Internalising and Externalising Behaviour, Attention Problems, Social Problems and Thought Problems) were found to be related to both aspects of ill child adjustment. When parents rated well children as having high levels of all types of maladaptive behaviour they also rated the ill child high on internalising and externalising behaviour. Correlations between maladaptive behaviour for well children and ill children ranged from .23 to .47 ($p < .01$).

Parents also rated higher levels of attention problems in well children where the ill child in the family participated in fewer social activities. Well child age was associated with well child behaviour problems. Younger well children were rated by their parents as high in attention and social problems. There was no association between any measures of well child adjustment and care time required for the ill child, amount of time the well child spent caring for the ill child (parent or well child rated) or well child participation in social activities.

High frequency of daily hassles was found to be related to high levels on all types of parent rated maladaptive behaviour in the well child. As stress increased so did parent ratings of internalising and externalising behaviour, attention, social and thought problems in the well child. Parenting style, maternal education and parental access to social support were not related to any well child behaviour problems.

Lower family income was found to be associated with higher parent ratings of well child externalising behaviour. Children from families with lower incomes were rated as more aggressive and rule breaking by their parents than children from more
wealthy families. Number of children in the family, number of respite hours per week or number of respite options were not related to any parent rated adjustment variables.

8.5 Correlates of Well Child (Self) Rated Well Adjustment

Well child (self) rated externalising behaviour was related to ill child externalising behaviour. Well children who rated themselves higher on aggression had ill siblings who were also rated as high in aggressive and rule breaking behaviour (by parents). Parent rating of the time well children spent caring for the ill child was also related to well child anxiety.
Table 23

*Correlations of parent rated well child adjustment and the ill child, parent and family variables*

<table>
<thead>
<tr>
<th></th>
<th>Internalising</th>
<th>Externalising</th>
<th>Attention Problems</th>
<th>Social Problems</th>
<th>Thought Problems</th>
</tr>
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<td><strong>Child Variables</strong></td>
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<td>Ill Child Internalising Behaviour</td>
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<td>.37**</td>
<td>.23*</td>
<td>.28**</td>
<td>.47**</td>
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<td>Ill Child Externalising Behaviour</td>
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<td>.42**</td>
<td>.37**</td>
<td>.35**</td>
<td>.42**</td>
</tr>
<tr>
<td>Care time required</td>
<td>.02</td>
<td>.09</td>
<td>.08</td>
<td>.07</td>
<td>.17</td>
</tr>
<tr>
<td>Parent rating of well child time spent caring</td>
<td>.04</td>
<td>.00</td>
<td>-.02</td>
<td>.06</td>
<td>.03</td>
</tr>
<tr>
<td>Well child rating of time spent caring</td>
<td>.03</td>
<td>-.11</td>
<td>-.09</td>
<td>-.11</td>
<td>.10</td>
</tr>
<tr>
<td>Ill child participation in social activities</td>
<td>-.01</td>
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<td>-.26**</td>
<td>-.18</td>
<td>-.18</td>
</tr>
<tr>
<td>Well Child Age</td>
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<td>-.19</td>
<td>-.25*</td>
<td>-.29**</td>
<td>-.08</td>
</tr>
<tr>
<td>Well child participation in social activities</td>
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<td>.01</td>
<td>.11</td>
<td>-.12</td>
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<td><strong>Parent Variables</strong></td>
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<td>Warm Involvement</td>
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<td>-.05</td>
<td>.02</td>
<td>-.03</td>
</tr>
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<td>Mother’s education</td>
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<td>-.17</td>
<td>.01</td>
<td>-.02</td>
<td>-.06</td>
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<tr>
<td>Access to support</td>
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<td>-.03</td>
<td>-.04</td>
<td>-.02</td>
<td>-.08</td>
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<td>-.05</td>
<td>.12</td>
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<td>Family Income</td>
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<td>-.18</td>
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<tr>
<td>Respite hours per week</td>
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<td>.03</td>
<td>.15</td>
<td>-.03</td>
<td>.13</td>
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<tr>
<td>No of respite options</td>
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<td>.07</td>
<td>.20</td>
<td>-.02</td>
<td>.12</td>
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</table>

n=77

Note: **p <.01; *p <.05
Table 24

*Correlations of well child adjustment and the ill child, parent and family variables*

<table>
<thead>
<tr>
<th></th>
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<th>Well child self rated anxiety</th>
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<td>Ill Child Externalising Behaviour</td>
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<td>Parent rating of well child time spent caring</td>
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<td>Ill child participation in social activities</td>
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</tr>
<tr>
<td>Well child age</td>
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<td>.12</td>
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<tr>
<td>Well child participation in social activities</td>
<td>-.24*</td>
<td>-.12</td>
</tr>
<tr>
<td><strong>Parent Variables</strong></td>
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<td>Daily Hassles Frequency</td>
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<td>Psychological Autonomy Granting</td>
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<td>-.31**</td>
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<tr>
<td>Warm Involvement</td>
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<tr>
<td>Mother’s education</td>
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<td>-.17</td>
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<td>Access to support</td>
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<td>-.14</td>
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<td>No of respite options</td>
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</table>

n=77

Note: **p <.01; *p <.05
Children who rated themselves as more anxious, were rated by their parents as spending more time caring for their ill sibling. Well child participation in social activities was related to well child self rated aggression. More aggressive children reported participating in fewer social activities.

Psychological autonomy granting was related to well child self rated internalising and externalising behaviour. Well children who rated themselves high in aggression and anxiety regarded their parents as granting less psychological autonomy. No other parenting variables were related to well child self rated adjustment. No family variables were related to well child self rated aggression or anxiety.

8.6 Variables for Regression Analysis

As the sample was relatively small, the number of independent variables chosen for the regression analyses needed to be limited. The rationale chosen for inclusion was that the potential predictor (independent variable) chosen correlated with at least one of the well child adjustment variables. These decisions were made separately for the parent-rated and child-rated measures. The six correlates of parent rated well child adjustment were selected for inclusion in the regression analysis. Child variables were ill child internalising and externalising behaviour, ill child participation in social activities and well child age; the parent variable was daily hassles frequency and the family variable was family income. The four correlates of well child (self) rated adjustment were included in the regression as follows: child variables were ill child externalising behaviour and parent rating of well child time spent caring for ill child and well child participation in social activities, the parent variable was psychological autonomy granting. There were no family variables included.
8.7 Predicting Parent Rated Well Child Adjustment

A series of seven regressions were conducted to assess the predictors of well child adjustment. Table 25 presents the results of the regression analysis for parent rated well child adjustment. All of the five measures of parent rated well child adjustment were significantly predicted, and are discussed in turn.

Parent rated well child internalising problems was significantly predicted by this set of variables (ill child internalising and externalising behaviour, ill child participation in social activities, well child age, daily hassles frequency, and family income) accounting for 27% of the variance. The only significant independent predictor was ill child internalising behaviour ($\beta = .38$). Parent rated well child externalising was significantly predicted with 40% of the variance accounted for. In this case the significant independent predictors were daily hassles frequency ($\beta = .31$) and (less) family income ($\beta = -.25$). Parent rated attention problems was significantly predicted the same set of variables, which accounted for 32% of the variance. Significant independent predictors were (less) ill child participation in social activities ($\beta = -.20$), daily hassles frequency ($\beta = .27$), and (younger) well child age ($\beta = -.17$) independent predictors and ill child externalising behaviour approaching significance. Parent rated social problems was significantly predicted by these variables, explaining 31% of the variance, with daily hassles frequency ($\beta = .36$) and (younger) well child age ($\beta = -.22$) the significant independent predictors. Finally parent rated thought problems was significantly predicted with 31% of the variance explained by these set of variables. Significant independent predictors were ill child internalising behaviour ($\beta = .31$) and daily hassles frequency ($\beta = -.24$) significant independent predictors. Overall, younger well siblings with more stressed parents and ill brothers and sisters with internalising problems were most likely to exhibit problems in adjustment.
Table 25

*Summary of regression analysis for parent rated well child adjustment variables*

<table>
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<th>Parent rated internalising behaviour</th>
<th>Parent rated externalising behaviour</th>
<th>Parent rated attention problems</th>
<th>Parent rated social problems</th>
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<td>-.10</td>
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<tr>
<td>Well child age</td>
<td>-.05</td>
<td>-.16</td>
<td>-.21*</td>
<td>-.22*</td>
<td>-.04</td>
</tr>
<tr>
<td><strong>Parent Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily Hassles Frequency</td>
<td>.18</td>
<td>.31**</td>
<td>.27*</td>
<td>.36*</td>
<td>.24*</td>
</tr>
<tr>
<td><strong>Family Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Income</td>
<td>-.09</td>
<td>-.25*</td>
<td>-.13</td>
<td>.09</td>
<td>-.08</td>
</tr>
<tr>
<td>(F)</td>
<td>4.3**</td>
<td>7.5***</td>
<td>4.1**</td>
<td>5.1***</td>
<td>5.7***</td>
</tr>
<tr>
<td>(Df)</td>
<td>6,69</td>
<td>6,69</td>
<td>6,69</td>
<td>6,69</td>
<td>6,69</td>
</tr>
<tr>
<td>(R^2)</td>
<td>.27</td>
<td>.40</td>
<td>.32</td>
<td>.31</td>
<td>.31</td>
</tr>
</tbody>
</table>

n=77

Note: ***p <.001; **p <.01; *p <.05; +p <.10
8.8 Predicting Well Child (Self) Rated Adjustment

Table 26 presents the results of the regression analysis for well child self rated adjustment. Both of these regressions were significant. Well child self rated aggression was significantly predicted by these variables (ill child externalising behaviour, parent rating of well child time spent caring for ill child, well child participation in social activities and psychological autonomy granting) accounting for 15% of the variance. Ill child externalising behaviour was a significant independent predictor ($\beta = -.22$), with psychological autonomy granting approaching significance ($\beta = -.20$). Well child self rated anxiety was also predicted with the same set of variables accounting for 12% of the variance. Psychological autonomy granting was the only significant independent predictor ($\beta = -.25$). Thus well children rated themselves as better adjusted when their parents were higher in autonomy granting and their ill siblings were less aggressive.

Table 26
Summary of regression analysis for well child (self) rated adjustment variables

<table>
<thead>
<tr>
<th></th>
<th>Well child self rated aggression $\beta$</th>
<th>Well child self rated total anxiety $B$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ill child externalising behaviour</td>
<td>.22*</td>
<td>.10</td>
</tr>
<tr>
<td>Parent rating of time spent caring for ill child</td>
<td>.09</td>
<td>.17</td>
</tr>
<tr>
<td>Well child participation in social activities</td>
<td>-.18</td>
<td>-.04</td>
</tr>
<tr>
<td><strong>Parent Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological autonomy granting</td>
<td>-.20+</td>
<td>-.25*</td>
</tr>
<tr>
<td>$F$</td>
<td>3.0*</td>
<td>2.4*</td>
</tr>
<tr>
<td>Df</td>
<td>4.68</td>
<td>7.64</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.15</td>
<td>.12</td>
</tr>
</tbody>
</table>

n=77

Note: ***p <.001; **p <.01; *p <.05; +p <.10
8.9 **Summary**

There were no significant differences in well child adjustment (as assessed by the behaviour rating scales) for any of the four categories of parenting style (authoritative, authoritarian, indulgent or neglectful) or degree of authoritativeness (most authoritative, moderately authoritative, somewhat authoritative and not at all authoritative).

The correlations indicated that well children with more parent rated behaviour problems were younger, from poorer families, had parents with higher levels of stress, ill siblings with more behaviour problems and had ill siblings who participated in less social activities.

Well children with more self rated behaviour problems also had ill siblings with more behaviour problems, spent more time caring for their ill sibling, spent less time participating in social activities and had parents who were less autonomy granting in their parenting style.

Parent ratings of well child behaviour problems were significantly predicted by the three categories of variables (parent, family and child variables). Significant independent predictors of parent rated well child behaviour problems were ill child behaviour problems, (younger) well child age and greater parent stress.

Well child self ratings of anxiety was significantly predicted by the three categories of variables (parent, family and child variables) and these three categories approached significance in predicting well child self rated aggression. Ill child externalising behaviour problems was a significant independent predictor of well child self rated aggression and low psychological autonomy granting was a significant independent predictor of well child self rated anxiety.

The consistency of the relationship between well child adjustment problems and ill child adjustment problems should be highlighted. Having an ill sibling with more
behaviour problems appears to be an important factor in well child adjustment
problems, according to parent ratings and well child self ratings. It has consistently
been identified as both a correlate and as an independent predictor in these analyses.
Chapter 9: Family Drawings and Child Attributions

9.1 Overview

This chapter presents the results of analyses for relationships between the well child’s attitude toward their ill sibling and well child adjustment. In addition, associations between well child adjustment, as assessed by child drawings, and the parent, family and child variables are presented.

9.2 The Well Child Experience: Attributions

In order to explore the relationship between children’s attributions about having an ill sibling and child adjustment, the well child’s descriptions of what is good and what is bad about having a sibling with a chronic illness or disability were coded and analysed.

Well siblings responded to the following open-ended question: “Having a sick brother or sister can be difficult, but it can be special too. What has it been like for you? (What is good and what is bad?)”. Responses were sorted into subcategories of positive aspects (self improving, compensations, absence of negatives and adds value to the family) and negative aspects (missing out, empathy for the ill child, physical or emotional outbursts and social reactions) of having an ill sibling.

9.2.1 Positive and Negative Aspects of Having an Ill Sibling

Positive comments were categorised into four groups: self improving, compensations, absence of bad things and adding value to the family. Table 27 shows the number and percent of comments in each of the four “positive benefit” categories.
Table 27

Frequencies and categories of positive aspects of having an ill sibling reported by well child

<table>
<thead>
<tr>
<th>Category</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self improving</td>
<td>24.5</td>
<td>24</td>
</tr>
<tr>
<td>Compensations</td>
<td>21.4</td>
<td>21</td>
</tr>
<tr>
<td>Positive moments</td>
<td>20.4</td>
<td>20</td>
</tr>
<tr>
<td>Adds Value</td>
<td>33.7</td>
<td>33</td>
</tr>
<tr>
<td>Total comments</td>
<td></td>
<td>98</td>
</tr>
</tbody>
</table>

N=102

“Self improving” relates to well child describing the benefits to themselves of having an ill child as a sibling for example “It’s been good because it has made me more tolerant and understanding of other people with disabilities”; “he has taught our family about ourselves” and “you realise how lucky you are”.

“Compensations” describes circumstances where the well child perceives the benefits of having a sibling with a chronic illness as receiving benefits that would not otherwise be forthcoming for example “being involved with VSK (Very Special Kids) has been great, there are camps and siblings days are heaps of fun”; “we can get in places without paying”; “we go straight to the front of the line” and “we get to go to special places to cheer him up”.

Well children also related the good thing about having an ill sibling only in terms of the absence of the bad things. These comments were categorised as “Positive moments only when the negative was absent” for example “when he’s in respite I get to spend more time with mum and dad”; “she’s not sick all the time” and “the only good thing has been him gone, he is always mean to me”.

A final category was “Adding value to the family” in which the well child described the good things about their ill sibling in terms of what the child with a chronic illness brought to the family for example “he is happy most of the time and that makes the family happy, he is so loving you always feel good around him”; “if you tell him secrets he won’t tell anyone”; “he is funny and he loves me and I love him (sometimes)” and “he is very smart in strange things, he knows about things that you would never expect him to know about”. Most well children described the good things about having a sibling with a chronic illness or disability in terms of the personal characteristics of their sibling and the value they brought to the family such as “he’s very cuddly and it’s too quiet when he’s not around”. Negative responses were classified into four categories: missing out, empathy for ill child, physical or emotional outbursts and social reactions. Table 28 shows the number and percent of comments in each of the four negative aspect categories.

Table 28

<table>
<thead>
<tr>
<th>Frequencies and categories of negative aspects of having an ill sibling reported by well child</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missing out</td>
<td>34.5</td>
<td>19</td>
</tr>
<tr>
<td>Empathy</td>
<td>23.6</td>
<td>13</td>
</tr>
<tr>
<td>Physical or emotional outbursts</td>
<td>31</td>
<td>17</td>
</tr>
<tr>
<td>Social Reactions</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Total comments</td>
<td></td>
<td>55</td>
</tr>
</tbody>
</table>

N=102

Responses that described the negative aspects in terms of missing out on things they expect other children get were categorised as “Missing Out”, some examples were “when I have things on at night mum can’t usually come”; “don’t get many friends over, don’t get to go to many places” and “when we go to hospital it ruins my plans”.
Responses that described the ill child’s loss were categorised as “Empathy for the Ill Child”. Examples included “the bad thing is that it’s a bit depressing to think that she can’t live a proper life and be like and average girl her age” “he still has injections every day and goes to hospital sometimes” “worried that my sister might die or get really sick” and “the only bad thing is how painful it is for her and thinking of her future”.

Some responses described “Physical or emotional outbursts” as a negative aspect of having an ill sibling. Examples included “my brother is very annoying but sometimes he is really cool. He is annoying because when we are playing games (monopoly etc) he has a spaz at me if he looses. He lies and blames it on me. I also hate it that he copies me, there is nothing worse than a copy cat, he plays with my ear too much and he brakes things”; “he breaks a lot of my stuff” and “he makes a lot of noise and tries to scratch someone when he is angry”.

The final category of negative experiences was “Social reactions” and refers to community reactions to the illness. Examples included “it’s annoying when other people are referring to people as ‘retards’ or if they see a disabled person and start bagging them”; “it’s hard for me when we were in shops and people would stare but I am so over that” and “he gets annoying sometimes, he is embarrassing in the shops when he screams”. Well children most often listed missing out on things, when asked what is bad about having a sibling with a chronic illness or disability, for example “all of us can’t go to soccer, someone has to stay and look after him”.

9.3 Analysis of Well Child Attributions

Comments were added to provide a total good comments score, a total bad comments score and an overall perceived consequences score (good comments minus
bad comments). Ninety-six children provided at least one positive or negative comment, only six children were unable to think of something positive or negative about having an ill sibling. There were 136 positive responses from 83 children and 174 negative responses from 86 children. The total perceived consequences score was significantly negatively correlated with child rated externalizing ($r = -.29, p < .01$) and there was a trend toward a significant negative correlation with parent-rated well child externalizing ($r = -.18, p = .07$). Externalising behaviour was associated with production of relatively fewer positive comments in relation to negative comments about having an ill sibling.

9.4  Analysis of Children’s Drawings

Details of the method for analysing the child drawings follow. The children’s drawing task was designed to serve three purposes: as an introductory activity, to understand the structure of the family from the child’s perspective and as a method of identifying emotional problems. The results are presented in relation to each of these purposes.

In relation to the first purpose, the researcher observed 26 children during personal visits to administer the assessments. All of the children expressed pleasure at the presentation of a range of pencils and paper and the researcher’s request to draw a picture of their family. It was evident from the researcher’s observations that the children became more relaxed and communicative as they drew, and this was a successful way of relaxing the children and removing the apprehension about the assessments. The drawing task also provided a way for some of the ill children to become involved in the assessment process. In some cases younger siblings (below the participation criteria age of 7 years) or ill children approached the researcher and well siblings and expressed a desire to participate. In these circumstances children were also
given some paper and pencils in an inclusive way and encouraged to draw a picture as well. In order to make the participation in the research project a positive activity, the researcher remained inclusive and encouraging of the participation by the whole family if desired.

The second purpose of the drawings was to provide a method of understanding the structure of each family from the child’s perspective. Children were encouraged to draw whoever they considered as part of their family. Family drawings included pets (Figure 1) and grandparents (Figure 2). Two children included deceased siblings in their drawings (Figure 3).

An observation of the drawings of the family from the child’s perspective revealed some interesting themes. Firstly not all of the children agreed to participate in the drawing activity. Of the 102 well children participating in the research, eight did not produce a drawing (resulting in n= 94 family drawings). All of these children were participants who participated by mail administration. Six of the children who consented to draw their family drew very infant like scribble type drawings (Figure 4).

Most children drew the parents that resided in their home, with themselves and their ill siblings clearly close to the rest of the family with all family members identified (Figure 5). There were some exceptions to this general finding. Three children drew their parents with monstrous features such as fangs or a devil tail (Figure 6). Several children provided drawings with an obvious distance between one or several family members. Three children drew their ill siblings noticeably apart from the rest of their family (Figure 7) two children drew their parents physically separated from the children in the family such as in boxes (Figure 8) or on separate pages. One child drew each of the children on separate pages and did not draw the parents at all. Some children omitted family members, one child omitted himself (Figure 9) and one drew only
herself (Figure 10). One child drew and identified all family members using first names, but used the generic term “sister” to identify their disabled sibling.

A series of three MANOVAs were performed to explore the relationships between the well child adjustment variables and these drawing characteristics. Seven dependent variables were used as in previous analyses: Parent Rated Internalising and Externalising behaviour, Attention problems, Social problems and Thought problems and Child Rated Internalising behaviour (anxiety) and Externalising behaviour (aggression). The independent variables were drawing submitted (yes or no); scribble (yes or no), and indication of distance from the family (yes or no) which included all the types of distance indicators listed above.

There were no significant differences between adjustment measures for children who submitted a drawing and children who did not submit a drawing $F(1,92) = 1.28$, $p > .05$, or between children who indicated distance in their family and children who did not $F(1,92) = .82$, $p > .05$. There was a statistically significant difference between children with scribble drawings and children with no scribble drawings on the combined dependent variables $F(1,92) = 2.73$, $p < .05$; Wilks Lambda = .82; partial eta squared = .18. When the results for the dependent variables were considered separately, the differences to reach significance were parent rated social problems $F(1,92) = 9.04$, $p < .01$, child rated aggression $F(1,92) = 7.57$, $p < .01$ and child rated anxiety $F(1,92) = 8.64$, $p < .01$. Children who drew scribble drawings on the drawing assessment rated themselves as more aggressive and anxious (Aggression; $M=2.75$, $SD=1.7$ and Anxiety: $M=17.50$, $SD=6.0$ respectively) than children with non-scribble drawings (Aggression: $M=1.28$, $SD=1.2$ and Anxiety: $M=10.03$, $SD=6.0$ respectively). Children who drew scribble drawings were rated by parents as having more social problems ($M=7.33$, $SD=7.1$) than children who did not ($M=3.26$, $SD=2.8$).
9.5  Method for Analysing Drawings

The final purpose was to provide an exploratory method of evaluation of well child adjustment by drawing analysis. The analysis of the child drawings was based on the method proposed by Koppitz (1968; 1984) which uses a child’s drawing of one human figure. In order to accommodate the other aims for the drawing in this study, the whole family was drawn. However, the child’s drawing of himself or herself within the family drawing was selected for analysis by the Koppitz method. The drawing of self was chosen because it was the only figure consistently drawn by all children (some children omitted a parent or a sibling from their family drawing).

Koppitz (1966; 1968; 1969; 1983; 1984) developed a method of psychological evaluation of human figure drawings of children aged 5-12 years and later extended to include children aged up to 14 years. Therefore the evaluation criteria are applicable to all children aged up to 14 years in the current study (n= 83 of 102 children) in the sample. However, Koppitz suggests children aged 15 years and over are more self-conscious about their drawing ability and mostly produce stick figures or cartoons which cannot be assessed. According to Koppitz, it is mostly children with some artistic ability who produce assessable drawings in the older age bracket, so the psychological evaluation of drawings for children aged 15 and over is not recommended.

In Koppitz’s (1968, 1969) method, children are given a pencil and paper and asked to “draw one whole person, you can draw any kind of person you want to draw but not a stick figure” at the completion of the drawing the child is asked several questions about the drawing such as whether the drawing is of a real person, how old the person in the drawing is and what is the person in the drawing doing, thinking and feeling. Koppitz recommends the following six steps for a complete psychological evaluation of a child: evaluate the child’s behaviour and attitudes while they produce
the drawing, take an overall impression of the drawing, examine the drawing from a
developmental point of view, explore the emotional indicators of the drawing, analyse
the content of the drawing and examine the drawing for signs of neurological
impairment.

A complete psychological evaluation of the children was not required for this
study, so all the six steps were not used. The focus of the drawing analysis was the 30
emotional indicators developed by Koppitz (1969) to assess the emotional state of
children. Koppitz developed a list of 30 emotional indicators which were found to occur
significantly more often, but not exclusively, on the drawings of children with serious
emotional problems compared to children with normal adjustment. A total score is not
produced because the emotional indicators are not mutually exclusive. Several
emotional indicators relate to the same or similar feelings so the presence of more
emotional indicators does not indicate an increase in problem severity. Emotional
problems are suggested by the presence of two or more emotional indicators on a human
figure drawing, according to the Koppitz method.

In order to gain empirical support for the Human Figure Drawing assessment,
Koppitz (1983, 1984) studied 76 children aged 5-12 who were assessed by teacher
ratings to be well adjusted. These children were matched in age and gender distribution
with 76 children who attended a guidance clinic. The human figure drawings of the
well adjusted children were compared with drawings of the children with adjustment
problems. Among the well adjusted children 95 percent drew either none or one
emotional indicator, five percent drew two indicators. Of the clinical group 75 percent
drew two or more emotional indicators. More recently Cattee and Cox (1999)
compared 44 boys with emotional and behavioural difficulties classified using DSM IV,
44 boys matched for chronological age and 44 boys matched for mental age scored
using the WISC III. There was a small but significant difference in the number of indicators scored by the clinical group compared to the matched control groups. The majority of the clinical children produced two or more indicators in their drawings, compared to the children in the matched control groups who scored none or one indicator.

The 30 emotional indicators are grouped into five emotional categories of impulsivity, insecurity, anxiety, shyness/timidity and anger/aggressiveness. Between five and seven emotional indicators relate to each category. A summary of the emotional indicators in each category follows. A checklist was developed with definitions of each of the categories and the relevant indicators for the drawing analysis procedure. The checklist is presented in Appendix B and provides a more detailed description of each emotional indicator.

The emotional category of impulsivity is defined as a tendency to act spontaneously with little forethought or planning, and to show low tolerance for frustration. There are five emotional indicators which suggest impulsivity: poor integration of body parts; gross asymmetry of limbs; pronounced transparency of major portions of the body; big figure (where the figure is 9 inches (23cm) or more in height); and omission of neck.

Insecurity and feelings of inadequacy refers to feelings of low self concept and poor levels of self-confidence. Children express concern over mental adequacy and relate feelings of helplessness. The child regards himself as an outcast, or as a ridiculous person who has difficulty building relationships with other people. There are seven emotional indicators which suggest insecurity and feelings of inadequacy: slanting figure; tiny head; hands cut off; monster or grotesque figure; omission of arms; omission of legs and omission of feet.
Anxiety is defined as a feeling of distress, apprehension or uneasiness. It can relate to the body, actions or future events. The six emotional indicators of anxiety are: shading of face; shading of body and/or limbs; shading of hands and/or neck; legs pressed together; omission of eyes; and clouds, rain, flying birds.

Shyness and timidity refers to cautious and reserved behaviour. Children express a lack of self-confidence and are easily embarrassed or frightened. They tend to withdraw from risky or difficult situations. There are five emotional indicators of shyness and timidity: tiny figure; short arms; arms clinging to body; omission of nose; and omission of mouth.

Anger and aggressiveness is defined as offensive action or revengefulness aimed at others possibly from frustration. It can be directed toward others, toward oneself or toward objects. The five emotional indicators of anger and aggressiveness are: crossed eyes; teeth; long arms; big hands; and nude figure.

9.6 Analysis for Emotional Indicators Using the Drawing Method

Not all of the 102 well children participating in the study produced drawings assessable using Koppitz’s (1968, 1984) 30 emotional indicators. Assessable drawings were provided by 63 well children (\(M\) age = 10.7, \(SD=1.7\)), 51% were males and 49% were females. The 39 children who did not provide assessable drawings were excluded for several reasons. The most common reason was age limitation, 15 children were aged 15 or over, in addition eight drew only faces, seven drew stick figures, one drew cartoon figures and a further eight chose not to draw a picture at all. Assessable drawings were rated on the presence or absence of the 30 emotional indicators categorized into five emotional criteria (impulsivity, insecurity, anxiety, shyness and aggression). An example of drawings with an indicator present is provided for each emotional criteria.
Figure 11 shows a drawing with an emotional indicator for impulsivity present. The drawing shows a human figure with *no neck*, in that the head is directly attached to the body without any indication of a neck and no clear neckline of a shirt or sweater. This drawing scored present on the *no neck* emotional indicator in the impulsivity category. Eighteen percent of children were rated as having at least one impulsivity indicator present.

Figure 12 shows a drawing with the presence of *hands cut off*, an emotional indicator for insecurity. The human figure in the drawing has no hands, the arms are drawn with neither hands nor fingers and the hands are not hidden behind the body or in pockets. This drawing scored present on the *hands cut off* emotional indicator in the insecurity category. Twenty four percent of children were rated as having at least one insecurity indicator present.

Figure 13 shows a drawing with the presence of *legs pressed together*, an emotional indicator for anxiety. The human figure in the drawing has both legs touching with no space visible between. This drawing scored present on the *legs pressed together* emotional indicator in the anxiety category. Eight percent of children were rated as having at least one anxiety indicator present.

Figure 14 shows a drawing with the presence of *tiny figure*, an emotional indicator for shyness. The human figure in the drawing is less than two inches (five centimetres) in height. This drawing scored present on the *tiny figure* emotional indicator in the shyness category. Twenty eight percent of children were rated as having at least one shyness indicator present.

Figure 15 shows a drawing with the presence of *teeth*, an emotional indicator for aggression. The human figure in the drawing has one or more teeth visible. This
drawing scored present on the *teeth* emotional indicator in the aggression category.

Eleven percent of children were rated as having at least one aggressive indicator present.

Although the presence of two emotional indicators is the indicator of problems for children (i.e. one emotional indicator, or more than two indicators is not suggestive of more or less problems), the number of emotional indicators present in each category were recorded and tallied with ages and genders to give an overview of the types of indicators present in the drawings from this sample. Table 29 shows the number of drawings with emotional indicators from each category and the mean age and gender of children drawing indicators.

Table 29

*Total number of drawings with emotional indicators in each category and the mean age and gender frequency of children drawing indicators*

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Present</th>
<th>Age</th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Impulsivity</td>
<td>18</td>
<td>17.6</td>
<td>9.9</td>
<td>1.5</td>
</tr>
<tr>
<td>Insecurity</td>
<td>25</td>
<td>23.5</td>
<td>10.7</td>
<td>2.1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>8</td>
<td>7.8</td>
<td>10.6</td>
<td>1.8</td>
</tr>
<tr>
<td>Shyness</td>
<td>28</td>
<td>27.5</td>
<td>10.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Aggression</td>
<td>11</td>
<td>10.8</td>
<td>9.6</td>
<td>1.9</td>
</tr>
</tbody>
</table>

n = 63

The most common indicators were in the shyness category (27.5%). Most of the indicators in the impulsivity and aggression categories were drawn by males, and most of the indicators in the anxiety and shyness categories were drawn by females.
9.7 Frequencies of Emotional Problems

Children were assessed as having no emotion problems if they scored as having no emotional indicators, or only one indicator present in their drawing. Of the 63 assessable drawings, 27 (14 females and 13 males) were assessed as having no emotional problems (M age = 11.09, SD=1.4).

Drawings with two or more emotional indicators present were classified as having emotional problems. The emotional indicators did not have to come from different categories, and a higher total number of emotional indicators did not reflect more emotional problems. Of the 63 assessable drawings, 36 were assessed as having emotional problems (2 or more emotional indicators) 18 females and 18 males (age M=10.4, SD=2.0). Note that age was not significantly related to whether the child was assessed as having an emotional problem using this method F(1,61)=2.4, p>0.05 (No assessable problem M=11.1 years and Assessable problem M=10.4 years).

9.8 Emotional Problems and Child, Parent and Family Variables

A MANOVA was performed to explore the relationship between well child adjustment as assessed by the drawings, and the child, parent and family variables assessed in the previous chapter as significant correlates and predictors of well child adjustment. As in previous child, parent and family analyses, the reduced data (n=77) set was used for ill child and family factors, with one randomly selected child from each family. This eliminates multiple entries of the same family. From this family data set only 51 children produced an assessable drawing. The small sample size required for these analyses (n= 51) increases the possibilities of a Type 2 error, that is, of missing significant associations between variables. Additionally, as the drawing measure only provides categorical (not continuous) data, the measurement is less sensitive and the power of statistical analyses weaker, further increasing the possibility of Type 2 errors.
The dependent variables were the child, parent and family factors with the strongest relationships to child adjustment, namely ill child behaviour, daily hassles frequency, psychological autonomy granting and well sibling age. The independent variable was drawing rated emotional problems (yes or no). Well children with emotional problems did not significantly differ from children without emotional problems in ill child, parent or family variables $F(5,44) = 2.06, p > .05$.

9.9 Summary

Well children who listed more negative (than positive) attributes about having a sibling with a chronic illness were more aggressive and rule breaking in their behaviour. Well children who produced scribble drawings of their family rated themselves as more aggressive and anxious, and were rated by their parents as having more social problems, than children who produced drawings where figures were identifiable. Well children with emotional problems (as assessed from the child family drawings) did not differ significantly from children without emotional problems in any of the parent, child or family variables.
Figure 1. A drawing by a boy age 9 who included his pet in his family.
Figure 2. A drawing by a boy age 12 who included his grandparents in his family.
Figure 3. A drawing by a boy aged 9 who included his deceased sibling in his family.
Drawing omitted due to privacy/anonymity concerns. Contact author for further details

*Figure 4.* A scribble drawing by a boy age 11.
Figure 5. A drawing by a girl age 15 who drew ill sibling close the rest of the family and clearly identified.
Drawing omitted due to privacy/anonymity concerns. Contact author for further details

Figure 6. A drawing by a boy age 13 who drew parents with monstrous features.
Drawing omitted due to privacy/anonymity concerns. Contact author for further details

Figure 7. A drawing by a boy age 13 whose ill sibling is considerably apart from the family.
Drawing omitted due to privacy/anonymity concerns. Contact author for further details

Figure 8. A drawing by a boy age 11 who separated his parents from the children in the family.
Figure 9. A drawing by a boy aged 13 who omitted himself from the drawing.
Drawing omitted due to privacy/anonymity concerns. Contact author for further details

*Figure 10.* A drawing by a girl aged 13 who only included herself in the family.
Figure 11. Example of a human figure drawing by a boy aged 8 with the impulsive emotional indicator “no neck” present.
Figure 12. Example of a human figure drawing by a boy aged 12 with the insecurity emotional indicator “hands cut off” present.
Figure 13. Example of a human figure drawing by a girl aged 11 with the anxiety emotional indicator “legs pressed together” present.
Figure 14. Example of a human figure drawing by a girl aged 7 with the shyness emotional indicator “tiny figure” present.
Figure 15. Example of a human figure drawing by a boy aged 9 with the aggression emotional indicator “teeth” present
Chapter 10: Relationships Between the Three Measures of Well Child Adjustment

The relationships between all three measures of well child adjustment specifically (a) parent rated measures using behaviour rating scales, (b) well child self rated measures using behaviour rating scales, and (c) projective/expressive measures in the form of family drawings were analysed. Correlations were performed to analyse the relationships between the continuous variables (parent rated and child rated behaviour scales) and MANOVAs were performed to analyse the relationship between the categorical variables (emotional problems “yes” or “no”) as assessed by emotional indicators on the child family drawings and the continuous variables on the parent and child rated behaviour scales.

10.1 Parent and Child Rated Behaviour Rating Scales

Table 30 presents the results of the correlational analyses of the parent rated and well child rated adjustment measures. Parent rated measures of well child adjustment (internalising, externalising, attention seeking, social problems and thought problems) were all strongly related to each other (correlations ranging from .56 to 71; \( p < .05 \)). Well child ratings of adjustment were also strongly related; children who rated themselves high on internalising behaviour also rated their externalising behaviour high \( (r = .64, p < .01) \). All parent rated measures of well child adjustment were moderately correlated with well child (self) rated measures of adjustment (correlations ranging from .20 to 36; \( p < .05 \)). Child rated externalising behaviour was weakly related to social desirability when the child self rated their aggressive behaviour. Children who rated themselves as more aggressive were less likely to be influenced by social desirability \( (r = -.25, p < .05) \).
Table 30
Correlations between Parent rated well child adjustment and well child (self) rated adjustment variables

<table>
<thead>
<tr>
<th></th>
<th>Parent Rated</th>
<th></th>
<th></th>
<th>Child Rated</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Internalising</td>
<td>Externalising</td>
<td>Attention</td>
<td>Social</td>
<td>Thought</td>
<td>Internalising</td>
</tr>
<tr>
<td>Parent Rated</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalising</td>
<td>.64**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attention</td>
<td>.56**</td>
<td>.71**</td>
<td></td>
<td>.64**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>.69**</td>
<td>.65**</td>
<td>.64**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thought</td>
<td>.65**</td>
<td>.65**</td>
<td>.60**</td>
<td>.61**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Rated</td>
<td>.30**</td>
<td>.21*</td>
<td>.20*</td>
<td>.31*</td>
<td>.21*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>.35**</td>
<td>.36**</td>
<td>.34**</td>
<td>.36*</td>
<td>.20*</td>
<td>.64**</td>
</tr>
<tr>
<td>Social Desirability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>-.06</td>
<td>-.17</td>
<td>-.08</td>
<td>-.08</td>
<td>.04</td>
<td>-.00</td>
</tr>
</tbody>
</table>

N=102

Note: *p < .05; **p < .01
10.2 Behaviour Rating Scales and Family Drawings

A MANOVA was performed to investigate the relationship between being categorized as having emotional problems on the drawing analysis (yes and no) and parent rated and well child (self) rated adjustment problems. Eight dependent variables were used: Parent Rated Internalising and Externalising behaviour, Attention problems, Social problems, Thought problems, and Child Rated Internalising behaviour (anxiety), Externalising behaviour (aggression) and Social Desirability. The independent variable was the presence of emotional problem rating (problem or no problem).

There was a statistically significant difference between children assessed as having emotional problems and children assessed with no emotional problems on the combined dependent variables $F(8,53) = 3.39, p < .01$; Wilks Lambda = .64; partial eta squared = .37. When the results for the dependent variables were considered separately, the differences to reach significance were child rated aggression $F(8,53) = 5.90, p < .05$ and child rated anxiety $F(8,53) = 6.44, p < .05$. Table 31 presents the means, standard deviations and F values for the MANOVA comparing child adjustment scores assessed with behaviour rating scales, and emotional problems (yes or no) assessed by the child drawings. Children who scored as having emotional problems on the drawing assessment rated themselves as more aggressive (Aggression; $M=2.0, SD=.2$) and anxious (Anxiety; $M=13.1, SD=.2$) than children with no emotional problems (Aggression; $M=1.1, SD=.3$) and (Anxiety; $M=8.9, SD=1.2$) respectively. Thus there was a consistency between the child self ratings and the child drawings in the assessment of child adjustment.
Table 31
Mean, standard deviations and F values for adjustment scores for children with emotional problems and no emotional problems on the drawing measure.

<table>
<thead>
<tr>
<th></th>
<th>Emotional problems N=36</th>
<th>No emotional problems N=27</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Parent Rated</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalising Behaviour</td>
<td>11.0</td>
<td>8.6</td>
<td>11.8</td>
</tr>
<tr>
<td>Externalising Behaviour</td>
<td>10.6</td>
<td>7.7</td>
<td>7.7</td>
</tr>
<tr>
<td>Attention Problems</td>
<td>3.8</td>
<td>3.3</td>
<td>4.3</td>
</tr>
<tr>
<td>Social Problems</td>
<td>4.7</td>
<td>4.1</td>
<td>4.1</td>
</tr>
<tr>
<td>Thought Problems</td>
<td>3.8</td>
<td>3.9</td>
<td>3.6</td>
</tr>
<tr>
<td>Child Rated</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalising Behaviour</td>
<td>13.1</td>
<td>7.7</td>
<td>8.9</td>
</tr>
<tr>
<td>Externalising Behaviour</td>
<td>2.0</td>
<td>1.5</td>
<td>1.2</td>
</tr>
<tr>
<td>Social Desirability</td>
<td>3.1</td>
<td>2.3</td>
<td>3.8</td>
</tr>
</tbody>
</table>

Note: *p <.05; ** p <.01; *** p <.001

10.3 Summary

There was evidence of relationships between the three measures of child adjustment, although the results were not consistent across all three measures. The subscales of the parent and child rated behaviour ratings scales were all moderately related and child drawings were related to child rated internalising and externalising behaviour.
Chapter 11: Summary of the Results

This chapter presents a brief summary of the results presented in Chapters 7, 8, 9 and 10. The summary includes well child adjustment compared to population norms, relationships between well child adjustment (parent rated, child rated and child drawings) and parent, family and child variables, and relationships between the three measures of well child adjustment.

In Chapter 7, the results indicated parents rated their well children with a chronically ill or disabled sibling as having more behaviour problems (both internalising and externalising) compared to age and gender matched population norms. Well children reported no difference between their behaviour and normative data, but scored significantly higher than age and gender matched norms on measures of social desirability.

In Chapters 8 and 9 the most consistent associations between well child adjustment (parent rated, child rated and child drawing measures) and parent, child and family variables were with ill child internalising and externalising problem behaviours and high parental stress. Associations were found between these variables and more than one measure of well child adjustment. In addition several other variables (low family income, younger well child age, low psychological autonomy granting by parents, less ill child participation in social activities, more time spent by well child caring for ill sibling, less participation in social activities by ill child) were associated with at least one measure of well child adjustment. Table 32 presents a summary of the significant associations between all measures of well child adjustment and child, parent and family variables.

In addition, although the child drawing measure revealed no significant relationships with any of the child, family or parent variables, well children who drew
scribble drawings did have more behaviour problems (both parent and child rated).

Finally, although not a measure of child adjustment, analysis of well children’s attitudes toward their ill siblings revealed a relationship between more negative feelings toward siblings with a chronic illness or disability and higher levels of anxiety and aggression.

The results in Chapter 10 provided some evidence of relationships between the three measures of child adjustment. The parent and child rated behaviour ratings scales were moderately correlated, and child drawings were related to child self rated behaviour.
<table>
<thead>
<tr>
<th>Table 32</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Significant associations between well child adjustment and child, parent and family variables</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent-rated well child adjustment</th>
<th>Child variables</th>
<th>Parent variables</th>
<th>Family variables</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Externalising</strong></td>
<td>Associated with ill child externalising and internalising</td>
<td>Associated with daily hassles frequency</td>
<td>Negatively associated with family income</td>
</tr>
<tr>
<td><strong>Internalising</strong></td>
<td>Associated with ill child externalising and internalising</td>
<td>Associated with daily hassles frequency</td>
<td></td>
</tr>
<tr>
<td><strong>Attention Problems</strong></td>
<td>Associated with ill child externalising and internalising</td>
<td>Associated with daily hassles frequency</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negatively associated with ill child participation in social activities and well child age</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Problems</strong></td>
<td>Associated with ill child externalising and internalising</td>
<td>Associated with daily hassles frequency</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negatively associated with well child age</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Thought Problems</strong></td>
<td>Associated with ill child externalising and internalising</td>
<td>Associated with daily hassles frequency</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Child-rated well child adjustment</th>
<th><strong>Externalising</strong> (aggression)</th>
<th><strong>Internalising</strong> (anxiety)</th>
<th>Child drawings (Koppitz method of assessment)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Externalising</strong></td>
<td>Associated with ill child externalising</td>
<td>Associated with parent rating of time sibling spends caring for ill child</td>
<td>No significant differences between those assessed with ‘emotional problems’ and those not</td>
</tr>
<tr>
<td></td>
<td>Negatively associated with well child participation in social activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Internalising</strong></td>
<td>Associated with parent rating of time sibling spends caring for ill child</td>
<td>Negatively associated with psychological autonomy granting</td>
<td>No significant differences between those assessed with ‘emotional problems’ and those not</td>
</tr>
<tr>
<td><strong>Child drawings</strong></td>
<td>No significant differences between those assessed with ‘emotional problems’ and those not</td>
<td>No significant differences between those assessed with ‘emotional problems’ and those not</td>
<td></td>
</tr>
<tr>
<td>(Koppitz method of assessment)</td>
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</tbody>
</table>

No significant differences between those assessed with ‘emotional problems’ and those not
Chapter 12: Discussion

12.1 Major Findings

12.1.1 Describing the Families

The first general study aim was to describe social, family and personal characteristics of a group of well children with siblings who have a chronic illness or disability. Results showed the well children in this sample were mostly from dual parent families with high parental education and high family income. This sample differs from samples accessed in previous research (Carter et al., 1992; Emerson, et al., 2006; Newacheck et al., 1998) and from the anecdotal reports of field workers in Victoria who suggest that families with an ill or disabled child are often characterised by parental separation and low incomes. Previous research indicates high levels of marital conflict and reduced family incomes in families with a chronically ill child (Berant et al., 2003; Berge et al., 2006; Hauenstien, 1990; Quittner et al., 1998; Sheeran et al., 1997). Leventhal and Sabbeth (1986) identified the high demand of caring for a chronically ill child as a major factor in family conflict suggesting care demands take time and energy away from other important tasks which foster the marital relationship. Research has also found families of children with chronic illness or disability face high levels of financial pressure from increased medical costs and reduced employment opportunities (Allan et al., 1974; Carter et al., 1992; Leventhal & Sabbeth, 1986).

The inconsistency between the prevalence of low family incomes and parental separation found in previous studies, and the high incomes and dual parent families in the current study, is evidence of a restricted demographic band in this sample. The full implications of this sample limitation are discussed in more detail later in this chapter, however at this point it should be noted that the findings in relation to social, family and
personal characteristics of families should be considered in the context of the high socioeconomic status of this sample.

In the current study, well children had little access to support activities outside the family with most children (62.8%) having none or only one support activity, usually a sporting group or a sibling specific support group. One reason for the limited participation in activities outside the home is likely to be the difficulty in transporting children to extracurricular activities when there is an ill child who requires care. Previous literature indicates that the time well children spend in activities outside the home decreases as the ill child’s symptoms worsen because parents need to provide more medical care and attention for the ill child (Bluebond-Langer, 1996). The provision of support for well children, as well as for parents of chronically ill children, has been found to be an important factor in well child adjustment (Mindence, 1994) and support for children outside the family unit has been identified in the resilience literature as a factor associated with better outcomes for children (Werner, 1993; 1995; 1996; Werner & Smith, 1977; 1982; 1993). Werner and Smith suggest the ability to access support with their community provides at risk children with a refuge from a home situation that is often unsettled. It may also provide encouragement for the child and reinforce his or her confidence (Rolfe, 2004), as well as providing access to other supportive adults who can act as mentors or role models.

It appears access to sporting, social and artistic groups outside the family home may be important for building resilience in children. Therefore the limited participation of well children with a chronically ill sibling in these organisations may be hindering their ability to develop resilience. In support of this, well child participation in external social support activities was associated with better adjustment in this study. Well children who participated in more social activities outside the home assessed themselves
as significantly less aggressive in their behaviour. It is not possible to say whether this relationship reflects better child adjustment for children who participate in more social activities, or whether more aggressive children are less likely to be included in external groups because of their aggressive behaviour. It is possible that parents are avoiding the problems caused by including their somewhat aggressive children in activities with other children, or that the aggression is part of a broader problem in managing social interactions with others, making participation in social activities problematic. Another possible explanation is provided by Stoneman et al. (1991), who suggest the financial expense associated with participation in activities outside the home, is a problem for families with a chronically ill or disabled child. It appears, from the lack of participation by well children from this relatively affluent sample, that there may be more reasons operating than purely financial. It is also possible that these families are still challenged by the expenses of living with a chronically ill child. Income is not the only indicator of financial security; expense may be an issue for these families as well. Further research could benefit from a more thorough exploration lack of participation in social activities, including the possible reasons.

In the current study, parents most commonly relied on friends for support and most often had three sources of social support available to them, although some families reported receiving no support at all. Previous research has often found parents to be socially isolated when they have a child with a chronic illness or disability (Carter et al., 1992). The higher level of support for parents in this study is possibly associated with their relatively high level of resources – good income, mostly dual parent and high education levels. These resources provide many benefits for families. Parents are more likely to have the resources to access fee paying support services, and the support of a spouse relieves the care burden, freeing partners for social contact as well as providing
access to social networks through their own family, friends and colleagues. Finally, the higher maternal education level prevalent in this sample is likely to increase the parent’s ability and confidence to be more proactive in seeking out support. Taking these factors into account it is not surprising that most of the parents in this study had access to more than one support option.

In the current study, most families indicated that they used only one respite option for about two hours per week or less. Respite has been found to increase optimism and reduce stress in parents (Bruns & Burchard, 2000). This would suggest low levels of respite utilisation could be a contributing factor in levels of parent stress in this sample and that increasing respite may help reduce this stress. However, no evidence of a relationship between parent stress and access to respite was found in the study. Perhaps this is because of the short-term nature of benefits from respite (Meltzer & Johnson, 2004). Respite may need to be ongoing for the real benefits to be felt. Another possibility is that the relationship between respite and parent stress is more complex than the simple “more is better” paradigm suggested by Meltzer and Johnson. Access to plenty of ongoing respite, which is not high quality or does not suit the requirements of the family, may be just as problematic as no respite at all, ultimately having no impact on reducing parent stress. A number of problems with respite were reported by parents in the current study, most commonly relating to difficulty in accessibility or suitability of times. Parents also reported concerns over the quality of the respite care available and problems with the experience of feeling guilty and worried when leaving their child in respite, both stressful experiences related to utilisation of respite. All of these challenges relating to utilisation of respite are likely to contribute to increases stress levels in parents.
Previous studies have also reported problems with respite such as parental worry about the ill child, difficulty in accessing social networks in the short respite time available (Valkenier et al., 2002), exclusion from respite of children with challenging behaviours and general unhelpfulness of the respite services offered (McGill et al., 2006). McGill et al. raise questions about the equity of respite services, suggesting articulate middle class families with financial and psychological resources are more likely to access suitable services than the more disadvantaged families and those with children who have more challenging behaviours. The potential links between parental stress and respite warrant further research, in particular identification of the factors associated with utilization of respite for families. It appears what may be needed is a more individual approach to respite services for families, tailoring provision of respite to the particular needs of the ill child and the whole family and providing flexibility in time of day or evening as well as duration, location and provider. In addition, consideration needs to be given to employing techniques that will connect with the more disadvantaged families in the community who are not able to access the less obvious avenues to respite services or readily articulate their family’s needs.

In summary, in contrast to previous literature, the families in this sample had a high socioeconomic status (family income, parental education, dual parent families) and access to several sources of support. However, even in these better resourced families, well children had limited access to support activities outside the family home. Families also reported using little respite each week, and had limited respite options suggesting access to respite is likely to be a problem for families with a chronically ill or disabled child in Australia.

The second general aim of the study was to test a series of hypotheses about these well siblings of ill and disabled children. These hypotheses are discussed in turn.
12.1.2 Hypothesis 1: Child Adjustment and Population Norms

The first hypothesis, that parent and child (self) rated well child behaviour problems would be higher than the population norms for children of similar age and gender was supported. Parents rated their well children as having more internalising and externalising problems than are evident in age and gender matched population norms. Parents also reported higher scores for well children on all the individual subscales of maladaptive behaviour compared to norms. Specifically, well children were perceived by their parents as more aggressive, more rule breaking, more anxious and depressed, more withdrawn and more likely to have somatic complaints, attention problems, social problems and thought problems than their peers in the population.

These parent rated results reflect findings of several meta analyses showing that well children with a chronically ill or disabled sibling have more adjustment problems than children with healthy siblings (Lavigne & Faier-Routman, 1992; Sharpe & Rossiter, 2002; Williams, 1997). The current findings also support a comprehensive study of children with siblings diagnosed with spinal muscular atrophy and healthy controls (Laufersweiler-Plass et al., 2003) where well siblings were found to have higher internalising problems scores than the control group of children with healthy siblings. The more specific finding of higher internalising behaviours is supported by the large study by Cadman et al. (1988), who found well children at twice the risk of depression and anxiety than children without a seriously ill sibling in the family. Similarly, Silver and Frohlinger-Graham (2000) found higher levels of anxiety, depression, interpersonal sensitivity and hostility in well girls with a chronically ill sibling compared to well children with healthy siblings. A longitudinal study, (Houtzager et al., 2005) also found higher levels of emotional problems in children with a sibling with cancer compared to healthy controls, with half the well children
experiencing problems at rates twice as high the reference group. The higher rate of anxiety in these well children was still present at the two year follow-up suggesting an increase in internalising problems may be a longer term effect. The current findings also support previous research reporting higher levels of emotional problems in children with a chronically ill sibling (Giallo & Gavidia-Payne, 2006; Taylor et al., 2001) and higher anxiety, lower self concept and higher depressive affect (Hollidge, 2001) compared to population norms.

Similarly, the current parent rated finding that children with a chronically ill or disabled sibling have more externalising problems than children in the general population supports the findings of previous research. Laufersweiler-Pass et al. (2003) found rates of problem behaviours were two to three times higher in well children with chronically ill children than peers with healthy siblings. Well children with ill siblings have also been found to display more hostile behaviour compared to controls matched for age, gender birth order and age spacing (Silver & Frohlinger-Graham, 2000).

The current results provide evidence that, according to the parents, Australian children are similar to children in the mainly American-based studies in their higher risk for negative outcomes. It is of course possible that parents are exaggerating their well children troubles, perhaps their concern that the well children are suffering because of the family focus on the ill siblings is impacting on their perception of the well child’s behaviour. It is also possible these parents have a heightened alertness for problems as a result of their focus on observing and responding to any changes in the condition of their ill child. Parents have been found to rate their well child as having more behavioural problems immediately following a cancer diagnosis in a sibling (Sahler et al., 1994), suggesting the increased focus on illness does have an effect on parent ratings of behaviour problems. This focus on what is “wrong”, a skill necessary for care
and treatment in the ill child, may make them more sensitive in their awareness of problems in their well children, and lead to over-reporting of problem behaviours. Some previous research has found well children with a chronically ill sibling have no more problem behaviours than their peers the general population (Noll et al., 1995; Stawski et al., 1997; Thompson et al., 1994) although these researchers also used parent ratings to assess behaviour problems.

Interestingly, the parents in the current study also rated their child with a chronic illness or disability as having behaviour problems higher than norms, and rated the ill child as having more adjustment problems than the well children. This does suggest either heightened alertness to problems or relatively chaotic families where all the children have behaviour problems, or perhaps both. A further possibility is potential bias by the same rater (the parent) rating both their ill and well children, thereby forcing a direct comparison between siblings. Future research could benefit from the use of an additional rater to allow testing of informant effects.

In contrast to the parent rating finding of adjustment problems, the well children did not rate themselves any differently to population norms in their self ratings of internalising behaviour. This is consistent with previous research which has found parents rate their well children as having more problems than the well children rated themselves (Guite et al., 2004). Previous research comparing child self report measures of adjustment to control groups or norms is limited, but is generally inconsistent with the findings of the current study. Adolescents (aged 12-18) with a sibling diagnosed with cancer were found to self report internalising problems significantly higher than population norms (Houtzager et al., 2004). Well children have also self reported higher depression scores compared to population norms (Treiber et al., 1987) and controls (Engstrom, 1992) as well as higher levels of psychological distress compared to
children with a healthy sibling (Silver & Frohlinger-Graham, 2000). Well children with diabetic siblings also self reported lower self concept scores compared to controls with healthy siblings matched for age, family size and SES (Ferrari, 1987).

A possible explanation is that well children are underrating their problem behaviour because of social pressure to respond to questions about their own well being in a positive way. This explanation is supported by the finding that well children scored significantly higher on the measure of social desirability compared with the population norms suggesting a tendency for children to answer questions in a way they perceive they are expected to answer. Strohm (2002) gives some salient examples of well children describing how society pressures them to feel lucky that they are healthy, and how they try to be good and to achieve in life in order to make things right for their parents (see section 1.5). In addition, children may have been influenced by a real desire to avoid further worry and burden to their parents by reporting exemplary behaviour. This is consistent with the finding of Sharpe and Rossiter (2002) that increased internalising in well children is related to the desire to hide problems from parents. Sloper (2000) also found children did not want to discuss problems with their parents in order to avoid placing additional worry on their shoulders.

12.1.3 Hypothesis 2: Parenting Style and Child Behaviour

The second hypothesis, that well children with authoritative parents would have fewer behaviour problems than well children with parents who used authoritative parenting style to a lesser degree was not supported. Firstly, authoritative parenting was not associated with better adjustment outcomes for well children than authoritarian, permissive or neglectful parenting. Secondly, there was also no relationship between child adjustment outcomes and degree of parental authoritativeness in that children of
the most authoritative parents did not have better adjustment outcomes than children of moderately authoritative, somewhat authoritative or not at all authoritative parents.

This finding is not supported by previous literature, which found poorer adjustment outcomes for children of parents with a less authoritative parenting style (Bronstein et al., 1996; Kaufmann et al., 2000; Lamborn et al., 1991; Steinberg et al., 2006; Steinberg et al., 1994; Steinberg et al., 1992). This finding is also not consistent with previous literature, where closer relationships with parents, typical of authoritative parenting, has been found to be an important protective factors for children in adverse environments. Authoritative parenting factors such as higher parental warmth, good supervision and balanced discipline have long been associated with resilience in children (Rutter, 1974; 1990; 1993; 2000; Werner & Smith, 1982; Wilson, 1974).

A possible reason for the lack of support for this hypothesis is related to problems with the use of the measure of parenting style (the PSQ) on the younger age cohort in this study. Although the authors of the PSQ state no age criteria for the questionnaire, it is likely that the behavioural control subscale of the PSQ may not have been appropriate for children of this age group. The behavioural control questions related to how late children are allowed to stay out at night (on school nights and on weekends). It is likely many children in this study were too young for this question to be relevant to them, in that they were not old enough to go far from home without adult supervision at any time of the day or night. The published studies using the PSQ have all been on adolescent samples, while the children in the current study were as young as seven years old. The low alpha reliability score for this scale supports this possibility.

Another possibility for the lack of support for the hypothesis of a relationship between parenting style and child adjustment is suggested by the previously cited findings that children with a chronically ill sibling are particularly aware of the worry
and stress of their parents and are concerned with not adding to their problems. It is possible this highly empathic focus of the well children toward their parents influences them to respond to questions about parenting style in a positive light. Indeed, parental warmth (a dimension of the parenting style measure), was rated by the children very highly, on average, and there was not much variation across the sample. Future research using several different ways of assessing parenting style could add to the knowledge about the relationship between well child adjustment and parenting style for families with a chronically ill child.

The parenting style and child adjustment relationship has important practical applications for families as a potential way of providing improved outcomes for well children as well as alleviating some of the stress for these parents who worry about the impact of the chronically ill child on the rest of the family. With the best will in the world, the high demands on parental time and resources make it difficult for parents of chronically ill or disabled children to always act in authoritative ways, expressing warmth and affection, while setting limits and being involved in the activities of well children as much as they would like. Often the needs of the ill child must take precedence and the parents may be separated from the well children for periods of time, or under such stress they are unable to manage parenting as well as they would like. Research could identify some key practical ways parents can focus their limited resources to enhance their parenting. For example parents could reinforce making reasonable demands for maturity in the allocation of household or care tasks with well children, and employ alternative methods of demonstrating warmth and affection when they are physically absent from the home. Possibilities include by sending written messages home, making phone calls directly to the child, text messaging, or leaving the
well children with something special to care for in their absence to strengthen the parent-child connection during these times.

12.1.4 Hypothesis 3: Predictors of Well Child Adjustment

The third hypothesis, that better parent and well child (self) rated adjustment would be associated with and predicted by child, parent and family factors was partially supported with several significant relationships and predictors.

12.1.4.1 Child factors. The most consistent relationship with well child adjustment was ill child behaviour problems. According to the parents, well children were better adjusted when the ill children also had fewer behaviour problems. This was the case for total ill child externalising behaviour as well as the individual subscales of ill child rule breaking and aggressive behaviour. It was also the case for total ill child internalising behaviour, as well as the ill child internalising subscales of anxious/depressed, withdrawn depressed and somatic complaints, plus ill child attention, social and thought problems. When the ill child is anxious, depressed or solitary in their behaviour the well child was rated as more likely to behave in the same way. Similarly when the ill child is aggressive, disobedient and rule breaking in their behaviour, the well child is rated as more likely to display the same antisocial behaviours according the parents. When the ill child displayed problems with their attention focus, social relationships or unusual thoughts, the well child also displayed the same behaviours, according to parents.

A relationship also existed between well child self ratings of aggression and parent rated externalising behaviour in the ill child. The well children rated themselves as more aggressive when they had an aggressive and rule breaking ill sibling. There was no relationship between well child self ratings of anxiety and any behaviour
problems in the ill child. In addition, ill child internalising and externalising behaviour were significant independent predictors of several subscales of well child adjustment.

These findings are supported by previous research which has found ill child behaviour problems related to well child behaviour problems (Stawski et al., 1997). Stawski et al. suggest a direct link exists between ill child behaviour problems and well child behaviour problems; possibly the well child is modeling the behaviour demonstrated by ill child or vice versa.

Family systems theory however argues the relationship between ill child behaviour and well child behaviour is more complex. Minuchin (1974) proposes that relationships among family members are interconnected, suggesting it may be an oversimplification to suggest that the well child - ill child modelling behaviour occurs in isolation from the impact of other family members. According to the theory, the development of behaviour problems in well children is influenced by all the other relationships in the family, not just interactions between siblings. For example, in families with a chronically ill or disabled child, the differences in the needs of each child are accentuated and relationships are likely to be affected accordingly. Parents may find it hard to balance the desire for fairness and equity between siblings, and the different requirements of their children, making it difficult to apply one standard of discipline to their well children while allowing flexibility for the needs of the ill child. As a result the relationship between the parent and the ill child impacts on the well child, possibly in a negative way. Strohm (2002) presents a poignant example of this in a quotation from a parent.

“I know you used to get mad at me for not telling your sisters when they did something wrong, but if you correct someone on something and they learn from it, then it is an appropriate thing to do. But if they don’t learn from it, and you tell them over
and over and over again and they still don’t learn ... Well, I had to let it go sometimes, because if I kept correcting them and correcting them and correcting them again, then their whole lives would have been filled up with negativity and I didn’t want that for them” (Strohm, 2002, p. 42).

Here the parent describes a decision to not discipline the ill child for two reasons, firstly because the limitations of the child’s illness meant they were unable to learn from discipline in the same way the well child was, and secondly in order to avoid constantly being negative toward the ill child. Just as poignant is the expression of the dilemma experienced by the parent, knowing this inequity is causing a problem in the parent-child relationship but unable to change the situation.

Another quote from a sibling in Strohm’s (2002) research provides an example of the impact on the well child’s behaviour of parent - ill child interactions.

“... when I was quite small I would sometimes refuse to dress myself, even though I was quite capable of doing so. Having watched my mother dress my sister, I would say, ‘You dress her, you can dress me!’ My sister seemed to get so much more of my mother’s time. She was washed, dressed, fed, put to bed, and if she cried she usually got what she wanted. She would be collected in a big special bus to be taken to her special school. I resented the fact that she got so much attention. I desperately wanted the same” (Strohm, 2002, p. 32).

In this example the well child is increasing her demanding behaviour as a result of the ill child’s special needs. Already stressed parents may find it difficult to explain why one child gets extra help and attention. It may be easier to give in and risk increasing the demanding behaviour. Or parents may simply be so overwhelmed with all the hassles and stresses that their attention to behaviour problems in the well child is subsumed by the more salient stimulus of the ill child’s physical and medical needs. In
the context of family systems theory, the evidence of a relationship between ill child behaviour problems and well child behaviour problems provides further support for a family approach to childhood chronic illness. The interconnected nature of the family means problems in one family member impacts on everyone else in the family. It is important to provide resources to support the whole family unit, parents, well children and ill children in the family, in order to improve outcomes for well children, and the entire family (Gavidia-Payne & Hudson, 2002).

Well child age was also related to parent ratings of well child behaviour problems. Younger well children had more adjustment problems than those who were older, and younger age in well children was a significant predictor of more attention and social problems. There is little evidence of age as a factor in well child adjustment and what is published is conflicting (see section 3.6). Previous research by Ferarri (1983) found younger children were more negatively affected than older ones by having an ill sibling, while Stawski et al. (1987) found no age difference for total problem behaviours or externalising problems but older children had more internalising problems than younger. Some support for the current results relating to age can be found in the resilience literature, which presents participation in caring for younger children (suggesting higher age) as a protective factor in the face of adversity (Werner 1989). Werner suggests the responsibility gained from sharing in the role of caring for the ill child has beneficial effects on children. However this explanation was not supported by any relationship between participation in care tasks and parent rated adjustment problem in the current study. In fact, child rated adjustment was associated with participation in care tasks but in the opposite way. Children who rated themselves as more anxious were rated by their parents as spending more time caring for their ill sibling, which is not consistent with the proposal that participation in care is beneficial for well children.
It is likely that the relationship between participation in care and child adjustment is more complex than the scope of this study. Possibly other factors relating to care tasks are also important in child adjustment, for example the child attribution results (see hypothesis four) suggest the child’s attitude to performing care tasks may be important. As well, it is possible these findings are linked to the child’s worry about their parents. The more anxious children may try and help their parents (by caring for their ill sibling) in order to reduce some of the burden. Well child anxiety was not related to the child’s own reports of care behaviour (only the parent rating of child participation in care tasks) suggesting anxious children don’t think they help a lot, but their parents think they do.

Although a relationship between participation in care tasks and well child anxiety was found, the method of measuring participation in care tasks should be reviewed for future research as the method used in this study produced somewhat contradictory reports. Parents listed fewer care tasks than the children, but estimated the time taken to be longer. While it is possible well children simply took longer to do fewer tasks, closer inspection of the responses reveals the wording of the question may have influenced the children’s responses. The children were provided with five examples of tasks, in order to help them understand the question (e.g., helping make the bed), and many children simply listed the same tasks as the examples (or circled the examples) possibly without really considering what types of activities they performed. Parents did not tend to do this, and consequently listed fewer tasks. Further research could refine the method of assessing participation in care and explore this relationship in more detail.

The relationship between child participation in social activities and adjustment problems has already been briefly mentioned. Children who rated themselves as more aggressive reported participating in fewer social activities. This supports previous
research (Williams et al., 1999) that a well child’s perception of higher levels of social support is related to positive outcomes for children. It is not possible from the current study to determine why this is happening. As previously mentioned, a possibility is that the aggressive behaviour of the children makes it hard for them to participate in social activities so they are less likely to persist with groups outside the family. Another possibility is that not being able to participate in social activities, perhaps due to the needs of the ill child impeding the well child’s ability to participate, leads to frustration and more aggressive behaviour in the well children. Strohm (2002) gives a quotation as an example where a well child talks about their parents not being able to attend their activities due to the “inevitable autistic/psychotic tantrum” of the brother who would then need to be removed.

“I downplayed anything I did well that might require parental attendance, because my brother would have to be taken along, and he would invariably throw an autistic/psychotic tantrum and have to be removed. As a result, I didn’t ask my parents to attend when I was in choral performances or theatre or the like, or just said that I understood they couldn’t come because of my brother” (Strohm, 2002, p. 36).

Children may be embarrassed or resentful of their parents’ non-attendance or the implications of their ill sibling’s behaviour and avoid participation in external social activities. It is important to note no relationship was found between ill child behaviour and well child participation in activities outside the home. However, in the current study the wording relating to amount of participation in activities outside the home may have been unclear. Parents were asked to report the “support programs or other group activities their well child participates in” implying the group must be of an overtly supportive nature. This may have lead parents to omit activities they did not consider supportive. The most common groups reported were sibling-specific groups and
sporting groups, perhaps the ones the come to mind first. In addition, the framing of
this question would mean children who were currently not participating in a group for
some reason (school holidays, outside the sporting season) would be reported as having
no activities outside the family unit. In future research, the question should be clarified
to ensure any activities outside the family home are included, and extended to include
groups recently participated in as well as current attendance. Information about
frequency and regularity of meeting may also be useful to explore the details of any
relationship between participation in outside groups and child adjustment.

12.1.4.2. Parent factors. While the direct impact of having an ill
sibling may mean higher risk outcomes for well children, researchers have suggested
parent and family factors also play a role in better or poorer outcomes for healthy
siblings (Williams et al., 2002). In this study, the most consistent relationship between
parent factors and well child adjustment came from the parent stress variable. When
parents reported more stress in the form of daily hassles, they also scored their well
child higher on all the subscales of maladaptive behaviour. High parent stress was also
an independent predictor of parent rated well child externalising behaviour, attention
problems, social problems and thought problems in the regression analyses. This
supports previous findings that cumulative parenting stress places children at increased
risk of poor adjustment outcomes (Crnic et al., 2005) and high parental stress is a
predictor of poor behaviour outcomes in children (Friedman et al., 2004).

It seems to be stating the obvious to say that parents with chronically ill children
are under increased stress (Nereo et al., 2003; Woofson & Grant, 2006). Strohm (2002)
presents an overwhelming list of the many factors which combine to increase parental
stress in families with a chronically ill child including juggling appointments,
combating exhaustion, pressure on the marital relationship and on maintaining
relationships with other children, fear for their child, for themselves and for their family, worry about the pain of medical procedures, worry about the impact of the illness on the ill child’s development, and on the rest of the family, vision of their care giving role extending indefinitely, anger, anxiety, guilt, the need to give up work, medical costs adding considerable to the family’s expenses as well as the ongoing stress of day to care for a child with a chronic illness or disability which can be physically and emotionally overwhelming. Even negotiating service providers who are there to provide assistance to the family can be confusing and exhausting.

This study places previous findings of poor outcomes for children of stressed parents in the context of chronic illness. The implication of these findings for children with chronically ill siblings lies in the potential improvements to child outcomes, which may result from focusing resources on reducing parent stress. On a larger scale, outcomes for well children could be improved by providing more resources to directly reduce the causes of parents stress such as assistance with the financial and care burden for these families. However this option would prove to be expensive and resource intense, and the stress caused by worry about the ill child’s illness and future prospects cannot be addressed with such practical assistance alone. Providing parents with some skills and strategies in stress management and relaxation may go some way to reducing the experience of stress for the parents, as well as reducing the impact of stress on the family and ultimately improving adjustment outcomes for the well children. In addition it is important to note that the relationship between parent stress and child behaviour problems is bidirectional. Difficult behaviour by the well child both contributes to, and results from, high levels of parent stress (Nereo et al, 2003). Interventions, which address the problem behaviour in both the well and ill children, are also likely to reduce
stress in parents. Specific suggestions for interventions, which address child behaviour as well as parent stress, are addressed later in the chapter.

In this study there was some evidence for the relationship between child adjustment and parent’s use of psychological autonomy granting. Lower levels of parental autonomy granting were related to well child self rated anxiety and aggression. Well children who rated themselves more aggressive in their behaviour and more anxious regarded their parents as more coercive and undemocratic in their discipline. This finding is supported by previous research evidence that a parenting style, which is high in psychological autonomy granting, is associated with better child adjustment (Kaufmann et al., 2000; Lamborn et al., 1991; Steinberg et al., 2006; Steinberg et al., 1995; Steinberg et al., 1994; Steinberg et al., 1992; Strage & Brandt, 1999). Parents who exercise psychological autonomy granting in their parenting behaviour are promoting independence by allowing participation in decision making and explaining reasons for decisions. The enhancement of independence and self-regulation in children helps to develop their ability to apply adaptive strategies when faced with problems (Aunola et al., 2000). It is possible the benefits of encouraging independence in well children with a chronically ill sibling are magnified in a home environment where the attention of parents is often necessarily diverted to the care needs of an ill child. Well children with more skills in independence and self-reliance would be better able to manage for themselves and place less demand on their parents, possibly achieving the additional benefits of increased maturity and self-confidence as they find they are able to manage tasks for themselves. In the resilience literature, enhancement of competence and self-esteem as well as development of independence is a key characteristic of resilient children and has been associated with homes where parents provide clear and
consistent limits and encourage independence, self-respect and confidence (Werner & Smith, 1982).

In contrast, children in families low in autonomy granting are in environments which repress self-sufficiency and self-expression. In families with a chronically ill child where the time a parent can spend with the well child is limited, children who are not independent enough to be able to meet some of their own care needs may find themselves waiting for help, feeling ignored, and becoming frustrated and resentful of the attention received by their ill sibling. The well children in this environment may feel less capable, less confident and unable to manage without their parents during the periods of emotional or physical separation characterised by childhood chronic illness. It is easy to see how there is potential in this parenting environment for adjustment problems to develop in the well children. The finding of an association between psychological autonomy granting and well child adjustment suggests further research would be of benefit, despite the lack of evidence of any influences on well child adjustment of any of the four parenting styles (authoritative, authoritarian, neglectful and indulgent).

Further implications of these findings may come from the links between parental stress and particular parenting styles. Parents with higher levels of stress have been found to resort to more authoritarian approaches to parenting (see section 3.4), although no direct relationship between daily hassles and any parenting style was found in the current study. A family environment, which combines high daily hassles coupled with low autonomy granting, suggests a particular parenting style that is relatively chaotic. Parents may be unable to manage all the stresses in the family and become more authoritarian in an attempt to control the situation – unsuccessfully - resulting in more conflict, poor child behavioural outcomes and more parental stress. Further research
may help parents identify this downward spiral and be of benefit to families living in these difficult environments by providing ways to reduce stress and implement alternative parenting strategies.

12.1.4.3 Family factors. Belsky’s (1984) model of factors that influence parenting lists available resources, such as income, employment and social support, as important to enable effective parenting. Although social support and education were not significantly associated with child outcomes in this study, the limitations of a sample with high SES (family income and maternal education) must be considered in relation to these findings.

Family income was the main family factor related to child adjustment outcomes. Children from families with lower incomes were rated as more aggressive and rule breaking by their parents than children from more wealthy families, and low family income was a significant predictor of parent rated externalising behaviour in well children. A relationship between income, low emotional state in the parent and well child behaviour problems was suggested by Williams et al. (2002) who found income to affect maternal mood which in turn influences child behaviour. This is consistent also with the literature on SES and health outcomes (Lynch & Kaplan, 2000). The relationship between income and behaviour problems is of particular concern in light of the likelihood that many families with a chronically ill or disabled child suffer reduced income and other financial pressures (Emerson et al., 2006) such as high medical expenses, reduced employment opportunities due to care demands and various other reasons (see section 3.3). It seems reasonable to assume that well children from the more disadvantaged families (those not represented in this sample) are even worse off. Further support for this assumption can be found in the findings of epidemiologic
suggesting families with low incomes and less parent education are more likely to have children with special health needs (Newacheck et al., 1998).

The implications of this finding in relation to income can also be seen in the context of the cumulative effects of risk factors for children. Low income has been documented as a risk factor for poor child outcomes (Garmezy, 1991, 1996; Rutter, 1979; 1996; 2001; Werner & Smith, 1982, 1993) and sibling chronic illness appears to be a risk factor as well. Research has found the presence of more than one risk factor greatly increases the chances of adverse outcomes for children (Fergusson & Horwood 2003, Rutter, 1979). If children with a sibling with a chronic illness are also more likely to live in situations of poverty or significantly reduced income, they are likely to be exposed to more than one risk factor. Future research could explore poverty and sibling chronic illness in a sample with a broader socio-economic status to understand these relationships better.

Although family access to respite has been discussed earlier in this chapter, it is important to report here that access to and use of respite was not related to any well child adjustment variables. Although there is no direct link in previous research between child adjustment and access to respite, Bruns and Burchard (2000) found use of respite, increased optimism and reduced stress in parents, suggesting better child outcomes. A possible reason for the lack of support for a relationship between respite and child adjustment outcomes is the short-term benefits of respite (Meltzer & Johnson, 2004) which has already been discussed. Future research could explore the relationship between length of respite intervals and well child adjustment.

Resilience research also suggests smaller families are a protective factor for children faced with adversity such as sibling chronic illness. In this study no relationship was found between family size and child adjustment outcomes. Possibly
the range of families sizes in this study was too small to enable adequate study of this question (86% of families had 2 or 3 children).

12.1.5 Hypothesis 4: Attributions and Well Child Adjustment

The fourth hypothesis, that well child adjustment and more positive attitude on the part of the well child toward their ill siblings would be related, was partially supported. Well children with more externalising problems reported more negative (than positive) comments about having and ill sibling. Houtzager et al. (2005) similarly found maintaining positive expectations of illness outcomes predicted positive quality of life in well children with a sibling diagnosed with cancer, and Williams et al. (2002) found well children who expressed positive feelings regarding the ill child and positive attitudes toward the illness recorded fewer adjustment problems. Strohm (2002) presents a quotation from a sibling, which demonstrates the positive attributes of introspection, empathy and understanding a well child attributes to their experience of growing up with an sibling with a chronic illness or disability.

“`My brother’s special needs make me reflect quite a lot on what kind of person I would be if he wasn’t around, especially when kids use terms like ‘spastic’ to put people down. I wonder if I would be like them and not know anything about the problems faced by families in this situation” (Strohm, 2002, p. 81).

The relationship between negative perceptions and behaviour problems may be explained by the findings of Gardner (1998), who found children who felt parents were deflecting their feelings, often had feelings of resentment and struggled to cope. Children who present their parents with mostly negative perceptions, such as resentment at missing out, or anger at being treated differently, may receive deflecting responses from worried and overburdened parents resulting in an increase in well child anxiety or more problem behaviours. Further exploration of the processes between parents, indeed
any adults, and well children in these situations may shed light on the relationship between attitude and well child adjustment.

Another explanation may be a more direct relationship between the power of the thoughts themselves and children’s coping and behaviour problems. In research by Williams et al. (2002), well siblings’ attitudes to illness were related to self-esteem, and both attitude and self-esteem related to behaviour. Children also reported feeling responsible for causing illness by the “power” of their angry thoughts. It is possible these two findings are related in that “causing” bad events by negative thoughts is a source of stress, guilt and fear for the well children, evidenced in behaviour problems. Strohm provides a quote, which demonstrates this point.

“He was playing with my hat and then went very quiet under the dinner table. There was such a panic in the house – it was Christmas lunch. I never let my brother play with anything of mine after that – it was an obsession – in case it caused another seizure” (Strohm, 2002, p. 22).

The most common type of positive comments from well children about their ill siblings were in the self-improving category where children reported gaining an important quality from having a sibling with a chronic illness or disability. For example one sibling wrote “he has taught our family about ourselves”. The most common type of negative comment fell into the category of missing out on things, for example on sibling wrote “don’t get many friends over, don’t get to go to many places”.

Strohm (2002) presents a quote from an 11 year old girl, which provides a similar summary of the good and bad things about having a sibling with a chronic illness or disability, as well as demonstrating the empathy, maturity and insightfulness possible in children in difficult circumstances.
“I guess a good thing about having a sibling with a disability is that you develop more of an understanding about things than a person who has not got a sibling with a disability. Another good thing is that my brother looks up to me because I know a lot of stuff he doesn’t.

There are many bad things too, such as my brother will sometimes attack me because he simply can’t get his message across to me, so I feel hatred toward him. Sometimes I feel jealous of him because my parents make a lot of fuss over things he does and not as much fuss over things I do.

But, hey, if you think about it, these feelings are just the same as a child would have if their sibling didn’t have a disability so it isn’t that much different after all. I would say the good feelings are love and friendship and the bad feelings are jealousy, hatred and frustration.” Strohm (p. 148)

12.1.6 Hypothesis 5: Child Drawings

The fifth hypothesis that well child adjustment as measured by child drawings, would be associated with several child, parent and family variables was not supported. Well children with drawing-assessed emotional problems did not significantly differ from children without emotional problems on any of the ill child, parent or family variables. This may relate to the child drawing measure itself. Projective assessments such as drawings are criticised by psychologists as not well supported by psychometric data (Gregory, 2004; Merrell, 1999) and the evidence about whether drawings are able to distinguish between children with behavioural, social or emotional problems and children with normal adjustment is conflicting (Cummings, 1986). Additionally, a problem encountered with the assessment of the child family drawings in this study was that the sample size for assessable drawings was low, increasing the possibility of missing significant associations between variables. This was because cartoon drawings,
stick figures and drawings of only heads could not be included for assessment. This sample size could have been increased by providing more specific instructions to the children about the drawing for example requesting the children to whole people (not just heads) and to avoid drawing cartoon or stick figures. A balance needed to be reached however, between ensuring the drawing was a fun and positive experience for the children, and providing sufficient instructions to enable assessment without removing the expressive nature of the exercise. Interestingly though, child adjustment assessed through the child drawing method was related to child adjustment assessed by the parent and child rated behaviour ratings scales. This analysis forms part of hypothesis six and is discussed later.

This study also found what appears to be a high number (57%) of children assessed as having emotional problems using the Koppitz method of assessing drawings (36 out of 63 children). Koppitz does not provide any normative data for her method, however in a study of two groups of 79 fourth and fifth grade children, Koppitz reported one third of the children scored as having emotional problems. Perhaps this high number is because the measure is not sensitive enough to differentiate between slight and more severe problems in children. Another possibility is that the emotional indicators are sometimes, in fact, due to the normal developmental stages, producing a number of false positives. Figure 11, for example, shows a drawing of a head attached directly to the body (an indicator of impulsivity using the Koppitz method) and Figure 12 shows a drawing with the “legs pressed together” (an emotional indicator for anxiety). Both of these examples are also normal developmental drawing stages for children. However it is interesting to note that there was no significant difference between the ages of the children assessed as having emotional problems, and those with no emotional problems, in this small sample.
Regardless of the lack of support for this hypothesis, the value of the child drawings in this study remains evident in that assessment of child adjustment was only one reason for inclusion. The main advantage was that children found the projective expressive techniques safer and less threatening, as well as fun and enjoyable, so the use of the techniques helped the child to relax and enjoy the assessment experience.

In addition, one finding from the drawings was that, children who produced scribble drawings were more anxious and aggressive and had more social problems than children who produced recognisable drawings. Although scribble was not assessable using the Koppitz method, this result suggests that the drawing exercise itself may provide useful information about child adjustment beyond the Koppitz assessment method. The drawings also provided a vehicle for understanding the children’s perspective of the family structure by allowing the children to draw whoever they considered part of their family, and omit people as they chose. Some children find it difficult to put their feelings into words in the interview situation (Menke, 1987) particularly siblings of children with a chronic illness who are hampered by family and social pressure not to complain (Strohm, 2002), so the use of other expressive types of measures is potentially an important vehicle for the children to express their feelings. Future research using child drawings should consider these issues in order to increase the usefulness of the drawings as a measure.

12.1.7 Hypothesis 6: Relationships Between Behaviour Measures

The sixth hypothesis that (a) parent rated measures of well child adjustment using behaviour rating scales, (b) well child self rated measures of well child adjustment using behaviour rating scales and (c) projective/expressive measures of well child adjustment in the form of family drawings would be related, was partially supported. Associations were found between the three adjustment measures but not consistently
across all measures. All the domains on the parent rated and child rated behaviour rating scales were significantly related, suggesting agreement between parent and child ratings, however the correlations were modest rather than high.

There were also significant differences between children assessed as having or not having emotional problems (using the child drawing method) on behaviour problems (assessed by the behaviour rating scales), suggesting a measure of consistency in the projective and non-projective assessments. When considered independently, it was the child rated measures of aggression and anxiety, which were significantly related to the drawings. Children who had emotional problems as assessed by their drawings, rated themselves as more aggressive and more anxious than the children whose drawings did not indicate emotional problems, indicating the children were relatively consistent in what they said in their questionnaires and what they revealed with their drawings. However the links were small and more research is needed to further understand these relationships. Nevertheless the use of multiple measures and multiple informants in the current study provided a range of perspectives on well child adjustment which, although not identical, were generally supportive of each other. These findings suggest a degree of consistency in the child adjustment measures and add a valuable dimension to our understanding of well child adjustment. The benefits of this approach are discussed in more detail in Section 12.3 (Strengths of the study).

12.2 Limitations

A number of methodological issues should be considered in relation to the current study. First there is a lack of longitudinal research in the area of chronic illness and child adjustment. Cross sectional methodologies dominate the published research and only a few longitudinal studies have been published (Williams, 1997). A few studies have returned to the children 12 or 18 months after diagnosis, or a follow-up 5
years later, but there are no really long-term studies, such as those in the field of resilience research. The resilience literature supports the need for longitudinal research to identify child outcomes in adverse circumstances. Resilience theorists argue that negative and positive outcomes may be missed in cross sectional research. Certainly, work with adult siblings suggests some siblings may not be aware of their feelings and the impact on their life until they are older (Strohm, 2002) and cumulative risk in childhood has been found to predict behaviour problems in later adolescence (Appleyard et al., 2005). The current study is cross sectional, providing a snapshot of how children behave at one brief period of time. This is useful as a starting point, however future research would benefit from a longitudinal approach in order to understand how well children adjust as they mature.

In addition, the large age range of the well children for this study caused some problems. A large age range was selected in order to be inclusive of all children in the family and to increase sample size in view of the difficulty in recruiting participants for research in the area of childhood chronic illness. However, selecting measures, which are age-appropriate for such a large range of developmental stages, is difficult. As a result the younger children struggled with some of the concepts (e.g., parenting style) and some of the older children may have felt the questions were too “babyish” for them. It is difficult to find a middle ground in the selection of measures; future researchers should consider the best age option for their sample.

The sample is only of moderate size. A larger sample would provide better analysis options, however recruitment of participants in this field of research is difficult as discussed previously. Finding the time and energy to volunteer to participate in research is not feasible for many families with chronically ill children, despite a likely desire to contribute to investigative efforts in relation to well children in their family.
Further to the issue of the current sample, most of the families were accessed through support services, so families who heard about the research were predominately already in touch with some kind of advocacy or support service. Families with low education and literacy levels, English as a second language, from disadvantaged and migrant communities and areas with little access to support through illness and sibling support groups were not accessed despite all recruitment efforts. Stoneman and Rivers (2003) report the problem of restricted samples, which focus almost exclusively on middle class European-American children, is a problem encountered by many researchers into sibling issues due to the difficulty in recruiting participants from minority groups and families which span the full range of socio economic statuses.

In this study, most participants were required to contact the researcher to express their interest in participation, requiring a level of motivation, exertion and organisation which may be beyond the families who find coping with day-to-day life more of a struggle, who have fewer resources and less confidence in their ability to contribute to research. Further, these struggling families may be less inclined to expose their parenting, family and child functioning to scrutiny by strangers. The families who elected to participate may be those with better adjusted children, where parents may be happy to demonstrate their child’s positive adjustment to a researching psychologist and to the broader community. Nevertheless, despite all these reasons why the sample may be biased toward better adjusted children, the picture for well children in this study was one reflecting greater adjustment problems than among the normative population of similarly aged children. It is reasonable to assume that the situation for well children in more disadvantaged communities is worse. Future research would benefit from funding to access more disadvantaged families through provision of reassurance and
encouragement as well as assistance such as respite and interpreters for families with barriers to participation.

In relation to the measures, two of the measures in the current study would benefit from some improvement for future research purposes. Firstly, the child rated measure of aggression was not as useful as expected. The measure was the CBCL YSR, modified and shortened to remove items which were considered too threatening for child research purposes (see section 6.2.2). The scoring was also changed to include the modified aggression questions interspersed with the child rated anxiety questions (RCMAS). Although these modifications resulted in a more child-friendly questionnaire, they also caused a number of problems. Some children were uncomfortable with having to choose a “yes/no” response and many created their own mid point “sometimes” response on the questionnaire, creating problems with scoring. In addition, because of the modifications and reduction in the number of items, the child rated aggression scores were not comparable with published population norms. Future research would benefit from a measure of child rated aggression which is child-friendly but also reliable, valid and suitably normed.

Secondly, as referred to earlier in this chapter, the behavioural control subscale of the parenting style measure (PSQ) does not appear to be appropriate for this younger age sample, producing a low alpha reliability. In addition, the younger children appeared to struggle with some of the concepts in the questionnaire, for example the researcher was asked to explain the statement “My parents keep pushing me to think independently” to many of the children personally visited. Future research would benefit from a more age appropriate measure of parenting style, particularly behavioural control. More generally in relation to measuring parenting style is the issue of reluctance by well children with chronically ill siblings to add to the worries and
problems of their parents. As discussed, it is possible these levels of empathy and concern may influence the children to rate their parent’s method of parenting in a positive light. The inclusion of another method of rating parenting style (such as parent’s own ratings, or observations) would improve research in this area.

12.3 Strengths of the Study

The current study had several strengths. First was the use of two different measures of assessing child adjustment, a direct and objective measure (behaviour rating scale) and a projective/expressive measure (child family drawings). Published authors in the field of child assessment advocate using multiple methods of assessment whenever possible in order to obtain the most compete understanding of the emotional, social and behavioural functioning of a child (Gregory, 2004; Merrell, 1999). Open ended questions were also used to obtain information regarding the well child’s feelings about their chronically ill sibling. The importance of this approach has been highlighted by Menke (1987) who advocates using multiple ways of eliciting information from well children who have a sibling with a chronic illness, as they can be reluctant to reveal problems in interviews.

In addition this research used multiple informants. Research into well child adjustment has focused on parent rated measures and recent researchers have criticised the limitations using just one informant, nearly always the parent, and suggested using other raters such as child self ratings or teachers, in order to get a broader perspective of the issues for the child (see section 4.3).

Another strength of this study was the method of defining chronic illness and disability. Previous research has relied on a classification approach to childhood chronic illness, focusing on children with cancer, cystic fibrosis or epilepsy and considering implications from illness variables such as amount of medical intervention,
number of hospitalisations and amount of time required to care for the child. The focus toward the chronically ill child in this study was on the behaviour of the child, regardless of the illness symptoms or diagnosis. Although there are many illnesses and disabilities which can be defined as chronic, and all are severe in one sense, within this diagnosis children may be at various stages of illness progression, respond to treatment in different ways and have different symptoms and prognoses. The strength of the behavioural approach is that it is applicable to all types of chronic illness and disabilities.

12.4 Implications and Future Research

The finding that the ill child’s behaviour is an important predictor of well child behavioural outcomes adds valuable information to the research field. Previous research has focused on a single illness category such as cystic fibrosis or epilepsy and compared well child adjustment to norms or control groups. Breslau, Weitzman, and Messenger (1981) found no evidence of a relationship between well child problems and diagnostic criteria or level of disability. The current study suggests it is the behaviour of the ill child, which may or may not be related to the chronic illness or disability diagnostic criteria which is important. Future researchers should consider the impact of ill child behaviour when investigating a single illness group, particularly when there are no behavioural problems ordinarily associated with the diagnosis.

Another implication of the relationship between ill child and well child behaviour problems is the potential for behavioural and parenting interventions to improve outcomes for well children. As well as the interrelated nature of child behaviour problems, the bidirectional role of parenting stress in well child adjustment lends support to the view that problems with any one member of a family are in fact interconnected with all of the other family members. In the context of family systems
theory, the interrelated nature of the family suggests a whole family approach is the best way to provide behavioural interventions. In a review of the literature on behavioural supports for parents of children with intellectual disability and problem behaviours, Gavidia-Payne and Hudson (2002) advocate interventions, which include the whole family. When proposing behavioural interventions for children with an intellectual disability, they argue that parent training is most effective when adjunctive supports are provided such as stress management, marital therapy and problem solving training.

Similarly, Anthony et al. (2005) suggest it is important to examine parental stress levels as well as parenting practice when designing behavioural interventions for preschool children. In the case of families with chronically ill or disabled children, interventions should address both the well and ill child behaviour, as well as parenting stress, parenting style and family resources.

In addition, it is important that any interventions address the strengths of the children and families instead of just focussing on the problem behaviours and weaknesses. Researchers have been cautioned against focusing on only well child assets or problems, but to consider both (Bellin & Kovacs, 2006) and the same constructive approach could be applied to interventions. Leonard (1992) describes children with a sibling with a chronic illness or disability as simultaneously at risk for adjustment problems and for exceptional development. Well children may be highly anxious but also be highly empathic, or have low self concept and high competence (Hollidge, 2001). In the same way interventions not only need to be child and family centred, but also need to focus on highlighting and building the strengths of the child and family, not only on identifying and overcoming the weaknesses.

In relation to child behaviour problems, parenting programs which focus on enabling parents to teach skills to their children in the natural home environment and
using everyday family routines as a teaching agent have been found to be the most salient (Gavidia-Payne & Hudson, 2002). An example is Signposts, an intervention system for parents of children with intellectual disability and challenging behaviours (Hudson et al., 2003). The Signposts program provides parents with eight information booklets, a workbook and a video tape, designed to be implemented in several different ways to suit the needs of the family (i.e., with the support of a group, with support over the telephone or can be self directed). An evaluation of the Signposts program revealed children’s behaviour improved, as did parent stress and feelings of effectiveness in managing their child’s behaviour.

Resources are limited for siblings in Australia. Certainly in Victoria there are only a few services provided for siblings, mostly in the forms of sibling groups or camps. The Association for Children with a Disability has a comprehensive directory of sibling resources for rural Victoria and metropolitan Melbourne (www.acd.org.au/siblings/directory). Sibling groups are the most frequent type of sibling support available. Some groups provide structured activities, but mostly they are purely social groups aimed at providing the opportunity for children to meet with peers who have a sibling with a chronic illness or disability and talk about their experiences. An added benefit is the well children feel special to have a group of their own, particularly where the ill child in the family appears to have many appointments and therapies which may appear ‘special’ to the well child. Some service providers have internet chat rooms available for siblings, which serve the same purpose of communication and peer support but in a more accessible way.

However, despite the obvious benefits, several problems have been identified in relation to the existing arrangement for sibling groups. Giallo and Gavidia-Payne (2006) found participation in siblings groups to be a strong predictor of adjustment
problems in well children suggesting siblings groups do not universally benefit all siblings who participate, or that many siblings need more support than sibling groups alone can provide. A further possibility is that the well siblings with more problematic behaviours are more likely to be referred to these sibling support groups. In addition, service providers report problems in getting well children to attend organised sibling groups. Siblings Australia hosts a web based discussion group for service providers across Australia to share ideas and seek assistance. The most common appeal from these service providers has been how to get well children to attend organised sibling groups. Service providers commonly report the availability of organised, funded sibling groups, but they are unable to attract children to attend. Indeed this was the case recently at Swinburne University where a specifically designed, funded sibling program by a clinical psychologist was widely advertised but no interest was expressed.

The reluctance to attend groups may be related to the findings of the current study of a general low rate of participation in activities outside the home by well children. This is possibly due to the logistic difficulties of getting children to venues while negotiating wheel chairs or special medical equipment, as well as time, effort and commitment required by parents while already under pressure. Another possibility is that well children are embarrassed to attend sibling groups and talk about their problems. Having to attend a special group because of their sibling may feel like another thing that makes them different from their school friends without a chronically ill sibling.

A possible alternative to sibling groups run by service providers is school-based programs. This may be a better way to reach well children in an already established location avoiding the need for difficult transport and logistics for the parents. In addition, resilience literature suggests schools provide a central environment where at-
risk children can get vital access to mentors and supporting relationships outside the family home. Programs in schools may provide an opportunity for the well children to establish supportive relationships or build on existing associations. In addition in-school programs would have the advantage of providing education to children and teachers about the experience of having a chronically ill sibling, enhancing community knowledge of the issues for families with chronic illness or disability and reducing the prejudice, stigma and isolation well children feel. An example of a successful education program in schools was delivered as part of a program aimed at supporting children affected by parental mental illness entitled “Supporting Kids in Primary Schools: A Mental Health Promotion Project” (Joyce, Allchin, Malmborg, Candy & Cowling, 2003). The project delivered sessions for teachers, and for primary school children on the impact and nature of mental illness. For teachers, post session testing found knowledge about mental illness and confidence to provide support to children was increased, while prejudice was reduced. Children reported better understanding of mental illness and reduced association with derogatory terms when presented with terms relating to mental illness.

In addition to the education aspect of the in-school program, specifically designed siblings groups based on the US Sibshops (Meyer & Vadasy, 1994) model could be provided in school settings. Sibshops is a program which provides structured workshops specifically for well children with chronically ill or disabled siblings. It gives an opportunity for well children to obtain peer support and education within a recreational environment by acknowledging that being the brother or sister of a child with special needs is for some a good thing, for others a not-so-good thing and many somewhere in between. The handbook includes a range of activities designed to be fun and entertaining for children, while highlighting their personal strengths and building
important skills such as problem solving and stress management. A recent evaluation of the Sibshops program in Cork, Ireland (D’Arcy, Flynn, McCarthy, O’Connor & Tierney, 2005) found no difference in well child self-esteem after attending six Sibshops sessions, however the sample size (n=16) was possibly too small for significant differences to be evident. Importantly, the structured interviews with parents revealed the majority of siblings enjoyed and benefited from Sibshops. Recommendations from the evaluation have now been incorporated into the program including providing more information to the children and families before commencement.

In addition to the sibling groups, Very Special Kids (VSK), an Australian based organisation for children with a life threatening illness, have a “big brother, big sister” program which connects well children with a supportive volunteer adult outside the family home. The adult provides an avenue for additional support as well as some special attention. The program is useful for many families but needs to be supplemented by resources, which provide opportunities for the parents to spend time with their well children working on building the parent child relationship. This requires allocating resources to the adequate provision of respite for families, a difficult, complex and expensive option because of the very individual respite needs of each family. Time, energy and resources are needed to address the physical and emotional needs of the ill children as well as the concerns of the parents, however, adequate provision of respite is likely to have additional positive benefits including reducing parent stress and allowing well children the opportunity to participate in social activities outside the family home. These factors have been implicated in improved adjustment outcomes for well children in the current study.
The relationship between lower income, parent stress and child adjustment has already been discussed at length, as have the many reasons for increased financial hardship on these families. In light of this, practical resources such as financial assistance for families with chronically ill children need to be considered. Financial support could take the form of direct financial assistance or assistance with medical costs and equipment needs. Other possibilities include assistance to access flexible employment opportunities, improvements in access to and provision of respite to suit working arrangements in families as well as help to arrange work from home opportunities.

An area which may provide a rich source of data for future research, is the experience of adult siblings. As medical treatment advances and the life expectancy of children with an illness or disability increases, adult well children will continue to become increasingly concerned with meeting the ongoing needs for their ill or disabled siblings. As the parents age, well children may become responsible for their ill sibling’s ongoing care. Meyer and Vadasy (1994) report an increase in adult siblings expressing the need for support programs and information about services for their brothers and sisters. Few services provide support for adult siblings and the community could benefit from research into the needs and experiences of adult siblings.

12.5 Conclusion

The focus of this study was psychosocial adjustment in children with a chronically ill or disabled sibling. The study explored relationships between adjustment in well children and several family, parent and ill child variables. Several methods of assessing child adjustment were utilised including both parent and child informants, and using a direct and objective method of assessment (behaviour rating scales) and projective/ expressive methods of assessment (child family drawings). Detailed
information relating to family structure, parenting styles, parenting stress and the chronic illness or disability of the child was collected using published scales and researcher questionnaires.

Participating families were relatively high in socioeconomic status (parental education and family income). Well children were rated by parents as having more adjustment problems than evidenced in age and gender matched population norms. Well children with more behaviour problems were younger, from poorer families, had parents with higher levels of stress, and had ill siblings with more behaviour problems. They also spent more time caring for their ill siblings, had parents who used less autonomy granting in their parenting style and had ill siblings who participated less in social activities.

There was support for a relationship between how the well children felt about their ill sibling and well child adjustment. Well children who made more negative comments about having a sibling with a chronic illness had more behaviour problems.

This study adds to the body of evidence that children with a sibling who has a chronic illness or disability are at higher risk for adjustment problems than their peers with well siblings. The findings have implications for well child programs as well as family interventions. Future research could focus on exploring the utilisation of respite and issues for older siblings.
REFERENCES


& S. Weintraub (Eds.), *Risk and protective factors in the development of psychopathology* (pp. 120-140). New York: Cambridge University Press.


Taylor, V., Fuggle, P., & Charman, T. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of


Child Family Drawing, Demographics and Attribution Questionnaire

**Draw a Picture**

Please draw me a picture of your family. You can include anyone who you think is part of your family.

Here is some paper and a packet of pencils if you'd like to use them, but you draw with anything you like.

Please put everyone's name on your drawing so I know who they are.
Child Family Drawing, Demographics and Attribution Questionnaire

Sibling Questions

1. Are you? Please circle one  
   a. boy  
   b. girl

2. How old are you? (years and months) .......... Years and ...................... Months

3. What sort of things do you do to help care for your ill brother or sister?
   Please include everything you can think of.
   Examples may be
   â• getting food or drink
   â• teaching them to do things
   â• helping make the bed
   â• calming them down if they are upset
   â• keeping an eye on them

4. About how much time each day do you spend time helping to care for your ill brother or sister?
   a. None
   b. Less than 1 hour
   c. 1-2 hours
   d. 2-3 hours
   e. more than 3 hours

5. Having a sick brother or sister can be difficult, but it can be special too. What has it been like for you? (What is good and what is bad?)
Child Self Rated Adjustment Questionnaire (modified CBCL-YSR and RCMAS)

Here are some sentences that tell how some people think and feel about themselves. Please read each sentence carefully and circle **Yes** if you think the sentence is true about you. Circle **No** if you think the sentence is not true about you. Circle every answer even if it is hard to choose one that fits you. There are no right or wrong answers.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>I have trouble making up my mind</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>I get nervous when things do not go the right way for me</td>
<td></td>
<td></td>
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<tr>
<td>3</td>
<td>Others seem to do things easier than I can</td>
<td></td>
<td></td>
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<tr>
<td>4</td>
<td>I like everyone I know</td>
<td></td>
<td></td>
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<tr>
<td>5</td>
<td>I get in many fights</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Often I have trouble getting my breath</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I worry a lot of the time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I am afraid of a lot of things</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I am always kind</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I disobey at school</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I get mad easily</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I worry about what my parents will say to me</td>
<td></td>
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<tr>
<td>13</td>
<td>I feel that others do not like the way I do things</td>
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<td>14</td>
<td>I always have good manners</td>
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<td>15</td>
<td>My moods or feelings change suddenly</td>
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<tr>
<td>16</td>
<td>It is hard for me to get to sleep at night</td>
<td></td>
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<tr>
<td>17</td>
<td>I worry about what other people think about me</td>
<td></td>
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<tr>
<td>18</td>
<td>I feel alone even when there are people with me</td>
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<td>19</td>
<td>I am always good</td>
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Please turn over the page .........
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<table>
<thead>
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<th></th>
<th></th>
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<tbody>
<tr>
<td>20)</td>
<td>I disobey my parents</td>
</tr>
<tr>
<td>21)</td>
<td>Often I feel sick in the stomach</td>
</tr>
<tr>
<td>22)</td>
<td>My feelings get hurt easily</td>
</tr>
<tr>
<td>23)</td>
<td>My hands feel sweaty</td>
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<tr>
<td>24)</td>
<td>I am always nice to everyone</td>
</tr>
<tr>
<td>25)</td>
<td>I tease others a lot</td>
</tr>
<tr>
<td>26)</td>
<td>I am tired a lot</td>
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<tr>
<td>27)</td>
<td>I worry about what is going to happen</td>
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<tr>
<td>28)</td>
<td>Other people are happier than I</td>
</tr>
<tr>
<td>29)</td>
<td>I tell the truth every single time</td>
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<tr>
<td>30)</td>
<td>I have a hot temper</td>
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<tr>
<td>31)</td>
<td>I have bad dreams</td>
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<tr>
<td>32)</td>
<td>My feelings get hurt easily when I am fussed at</td>
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<tr>
<td>33)</td>
<td>I feel someone will tell me I do things the wrong way</td>
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<tr>
<td>34)</td>
<td>I never get angry</td>
</tr>
<tr>
<td>35)</td>
<td>I wake up scared some of the time</td>
</tr>
<tr>
<td>36)</td>
<td>I worry when I go to bed at night</td>
</tr>
<tr>
<td>37)</td>
<td>It is hard for me to keep my mind on my schoolwork</td>
</tr>
<tr>
<td>38)</td>
<td>I never say things I shouldn’t</td>
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<tr>
<td>39)</td>
<td>I wiggle in my seat a lot</td>
</tr>
<tr>
<td>40)</td>
<td>I am nervous</td>
</tr>
<tr>
<td>41)</td>
<td>A lot of people are against me</td>
</tr>
<tr>
<td>42)</td>
<td>I never lie</td>
</tr>
<tr>
<td>43)</td>
<td>I often worry about something bad happening to me</td>
</tr>
</tbody>
</table>
Parenting Styles Questionnaire

**MY PARENTS**

Using the numbering system above, please answer the next set of questions about the parents you live with. If you spend time in more than one home, answer the questions about the parents who have the most say over your daily life.

1. I can count on my parents to help me out if I have some kind of problem.

2. My parents say that you shouldn't argue with adults.

3. My parents keep pushing me to do my best in whatever I do.

4. My parents say that you should give in on arguments rather than make people angry.

5. My parents keep pushing me to think independently.

6. When I get a poor grade in school, my parents make my life miserable.

7. My parents help me with my schoolwork if there is something I don't understand.

8. My parents tell me that their ideas are correct and that I should not question them.

9. When my parents want me to do something, they explain why.

10. If I argue with my parents they say things like "You'll know better when you grow up".
11. When I get a poor grade in school my parents encourage me to try harder.

12. My parents let me make my own plans for things I want to do.

13. My parents know who my friends are.

14. My parents act cold and unfriendly if I do something they don't like.

15. My parents spend time just talking with me.

16. When I get a poor grade in school, my parents make me feel guilty.

17. My family does things for fun together.

18. My parents won't let me do things with them when I do something they don't like.

**MY FREE TIME**

Please tick the appropriate box for the next set of questions.

1. In a typical week what is the latest you can stay out on SCHOOL NIGHTS (Monday - Thursday)?

   I am not allowed out

   Before 8.00

   8.00 to 8.59

   9.00 to 9.59

   10.00 to 10.59

   11.00 or later

   as late as I want
Parenting Styles Questionnaire (PSQ)

2. In a typical week, what is the latest you can stay out on FRIDAY or SATURDAY NIGHT?

I am not allowed out
Before 8.00
8.00 to 8.59
9.00 to 9.59
10.00 to 10.59
11.00 or later
as late as I want

3. How much do your parents TRY to know? (Please circle one answer)

<table>
<thead>
<tr>
<th></th>
<th>Don’t Try</th>
<th>Try a Little</th>
<th>Try a Lot</th>
</tr>
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<tbody>
<tr>
<td>Where you go at night</td>
<td></td>
<td></td>
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<tr>
<td>What you do with your free time</td>
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<tr>
<td>Where you are most afternoons after school</td>
<td></td>
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<td></td>
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</tbody>
</table>

4. How much do your parents REALLY to know? (Please circle one answer)

<table>
<thead>
<tr>
<th></th>
<th>Don't Know</th>
<th>Know a Little</th>
<th>Know a Lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where you go at night</td>
<td></td>
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<tr>
<td>What you do with your free time</td>
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</tr>
<tr>
<td>Where you are most afternoons after school</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
1. Are you? (Please circle one)
☐ Female  ☐ Male

2. What is your relationship to the child participating in this study? (Please circle one)
☐ Parent  ☐ Guardian  ☐ Other (please describe) ........................................................................

3. What is your age? ........................................................................................................

4. What is your partner’s age (if applicable) ................................................................

5. How much adult support do you have at home?
☐ I’m a single parent (the only adult in the home)
☐ I’m living with a partner (e.g. married, de-facto)
☐ I’m living with other (e.g. relatives, friends, others)
Please describe ..............................................................................................................

6. Please complete the table below for all your children: age, gender, and residence. Please indicate which child has a serious illness or disability, and which sibling will be participating in this study.

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Gender</th>
<th>Living with you</th>
<th>Participating in study</th>
<th>Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td></td>
<td>Male/Female</td>
<td>Yes/No</td>
<td>Yes/No</td>
<td>Well/Ill</td>
</tr>
<tr>
<td>Child 2</td>
<td></td>
<td>Male/Female</td>
<td>Yes/No</td>
<td>Yes/No</td>
<td>Well/Ill</td>
</tr>
<tr>
<td>Child 3</td>
<td></td>
<td>Male/Female</td>
<td>Yes/No</td>
<td>Yes/No</td>
<td>Well/Ill</td>
</tr>
<tr>
<td>Child 4</td>
<td></td>
<td>Male/Female</td>
<td>Yes/No</td>
<td>Yes/No</td>
<td>Well/Ill</td>
</tr>
</tbody>
</table>

If you have any further children please continue over the page

7. What is your occupation? ..........................................................................................

8. What is the occupation of your partner? ................................................................(If applicable)

9. What is your total family annual income?
☐ Up to $15,000  ☐ $15,000 - $24,999  ☐ $25,000 - $34,999
☐ $35,000 - $44,999  ☐ $45,000 - $54,999  ☐ $55,000 and above

10. What is your highest level of education? (Please select one)
☐ Primary  ☐ Some Secondary  ☐ Completed Secondary  ☐ Tafe/Trade
☐ Some Tertiary  ☐ Tertiary degree  ☐ Post Graduate Degree

11. What is your partner’s highest level of education? (Please select one, if applicable)
☐ Primary  ☐ Some Secondary  ☐ Completed Secondary  ☐ Tafe/Trade
☐ Some Tertiary  ☐ Tertiary degree  ☐ Post Graduate Degree

12. What is the main language spoken at home? ............................................................

13. What is your postcode? ..........................................................................................
14. Please list or describe where you turn to if you need help or assistance in your life. (For example immediate family, extended family, parents, friends, community support programs, parent support groups, church etc) If none please state "none"

15. Please list or describe any support programs or other group activities your well child participates in (Sibling support groups, community youth programs, Scouts, sporting groups, etc) If none write "none"

16. Please list or describe any programs your child with an illness or disability participates in. If none write "none"

17. What type of things does your well child (the sibling participating in this study) do to share in the care for your child with an illness or disability? Please include everything you consider caring. Examples may be getting food or drink, teaching them to do things, helping make the bed, calming them down if they are upset, keeping an eye on them etc.

18. Approximately How much time each day does your well child (the sibling participating in this study) spend doing these caring activities?

☐ Less than 1 hour ☐ 1-3 hours ☐ 3-5 hours ☐ More than 5 hours

19. Please describe any major change or events your well child is experiencing which may be causing them significant stress or anxiety? (e.g parent separation, recent bereavement etc)

20. Please name and describe your child's illness or disability? If you child has both a chronic illness and a disability please describe both
21. How long has your child had the illness or disability?
   a. From birth
   b. Other

22. From what sources does your family receive respite
    (A break from caring for your child with an illness or disability)?

Please give details of how much respite you receive from each group below.

<table>
<thead>
<tr>
<th>Time Type</th>
<th>Family or Friends</th>
<th>Charities/Support Groups</th>
<th>Government Agencies (includes Hospitals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occasional or Regular hours</td>
<td>How often?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasional or Regular days</td>
<td>How often?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasional longer periods</td>
<td>How Often?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular longer periods</td>
<td>How Often?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you receive no respite care please explain the reasons?

........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

23. Do you find any difficulties associated with respite care?

........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

24. How much time approximately, is needed to care for your child with an illness or disability each day?
   □ Less than 1 hour  □ 1-3 hours  □ 3-5 hours  □ Continuous care

25. What does your child with an illness or disability do during weekdays?
   □ Attends school  □ At home  Other (please describe) ..............................................................
<table>
<thead>
<tr>
<th>Event</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>A Lot</th>
<th>Constantly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
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<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to plan &amp; do adult activities instead of kids activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**FOR THE PAST FEW WEEKS** If you have more than one child these events can include any or all of your children.

You (and family) sometimes get stressed by things that happen at home or in the community. Please circle each item and circle how often it happens to you.

**Daily Hassles**

(PSHS)
APPENDIX B
### Impulsivity

<table>
<thead>
<tr>
<th>Present</th>
<th>Absent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Tendency to act spontaneously with little forethought or planning, to show low frustration tolerance, weak inner control and/or inconsistency; to be expansive and to seek immediate gratification.

1. Poor integration of body parts
   - One or more parts not joined to the rest of the figure, part only connected by a single line, or barely touching
   - [ ]

2. Gross asymmetry of limbs
   - One arm or leg differs markedly in shape from another arm or leg; some parts are only connected by a single line or are barely touching other parts
   - [ ]

3. Transparencies
   - Transparencies are pronounced involving major portions of the body, or its limbs; this item is *not checked* if single lines of arms or legs are crossed
   - [ ]

4. Big Figure
   - The figure is 9 inches (23cm) or more in height
   - [ ]

5. Omission of neck
   - No connection exists between the head and body; the head is barely touching the body; the head is directly attached to the body without any indication of neck. This item is *not checked* if a clear neckline of a shirt or sweater is shown, even though the neck is not visible
   - [ ]

### Insecurity, Feelings of Inadequacy

Low self concept, lack of self-confidence, concern over mental adequacy, feelings of helplessness, and an insecure footing. The child regards himself as an outsider, as not quite human, or as a ridiculous person who has difficulty establishing contact with others.

6. Slanting figure
   - Vertical axis of the figure is tilted by more than 120° from the perpendicular
   - [ ]

7. Tiny head
   - The height of the head is less than one-eighth the height of the total figure
   - [ ]

8. Hands cut off
   - Arms are drawn with neither hands nor fingers. This item is *not checked* if hands are hidden behind the back of the figure or if the hands are in pockets
   - [ ]

9. Monster or grotesque figure
   - The grotesqueness of the figure must be deliberate on part of the child and not the result
   - [ ]
Checklist for Emotional Indicators (Koppitz, 1968, 1984)

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>of his immaturity or lack of drawing skill. The figure may represent monsters, a creature from outer space an outsider such as a foreigner or member of a minority group drawn by a pupil who does not belong to that group, a ridiculous person such as a clown or a bum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Omission of arms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No arms or hands are drawn, hands appear only without arms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Omission of legs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No legs or feet are drawn, feet appear only without legs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Omission of feet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legs only are drawn, both feet and legs are cut off by the edge of the paper</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Anxiety**

Distress or uneasiness of mind regarding the body (body anxiety), actions or future events, or as troubled unsettled or worried, or as a prolonged state of apprehension

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Shading of face</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deliberate shading of the whole face or part of it, including “freckles” “measles” etc: an even light shading of face and hands to represent skin colour is <em>not scored</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Shading of body and/or limbs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The shaded area designates the area of specific concern. Special emphasis on the genital area either through shading, heavily reinforced lines, or by drawing attention to the fly or zipper on pants reflects sexual anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Shading of hands and/or neck</td>
<td></td>
<td></td>
</tr>
<tr>
<td>As above</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Legs pressed together</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both legs touch with no space between them. In profile drawings, only one leg is shown</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Omission of eyes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a complete absence of eyes. This item is <em>not checked</em> if the eyes are drawn closed or as vacant circles, or if the eyes are covered by dark glasses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Clouds, rain, flying birds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any representation of clouds, rain, snow or flocks of flying birds indicates anxiety</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Shyness, Timidity**

Retiring, cautious, reserved behaviour; lack of self confidence, a tendency to be easily embarrassed or frightened, a tendency to withdraw from difficult or dangerous circumstances.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Tiny figure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The figure is two inches (5 cm) or less in height</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>20. Short arms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short stubs are drawn for arms, the arms are not long enough to reach the waistline of the figure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Arms clinging to body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is no space between the body and the arms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Omission of nose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither outline of nose nor nostrils appear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Omission of mouth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is no indication of a mouth. This item is <em>not checked</em> when the mouth is covered by an object such as a football helmet</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Anger, Aggressiveness**

Displeasure, resentment, exasperation, or indignation; offensive action in general, revengeful emotion aimed at others who are perceived as inflicting wrong; verbal or physical assaultive actions; rage resulting from frustration. Anger can be directed toward others, toward oneself or toward objects.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Crossed eyes</td>
<td></td>
</tr>
<tr>
<td>Both eyes are turned in or turned out. This item is <em>not checked</em> if the eyes are glancing sideways</td>
<td></td>
</tr>
<tr>
<td>25. Teeth</td>
<td></td>
</tr>
<tr>
<td>Any representation of one or more teeth appears</td>
<td></td>
</tr>
<tr>
<td>26. Long arms</td>
<td></td>
</tr>
<tr>
<td>Arms are excessively long, long enough to reach below the knee or where the knee of the figure should be</td>
<td></td>
</tr>
<tr>
<td>27. Big hands</td>
<td></td>
</tr>
<tr>
<td>The hands are as big or bigger than the face of the figure</td>
<td></td>
</tr>
<tr>
<td>28. Nude figure</td>
<td></td>
</tr>
<tr>
<td>Nude representation of the figure is drawn; realistic drawing of genitals, unmistakably symbolic representation of genitals appears; secondary sexual characteristics, breast are shown</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX C
Six aggression items from CBCL rejected due to confrontational nature of questions, and six aggression items selected from CBCL with factor loadings

<table>
<thead>
<tr>
<th>CBCL YSR Questions</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Six aggression items with highest factor loadings rejected due to</td>
<td></td>
</tr>
<tr>
<td>confrontational nature of question</td>
<td></td>
</tr>
<tr>
<td>97. I threaten to hurt people</td>
<td>0.73</td>
</tr>
<tr>
<td>57. I physically attack people</td>
<td>0.68</td>
</tr>
<tr>
<td>21. I destroy things belonging to others</td>
<td>0.67</td>
</tr>
<tr>
<td>20. I destroy my own things</td>
<td>0.65</td>
</tr>
<tr>
<td>16. I am mean to others</td>
<td>0.57</td>
</tr>
<tr>
<td>68. I scream a lot</td>
<td>0.55</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Next highest factor loadings accepted for inclusion in child</td>
<td></td>
</tr>
<tr>
<td>adjustment measure</td>
<td></td>
</tr>
<tr>
<td>37. I get in many fights</td>
<td>0.53</td>
</tr>
<tr>
<td>23. I disobey at school</td>
<td>0.52</td>
</tr>
<tr>
<td>87. My moods or feelings change suddenly</td>
<td>0.49</td>
</tr>
<tr>
<td>22. I disobey my parents</td>
<td>0.48</td>
</tr>
<tr>
<td>94. I tease others a lot</td>
<td>0.48</td>
</tr>
<tr>
<td>95. I have a hot temper</td>
<td>0.48</td>
</tr>
</tbody>
</table>
APPENDIX D
Comparison of published and unpublished version of the Parenting Style Questionnaire (PSQ)

<table>
<thead>
<tr>
<th>Unpublished Version</th>
<th>Original Version</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychological Autonomy Granting</strong></td>
<td></td>
</tr>
<tr>
<td>Item No.</td>
<td>Item</td>
</tr>
<tr>
<td>2</td>
<td>My parents say that you shouldn’t argue with adults.</td>
</tr>
<tr>
<td>4</td>
<td>My parents say that you should give in on arguments rather than make people angry.</td>
</tr>
<tr>
<td>6</td>
<td>When I get a poor grade in school, my parents make my life miserable.</td>
</tr>
<tr>
<td>8</td>
<td>My parents tell me that their ideas are correct and that I should not question them</td>
</tr>
<tr>
<td>10</td>
<td>If I argue with my parents they say things like “You’ll know better when you grow up”.</td>
</tr>
<tr>
<td>12</td>
<td>My parents let me make my own plans for things I want to do.</td>
</tr>
<tr>
<td>14</td>
<td>My parents act cold and unfriendly if I do something they don’t like.</td>
</tr>
<tr>
<td>18</td>
<td>My parents won’t let me do things with them when I do something they don’t like.</td>
</tr>
<tr>
<td>16</td>
<td>When I get a poor grade in school, my parents make me feel guilty.</td>
</tr>
</tbody>
</table>
Comparison of published and unpublished version of the Parenting Style Questionnaire (PSQ)

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Item</th>
<th>Scoring scale</th>
<th>Item No.</th>
<th>Item</th>
<th>Scoring scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I can count on my parents to help me out if I have some kind of problem.</td>
<td>4pt Likert</td>
<td>44a</td>
<td>I can count on my father to help me out if I had some kind of problem</td>
<td>true-false</td>
</tr>
<tr>
<td>3</td>
<td>My parents keep pushing me to do my best in whatever I do.</td>
<td>4pt Likert</td>
<td>44c</td>
<td>My father keeps pushing me to do my best at whatever I do</td>
<td>true-false</td>
</tr>
<tr>
<td>5</td>
<td>My parents keep pushing me to think independently.</td>
<td>4pt Likert</td>
<td>44e</td>
<td>My father keeps pushing me to think independently.</td>
<td>true-false</td>
</tr>
<tr>
<td>7</td>
<td>My parents help me with my schoolwork if there is something I don't understand.</td>
<td>4pt Likert</td>
<td>44f</td>
<td>My father helps me with my schoolwork if there is something I don't understand.</td>
<td>true-false</td>
</tr>
<tr>
<td>9</td>
<td>When my parents want me to do something, they explain why.</td>
<td>4pt Likert</td>
<td>44j</td>
<td>When my father wants me to do something, he explains why.</td>
<td>true-false</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>45a</td>
<td>I can count on my mother to help me out if I had some kind of problem</td>
<td>true-false</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>45c</td>
<td>My mother keeps pushing me to do my best at whatever I do</td>
<td>true-false</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>45e</td>
<td>My mother keeps pushing me to think independently.</td>
<td>true-false</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>45f</td>
<td>My mother helps me with my schoolwork if there is something I don't understand.</td>
<td>true-false</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>45j</td>
<td>When my mother wants me to do something, he explains why.</td>
<td>true-false</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>32j</td>
<td>When you get a poor grade do your parents encourage you to try harder</td>
<td>3pt Likert</td>
</tr>
<tr>
<td>13</td>
<td>My parents know who my friends are.</td>
<td>4pt Likert</td>
<td>43a</td>
<td>My parents spend time just talking to me</td>
<td>4pt Likert</td>
</tr>
<tr>
<td>15</td>
<td>My parents spend time just talking with me.</td>
<td>4pt Likert</td>
<td>43b</td>
<td>My family does something fun together</td>
<td>4pt Likert</td>
</tr>
<tr>
<td>17</td>
<td>My family does things for fun together.</td>
<td>4pt Likert</td>
<td>31a</td>
<td>When you get a good grade do your parents praise you</td>
<td>3pt Likert</td>
</tr>
</tbody>
</table>

Note 1: the original scale required weighted scoring to equalise the different scoring scales used
Note 2: a mean of questions 44 and 45 were taken if the child rated both parents
APPENDIX E
Resilience and vulnerability in children who have a sibling with a chronic illness or disability

Foreword
Over the past few years, many families across Australia participated in this research project. A number of service organisations contributed by assisting with advertising and recruitment. Here is a summary of the research project, including the findings. We hope this information is of interest.

Background
There is no doubt that all children face stresses. First there are the normal developmental stresses such as adapting to school, coping with hormonal surges of adolescence and just generally dealing with the complex set of freedoms and restrictions that form part of becoming a socialised human being. However, there are also chronic stresses (some of which are becoming very common nevertheless), like parental divorce, family discord, poverty, parental alcoholism, and illness or death occurring in the family. Research shows children from these adverse environments are more likely to succumb to problems like anxiety, depression, aggression, antisocial behaviour or substance use .... but this is not always the case. Some children from highly risky environments do not experience adverse outcomes. They grow up happy, healthy and fully functioning adults. These children are resilient, they have the capacity to cope with stress and maintain their stability. This study looked at resilience in children who had a sibling with a chronic illness or disability.

Siblings
What is so important about siblings? How are they likely to affect our childhood adjustment and resilience? The sibling relationship is one of the longest most people experience. Few relationships compare for longevity, beginning at birth and continuing throughout your lifetime to death. Such an intimate and enduring relationship has a profound impact on our early development. In childhood, we spend more time with our siblings than with anyone else. The sibling relationship plays a vital role in the development of crucial social skills such as language, teaching and care giving, perspective taking, establishing and maintaining friendships, and conflict resolution.

Study Aims
This study looked specifically at the stresses placed on a child when a sibling in the family has a chronic illness or disability and investigated why some children cope well and develop strengths from the experience, while others struggle and may develop problems.

The current study
The "well" child in the family, and one of their parents, completed a questionnaire which assessed information about the children's worries, anxieties and problems, as well as parenting stress and the style of parenting they used. A total of 102 children from 77 families participated in the study. The children ranged in age from 7 – 18 years (average age was 12), 51 were boys and 51 girls. 77 parents also participated, mostly mothers with an average age of 40 years.

What did we find?
- Well siblings of children with a chronic illness or disability had more behaviour problems than their peers when compared to population norms.

According to the parental reports, the children with chronically ill siblings were significantly more anxious and depressed and had more somatic complaints and thought and social problems than population norms. Parents clearly perceived a range of behaviour problems with the well child in the family. Concern over the well child and their behaviour problems must add to the already high level of stress associated with the care required for their child with a chronic illness or disability.

On the other hand, the well children did not assess themselves as having significant worries or problem behaviour. When compared to the available data on population norms, siblings saw themselves as having no more problems than the general population. So what may be the reason for the difference between what parents say about their well child's problems and what the well child says? One possibility is that the parents are over rating the behaviour problems in their children. It is possible the parents were very sensitive to problems to the need for vigilance regarding the health and wellbeing of their child with a chronic illness or disability. Perhaps the parents are simply more perceptive of behaviour problems, resulting in the high levels reported here. However parent reports of child behaviour problems are a universally accepted way of assessing adjustment problems in children, much more so than child self reports, so we can't negate the possibility that the well children do have more behaviour problems. In fact it seems this is the most likely scenario as past research in the US and the UK has found problem behaviours for siblings of chronically ill and disabled children.
• Well siblings may be reluctant to reveal any problems they are having

Another possible explanation for differences between parent and child ratings is that the well siblings are underestimating their own problem behaviour because of social pressure to respond to questions about their own well being in a positive way. In other studies well siblings have reported feeling pressure to be “perfect” to compensate for the things their disabled sibling can’t do. It is also possible the siblings may have been influenced by a real desire to avoid further worry and burden to their parents by reporting exemplary behaviour.

• Siblings have the capacity to ‘look on the bright side’

Well siblings reported positive things about having a brother or sister with a chronic illness such as increased tolerance, better understanding of others, the fun of sibling camps and not wanting to be without their sibling. The more positive comments they had to make about living with an ill or disabled brother or sister, the better they scored on overall measures of adjustment. These findings emphasise the adaptability of children, and the way resilient children can put a positive spin on difficult circumstances if the context is supportive. The study highlights the importance of research as well as any interventions addressing the strengths of the children and families instead of just focusing on the weaknesses.

• Behaviour problems in siblings were related to: high stress in parents, low family income and behaviour problems in the child with a chronic illness or disability

Where there were behaviour problems in the well siblings, the parents were more stressed, family income was lower, and the child with a chronic illness or disability also displayed higher levels of problem behaviours. Siblings were doing better when they shared in the household tasks and/or helped to care for their brother or sister with a chronic illness or disability. The participation may build maturity, independence and self confidence by allowing the sibling to take on some of the responsibility and contribute to the family workload. However past research has found siblings can suffer under too much care and responsibility, so a balance is required.

Implications

The impact of any behaviour problems in the child with a chronic illness or disability is a difficult one for parents. Parents may find it hard to balance the desire for fairness and equity between siblings, and the different requirements of their children. It is difficult to apply one standard of discipline to their well children while allowing flexibility for the needs of the ill child. As a result the relationship between the parent and the ill child impacts on the well child, possibly in a negative way, a stressful dilemma for parents. Clearly, parents under this much stress need help, not only in the form of respite from the care of their ill child, but also in the development of strategies to maintain family cohesion. Families with children who have problem behaviours are more likely to be highly stressed families; financial hardship can also increase parent stress. High levels of parent stress has been found in the past to impact on child behaviour by increasing problem behaviours. There is potential here for a cycle of stress and problems for these families. These research findings support the provision of broad assistance to families with a chronically ill or disabled child including assistance in ways to manage stress, assistance with financial problems and strategies for managing behaviour problems in the chronically ill or disabled child as well as the siblings.

The need for more access to respite was another feature of the findings, not just in quantity, but also flexibility, duration, regularity, frequency and quality of care. It was clear from the findings that families have different needs and preferences in relation to respite. This study supports the need for more resources into respite to enable greater flexibility in provision of services to improve outcomes for siblings and their families.

Summary

In summary, some well siblings in this study were doing very well. They were more likely to be from families with lower levels of stress, and more access to resources, including financial resources, higher levels of parental education, and greater access to support and respite care. Overwhelmingly, they were managing better in families where the ill or disabled child did not exhibit high levels of problem behaviour.

However, many families with a child with a chronic illness or disability are highly stressed, not only from the many pressures relating to the illness, prognosis and treatment but also from the ill child’s difficult behaviour, which may be a consequence of the illness itself or the reluctance of parents to set too many limits on the behaviour of a child who has so much to cope with. The high levels of parent stress are likely to have detrimental effects on both parents and children. Assistance to families can be directed at helping parents reduce stress and providing more effective ways to manage ill child behaviour problems as well as ways to reduce financial pressure and increase respite availability and usefulness.

Where to from here

Information about the results of this project have been provided to service organisations across Australia. Reports have been published in scientific journals and presented at conferences in Australia and NZ. Copies can be requested from Meredith Rayner at mrayner@parentingrc.org.au. Meredith is now working as a researching psychologist at the Parenting Research Centre, a non profit organisation which focuses on supporting parents to achieve better outcomes for children. You might like to have a look at the projects on the PRCs projects. (www.parentingrc.org.au)

Acknowledgements

The research was funded by a grant from the Australian Research Council. Thanks are due to the ARC, to organisations that assisted with recruitment of participants, and to participants themselves who gave up time in their already stressed lives to be part of the study.
Detailed information for families in response to enquiry

11th April, 2005

To the participants:

Dear Participant,

Thank you for taking the time to enquire about this study.

What is the study about?
Although we know a lot about the treatment of children with an illness, not much is known about the impact on other children in the family. The results of this study will provide us with information on how parents and caregivers can best understand and support children who have a seriously ill sibling. The research will be used to produce resources for parents with ill children across Australia.

What will you be asked to do?
In this study we will be asking a parent and a well child to answer a number of questions on a questionnaire.

- The parent questions will be about the behaviour of both the child and sibling with an illness, stress experienced by parents as well as some general information like gender and family structure.
- The child questions will be about the child’s experience in the family as well as some general information like age and how they participate in caring for their ill sibling.

Volunteering and Confidentiality
If you volunteer to participate you and your child will be free to withdraw at any time. The information you provide will be confidential, and only general, unidentifiable information about the whole group will be used in information sheets, journal articles and other publications.

Support Services
If participating in this study raises any personal concerns for you, you may like to speak to a counsellor at Lifeline on 13 1114 or Care Ring on 13 6169. Swinburne University’s Centre for Psychological Services on 9214 8653 offers a fee-for-service counselling resource on 9214 8653.
Ethical Conduct
This research conforms to the principles set out in the Swinburne University of Technology Policy on Research Ethics and the NHMRC guidelines as specified in the National Statement on Ethical Conduct on Research involving humans.

Further Information
If you have any queries regarding this study please contact the investigators, Professor Susan Moore on 9214 5694 or Meredith Rayner on 0425 71 9957 or email sibling.research@optusnet.com.au

Yours faithfully,

Meredith Rayner
Psychologist

If you have a complaint about the way you were treated during this study, please write to:
The Chair, Human Research Ethics Committee, PO Box 218,
date

name and address

Dear name,

Thank you for agreeing to participate in the research project into the impact on children of having a sibling with a serious illness in the family. This letter is to confirm the appointment, and give you some information about participating in the research. Some if this information we have already discussed.

**Your appointment**
Your appointment is for **Thursday January 22 at 11am**. I will come to your home on that day to help you and (child name) with the questionnaires. Completing the questionnaires takes about 1 hour but there is no time limit. You can take as long as you need.

**What is the study about?**
Although we know a lot about the treatment of children with an illness, not much is known about the impact on other children in the family. The results of this study will provide us with information on how parents and caregivers can best understand and support children who have a seriously ill sibling. The research will be used to produce resources for parents with ill children across Australia.

**What will you be asked to do?**
As you know, the study requires a parent and a child (sibling to the child with an illness or disability) to complete some questionnaires.
- The questions for the parent are about parent stress, child behaviour and some general questions like gender, family structure, children’s ages and type of social support programs your family receives.
- The questions for the child are about their stress, their behaviour, how they experience family life and some general questions like gender, age and participation in care for the sibling with an illness or disability.
Volunteering and Confidentiality
Remember your participation in this research is voluntary and your responses will be confidential. Only general, unidentifiable information about the whole group will be used in information sheets, journal articles and other publications. You and (child name) will be asked to sign consent forms confirming your understanding of this before we begin. Copies of the consent forms are attached for you to read, but I will go through this with you in detail on the day.

To ensure privacy and confidentiality for you both, you should compete your questionnaires in separate rooms if possible. If you wish, you can have a look at the questionnaires for (child name) before we start, but not after they have been completed.

Support Services
If participating in this study raises any personal concerns for you, you may like to speak to a counsellor at Lifeline on 13 1114 or Care Ring on 13 6169. Swinburne University’s Centre for Psychological Services offers a fee-for-service counselling resource on 9214 8653.

Ethical Conduct
This research conforms to the principles set on in the Swinburne University of Technology Policy on Research Ethics and the NHMRC guidelines as specified in the National Statement on Ethical Conduct on Research involving humans.

Thank you for your time. I hope that your participation in this research will be a valuable and rewarding experience for you and for (child name).

If you have any questions please do not hesitate to phone me on 0425 719957 or Professor Susan Moore at Swinburne on 9214 5694.

I look forward to seeing you on January 22, 2004.

Regards,

Meredith Rayner
Psychologist

School of Social and Behavioural Sciences
PO Box 218 Hawthorn
Victoria 3122 Australia
Telephone +61 3 9214 5209
Facsimile +61 3 9819 0574
http://www.swin.edu.au

Resilience and Vulnerability in Children who have a Sibling with Serious Illness
Researchers Professor Susan Moore and Meredith Rayner are Psychologists at Swinburne University
Contact details: Professor Susan Moore (03) 9214 5694  Meredith Rayner 0425 719957
Dear parent name,

Thank you for agreeing to participate in the research project into the impact on children of having a sibling with a serious illness in the family. This letter gives you more information about participating in the research, some if this you will already have read in other documents about the project.

What is the study about?
Although we know a lot about the treatment of children with an illness, not much is known about the impact on other children in the family. The results of this study will provide us with information on how parents and caregivers can best understand and support children who have a seriously ill sibling. The research will be used to produce resources for parents with ill children across Australia.

Volunteering and Confidentiality
Remember your participation in this research is voluntary and your responses will be confidential. Only general, unidentifiable information about the whole group will be used in information sheets, journal articles and other publications. You and Kelsey are asked to sign the enclosed consent forms confirming your understanding of this before you begin.

To ensure privacy and confidentiality for you both, you should compete your questionnaires in separate rooms if possible. If you wish, you can have a look at the questionnaires for (child name) before you start, but not after they have been completed.

Support Services
If participating in this study raises any personal concerns for you, you may like to speak to a counsellor at Lifeline on 13 1114 or Care Ring on 13 6169. Swinburne University's Centre for Psychological Services offers a fee-for-service counselling resource on 9214 8653.

Ethical Conduct
This research conforms to the principles set on in the Swinburne University of
Technology Policy on Research Ethics and the NHMRC guidelines as specified in the National Statement on Ethical Conduct on Research involving humans.

**What to do?**
As you know, the study requires a parent and a child (sibling to the child with an illness or disability) to complete some questionnaires.

Please note the questionnaires are designed to include families with a range of ages, illnesses and disabilities, while still remaining clear, simple and as brief as possible. No offence is intended by the use of the words “child”, “ill”, “well” or “disabled” throughout the questionnaires. These terms will not be used in any documentation resulting from this study.

**Parent Questionnaires**
There are 3 questionnaires to be completed by the parent. You can do them in any order you choose.
- **Parent Information** - is a demographic questionnaire. You have probably completed questionnaires similar to this before.
- **Daily Hassles** - is about parent stress
- **Child Behaviour Questionnaire** – is about the behaviour of you children. One side relates to your child with a chronic illness or disability. The other column relates to the child participating in this study. (If more than one child is participating you will need to use additional forms – one for each child). Please make sure you identify the child at the top the page.

**Sibling Questionnaires**
There are 3 questionnaires and one drawing for the sibling. You can do them in any order you choose.
- **Draw a picture** – on the paper provided please draw a picture of your family. Don’t forget to name everyone in you drawing.
- **Sibling Questions** – asks about you and your ill brother or sister.
- **Parenting Styles Questionnaire** – is about life at home
- **Think and Feel** – is about how you think and feel
The colour pencils inclosed are for the sibling to keep as a thank you for participating.

**Please don’t hesitate to contact me if you have any questions.**

A self-addressed, reply paid envelope has been included for the completed questionnaires. When finished please place the completed consent forms and completed questionnaires in the reply paid envelope and mail to me at Swinburne University.

Resilience and Vulnerability in Children who have a Sibling with Serious Illness
Researchers Professor Susan Moore and Meredith Rayner are Psychologists at Swinburne University
Contact details: Meredith Rayner 0425 719957 or sibling.research@optusnet.com.au
Professor Susan Moore (03) 9214 5694
Thank you for your time and contribution. I hope that your participation in this research project will prove to be a valuable and rewarding experience for you and for (child name).

If you have any questions please do not hesitate to phone me on 0425 719957 or Professor Susan Moore at Swinburne on 9214 5694.

Regards,

Meredith Rayner
Psychologist
CHECKLIST

Please check that you have completed:

**Parent Questionnaires**
- ☐ Consent form (and sibling consent form)
- ☐ Parent Information
- ☐ Daily Hassles
- ☐ Child Behaviour Questionnaire (one for each child participating in the research)

**Sibling Questionnaires**
- ☐ Consent form
- ☐ Draw a picture
- ☐ Sibling Questions
- ☐ Parenting Styles Questionnaire
- ☐ Think and Feel

**When Finished**
- ☐ Keep the colour pencils
- ☐ Place in reply paid envelope
  - questionnaires
  - family drawing
  - consent forms
- ☐ Mail back to Meredith Rayner at Swinburne
- ☐ Contact me if you have any questions
PARENT CONSENT FORM

I ................................................................. (parent name) have read/have had read to me and understood the information above. Any questions I have asked have been answered to my satisfaction.

I agree to participate in this study, realising that I may withdraw at any time.

I agree that research data collected for the study may be published or provided to other researchers on the condition that anonymity is preserved and that I cannot be identified.

................................................................. Signature  .................................. Date
SIBLING CONSENT FORM:

Hi (child name),

My name is Meredith Rayner and I want to find out some more about what it is like having a brother or sister who has an illness or disability, and how that affects you.

I would like you to help me by telling me about your experience. By helping me find out more about you, you may help other children in your situation who have trouble coping with their brother’s and sister’s illness or disability.

If you agree to participate, it will mean answering some questions on a questionnaire. Your answers will be totally private and if you change your mind you are able to stop at any time.

If you would like to help, please sign your name below.

I will also need to have permission from your parents so please ask them to sign too.

Signed by (child name) .................................................. Date

I give permission for my child to participate in this study. I understand that we may withdraw at any time.

Parent/Guardian Signature .................................................. Date
Flyer for adults

Swinburne University Sibling Research Project

Resilience and vulnerability in children with a chronically ill or disabled sibling

Swinburne University (Psychology) invites families of children with a chronic illness or disability to participate in a study. The study will examine the impact on the other "well" children in the family.

The study requires a parent and a well sibling (aged 8 - 18) from a family where a child has a chronic illness or disability to complete some questionnaires (approx 1 hour)

- The questions for the parent are about parent stress, child behaviour and some general questions like gender, family structure, children’s ages and type of social support programs your family receives.

- The questions for the sibling are about stress, how they experience family life and some general questions like gender, age and participation in care for the ill sibling.

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Although we know a lot about the treatment of children with an illness, not much is known about the impact on other children in the family.

Some children seem to adjust well and develop valuable life skills such as empathy and independence. Others seem to have more difficulty adjusting and are at a higher risk of developing emotional problems such as anxiety and depression.

What makes the difference? What can we learn from the children who cope well and how can we apply this to help the many who don’t?

The results of this study will provide us with information on how parents and caregivers can best understand and support children who have a chronically ill or disabled sibling. The research will be used to produce resources for parents across Australia.

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If you would like to participate, or find out more information about the study, email sibling.research@optusnet.com.au or phone Meredith Rayner on 0425 719957.

If you agree to be part of this research your participation is voluntary and your responses will be confidential. Only general, unidentifiable information about the whole group will be used in information sheets, journal articles and other publications.
Flyer for children

Do you have a brother or sister with a disability or a serious illness?

We want to hear from you .................

We are asking Australian kids ...... to tell us what life is like .... When you have a brother or sister with a serious illness or a disability.

All kids are different

- For some kids it's great
- For some kids it's no big deal
- For some kids there are good bits and bad bits
- For some kids it's really tough

So we want to hear from as many kids as possible

We want to know what it's like for YOU ...

understanding about you will help us help other kids!

We'll send you some questions to answer

The questions are easy and won't take you very long

We will also send you some questions for your mum or dad

Your answers will be secret so NOBODY will ever know what you have said (not even your parents).

You must be between 8 and 18 years old and have permission from your parents.

If you would like to know a bit more about joining in

Contact Meredith Rayner on 0425 719957 or email sibling.research@optusnet.com.au

If you agree to be part of this research your participation is voluntary and your responses will be confidential. Only general, unidentifiable information about the whole group will be used in information sheets, journal articles and other publications.

Resilience and Vulnerability in Children who have a Sibling with Serious Illness
Researchers Professor Susan Moore and Meredith Rayner are Psychologists at Swinburne University
Contact details: Professor Susan Moore (03) 9214 5694  Meredith Rayner  0425 719957
Hi,

Remember the research project you agreed to participate in this year?

**What is it like to have a brother or sister with a chronic illness or disability?**

We are nearly at the end of the year, and the end of the time available for families to participate. You might be interested to hear a bit about how it is all going so far:

- 87 siblings have participated (well done!) 46 are boys and 41 are girls
- The youngest age is 7 years old and the oldest is 18
- Visits have been made to 24 siblings, 63 have mailed their answers back
- Most siblings live in Melbourne, many are in rural and regional Victoria, some are in NSW and some as far as Queensland
- Most siblings have more than one brother or sister in their family
- Most live at home with their parents, some with just their mum or their dad
- Mostly it has been the mother who have answered the parents questions but sometimes it has been the father

We can't give you any information about our initial findings yet as some families haven't finished answering the questions. It might influence their answers if they were to hear what others have said. We will send you some information about the results next year.

The study is large enough to be important in Australia and overseas. The information so far has already been presented at a recent conference in Adelaide, and another one is coming up in Melbourne in February.

We still need another 13 participants to reach the target of 100. If you haven't finished answering the questions can you try and complete them return to us as soon as possible (January 31st is the last day).

If you know someone who might like to participate there is still time, but they need to contact us soon. You could give them the contact details below or the information sheet enclosed.

If you don't want to receive any more information just let me know (phone, mail or email).

Thanks for your help this year and hope you all have a great time over Christmas

**Meredith**
Meredith Rayner, Researcher & Psychologist

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Resilience and Vulnerability in Children who have a Sibling with Chronic Illness or Disability
Researchers Professor Susan Moore and Meredith Rayner are Psychologists at Swinburne University  
**Contact details:** Professor Susan Moore (03) 9214 5694, Meredith Rayner 0425 719957  
Mail H24, Swinburne University, PO Box 218, Hawthorn, Vic 3122, sibling.research@optusnet.com.au
Table of organisations contacted to participate in study, and response rates

| Unknown Source | Emailed researcher independently | 29 | 21 |
| VSK | Support workers invited families directly | 22 | 21 |
| Special Developmental Schools across Victoria | Newsletters and Flyers, responses collected and names returned | 24 | 20 |
| Interchange outer eastern | Personal visit parent meeting and advertised in newsletter | 6 | 5 |
| Personal Contact | Personally invited by researcher | 3 | 3 |
| Mackillop Family Services | Support workers will invite families directly | 3 | 2 |
| Word of mouth | Invited by existing participants | 2 | 2 |
| Asthma Victoria | Website | 1 | 1 |
| Epilepsy Foundation | Website and Mailout with newsletter | 2 | 1 |
| MOIRA | Newsletter | 1 | 1 |
| Commonwealth Carer Respite Centre | Support Workers to hand out flyer | 5 | 0 |
| Kinglake Careers Support Group | Email flyer, no commitment | 1 | 0 |
| Association for Children with a Disability | Newsletter and Parent Support Workers to hand out flyer | None evident | None known |
| Autism Victoria | Hand out flyers at information session | None evident | None known |
| Brain Foundation | Website | None evident | None known |
| Broad Insight Childhood Intervention | Flyer in office | None evident | None known |
| Chronic Illness Alliance | Contacts in member organisations | None evident | None known |
| Cystic Fibrosis Victoria | Website and Newsletter | None evident | None known |
| Diabetes Australia-Victoria | Newsletter and retail store nurses to hand out flyer | None evident | None known |
| Genetic Support Network Victoria | Newsletter | None evident | None known |
| Interchange Westemport | Email flyer, no commitment | None evident | None known |
| Khaki Rebels | Email flyer, no commitment | None evident | None known |
| Leukemia Foundation | Email flyer, no commitment | None evident | None known |
| Noahs arc | Email flyer to be handed to parents | None evident | None known |
| Try Youth caring kids camp | Email flyer to be mailed out with newsletter | None evident | None known |
| Westarc | Email flyer, no commitment | None evident | None known |
| Yooralla Society | Email flyer, no commitment | None evident | None known |
| Assessment Counselling Therapy | No response, private practice | n/a | n/a |
| Bear Cottage Sydney | No response, hospital ethics required | n/a | n/a |
| Carenet | No response | n/a | n/a |
| CHIPS | No response, hospital ethics required | n/a | n/a |
| Tumbatin Clinic | No response, hospital ethics required | n/a | n/a |
| Wimmera Uniting Care | No response | n/a | n/a |
| Yooralla Society Eastern | No response | n/a | n/a |
| **TOTAL** | **99** | **77** |
APPENDIX G
<table>
<thead>
<tr>
<th>Parent report of well child adjustment</th>
<th>Mean</th>
<th>Range</th>
<th>Sd</th>
<th>Skew</th>
<th>Kurtosis</th>
<th>Alpha</th>
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<td></td>
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<td></td>
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<td>Aggressive Behaviour</td>
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<td>5.3</td>
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<td>.83</td>
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<tr>
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<td>.7</td>
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<td>Aggressive Behaviour</td>
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<tr>
<th>Revised Children’s Manifest Anxiety Scale</th>
<th>Mean</th>
<th>Range</th>
<th>Sd</th>
<th>Skew</th>
<th>Kurtosis</th>
<th>Alpha</th>
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<tbody>
<tr>
<td>Total Anxiety</td>
<td>10.2</td>
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<td>6.3</td>
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<td>.2</td>
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<td>Physiological Anxiety</td>
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<td>Worry/Oversensitivity</td>
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<td>0-11</td>
<td>3</td>
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<td>Lie</td>
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<th>Skew</th>
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<td>Frequency</td>
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<td>42-100</td>
<td>11.7</td>
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<td>Intensity</td>
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