FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES: FAMILY ENVIRONMENT, SOCIAL SUPPORT AND SIBLING WELL-BEING

By

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Abstract

The functioning of families of children with developmental disabilities has been of interest to researchers for some time. To date, little research has focused on the experiences of New Zealand families. The aim of this research is to investigate relationships between various aspects of the family environment and family functioning, and to explore siblings' level of self-concept and satisfaction with the sibling relationship. It is expected that families who receive more support from external levels of the environment will be able to function more effectively in their immediate environment (Bronfenbrenner, 1979; Hornby, 1994). Twenty-one parents and nineteen siblings of children with developmental disabilities volunteered to take part in this study. Parent participants completed questionnaires about family demographics, the level of support received from external sources, their perceptions of the family environment, and level of stress related to child characteristics; pessimism and family problems. Sibling participants completed questionnaires about their satisfaction with the relationship with their brother or sister, their self-concept, and their own perceptions of the family environment.

The results indicate that there are a number of relationships between various aspects of the environment and family functioning. Siblings who are more satisfied with their relationship have higher self-concept scores, however the self-concept scores were lower than expected. Families who receive higher levels of support have more positive perceptions of the family environment, and families who have more support and more positive views of the environment have fewer concerns on the resources and stress scale. The results indicated that families consider that they are receiving adequate support from professional services, however support from family and friends appears to be lacking.

This study has provided insight into the functioning of New Zealand families who have children with developmental disabilities, and has suggested a number of avenues for future research.

Chapter One

History of Children with Developmental Disabilities in New Zealand

A 1996 New Zealand household disability survey found that over 84,000 children were living with a physical or intellectual disability (Macaskill, 1997). Of these, 12 per cent, or over 10,000, had an intellectual disability. This number is likely to have risen in the last 10 years; a conservative estimate may be that there are at least 12,000 families now living with a child with an intellectual disability. These families require additional support, information and resources. This aim of this thesis is to explore the level of support received by parents; their perceptions of the family environment; and the impact it has on other siblings in the family, particularly on their self-concept; their satisfaction with the relationship with their brother or sister; and their own perceptions of the family environment. The thesis will first cover the history of disability and support in New Zealand. It is important to review this history as it explains the background of how children with disabilities were treated in society. The section will discuss the historic use of institutions, their closure, and current attitudes towards people with intellectual disabilities. The next section will describe the type of disability experienced by the children of participants in this study, and how each can impact on the family. This will be followed by a review of the literature focusing on stress experienced by families of children with developmental disabilities. The next two sections will cover the importance of sibling relationships, what happens when one sibling has a disability, and the psychological adjustment of siblings of children with disabilities. The final section will discuss the ecological systems theory, which explains the theoretical background for the current study.

1.1 Issues for parents of children with disabilities

Attitudes surrounding the attributes and place of children with disabilities in families and communities have undergone significant changes over the last 100 years. In the past children were expected to live in institutions, away from their families and the community. Now, the majority of children with disabilities are able to live with their families. This section will discuss the changes in attitudes from the early 1900s to the present day, from the creation of institutions such as Templeton Hospital and Levin Farm, to the closure of the last large institution in the late 1990s. This section will also cover how government policies have changed from children being institutionalised and parents not being provided with adequate support, to facilitating children being able to live in the community.

Parents of children with developmental disabilities have many issues to face. Firstly, they may come to the realization that their child is not developing typically. This may begin a long and arduous process of investigation and tests in the journey to finding a diagnosis. This process may be easier for parents of children with Down syndrome, which is generally detectable at, or soon after, birth. For parents of children with autistic spectrum disorder a diagnosis may not be reached for many years, possibly leaving parents at a loss as to what to do with their child. Then, once a diagnosis has been given, parents must face the fact that their child does in fact have a disability, and, in many cases, may never be able to live a fully independent life. Parents also begin to face issues such as what kind of treatment is available for them, where their child will go to school, and whether the parents or child are entitled to any government assistance. Many parents will also face the question of whether they are able to care for their child themselves, or whether they feel they do not have necessary skills or resources and it may be better for someone else to care for the child. The majority of parents are able to keep their child at home with the family, whereas other children may be brought up by grandparents, other family members, or in a foster family. The fact that most children with disabilities remain with their family shows how far New Zealand society has come in recent years. During the 1930s and 1940s parents often had little choice about whether to keep their child at home. If a child was born with a disability, doctors often discouraged the mother from seeing the child, or taking it home. If the parents chose to take their child home, no services were provided to help the mother or family as it was generally believed that such services would encourage families to keep their children whereas medical professionals felt it was their duty to control any such inclination. Parents were even discouraged from keeping contact with their child if it was in an institution as they believed that any involvement would promote a breakdown within the family (Millen, 1999). In current society the concept of disability is becoming increasingly normalized and children are less likely to be institutionalised and segregated from their peers, and children and their families have increasing access to community services and facilities not previously available to them (Baxter, Cummins, & Yiolitis, 2000).

1.2 Attitudes towards disability in the early 1900s

In the early part of the 1900s through until the late 1970s parents were not generally encouraged to keep their child at home. A common attitude from medical professionals was to simply put the child into an institution and forget about them. Following World War I and II people began to acquire a passion for perfection, and parents, shamed by failing to produce a perfect child, would place defective children in institutions, out of sight of family and society (Shephard 1980). The building of institutions began in 1917, when land was purchased at Templeton in order to build a hospital for psychiatric patients who at the time resided at Sunnyside Hospital (Shephard, 1980). People with intellectual disabilities had until then been placed in the same institutions as people with mental illnesses, as no distinction between the two was made until 1911, when the Mental Defectives Act was created to replace the Lunacy Act of 1907 (Millen, 1999). The new act created seven classes to define the term 'mental defective', for example people were labeled as 'idiots'; 'imbeciles', 'feeble-minded' or as 'socially defective' (Millen, 1999). The act also stated that everyone classified as mentally defective should, from the age of 5 years old, be sent to live in mental hospitals. The act focused on the difficulties faced by parents and guardians, and while people could be charged with neglecting intellectually disabled people, the act paid little attention to their individual rights (Millen, 1999).

1.3 The creation of institutions

Templeton Hospital was originally intended for people with mental illnesses, however, they were soon removed back to Sunnyside Hospital to make way for people with intellectual disabilities. The first Templeton residents were a group of young boys with intellectual disabilities aged between 5 and 20 years old who were originally placed in Sunnyside Hospital because of a lack of any other suitable home (Shephard, 1980). By 1937 Templeton Hospital had eight villas, and an occupational block was completed in 1936 with the aim of teaching boys a trade. Dr Clarence Beeby believed that children with intellectual disabilities were not educable in any but the humblest sense of the term, and that "the most that can be done is to relieve their mothers of the constant care that is needed and to train them in simple habits and in some degree of self-control that will make their care easier and their lives a little happier" (Hunt, 2000 p2). This statement sums up the attitude of the time, that children with disabilities were not capable of gaining an education of any kind, and should be committed to institutions so that parents were not burdened with their care. Templeton Hospital became such a success in caring for children with disabilities that parents in the North Island began demanding a similar institution for their children (Hunt, 2000). An institution known as Levin Farm was soon built at Levin, and by 1949 housed 269 people with disabilities, ranging in age from 9 months to 67 years old. The presence of Levin Farm allowed family doctors to provide hope to parents of children with intellectual disabilities. However, while medical professionals encouraged parents to place their children in an institution, it was a traumatic experience for many parents. Many parents had to struggle with society telling them that their child, who was generally dearly loved, was defective and should be removed from the community. Parents were advised not to visit or contact their child for between one and three months in order to give the child time to settle in. One mother stated that "it was quite the most devastating time of our lives. We never got over the feeling that we had abandoned him. If only there had been help available, or respite care at that time we might have managed much longer" (Hunt, 2000 p90).

Many parents eventually became disillusioned with the institutions that were designed and promoted as a positive place to send their children. The Intellectually Handicapped Children and their Parent's Association (IHCPA) was founded in the late 1940s to address these issues (Millen, 1999). The organization grew rapidly, as parents felt their needs were not being met by the government, and a common consensus was that the outcome for their child could be better if they were provided with a proper education. A petition was organized to ask the government to look into the lack of suitable care for children, and to investigate the differences between health, education and social opportunities provided to 'normal' children but denied to children with disabilities. The parents also requested that cottage homes be used to house children, rather than the large institutions. A report from the consultative committee, known as the Aitken report, was released in February 1953 (Millen, 1999). Contrary to the IHCPA's request, the report endorsed the use of residential institutions and again encouraged parents to place their children in these institutions from the age of 5 years. The report acknowledged that the conditions at Levin Farm and Templeton Hospital were not all they should be, but saw nothing essentially wrong with the concept of mentally deficient colonies, instead recommending that the government build more such colonies as mentally deficient people should not be kept in mental hospitals or at home (Millen, 1999). Thus even though parents were now asking why children should be kept in large institutions alongside adult residents, the government continued to endorse their use. The professional attitudes from the earlier 1900s had continued into the 1950s, and where parents had in the past generally accepted the medical establishments' decisions, they were now questioning the use of the institutions. Many parents were willing to keep their children at home; however the lack of support from the government meant that in many cases, this was impossible, particularly if funding was needed for wheelchairs or other equipment.

1.4 Beginning of a change in attitude

It was not until the mid 1960s that international literature began to accept the superiority of community care over institutional care (Hunt, 2000). A report by the Royal Commission on Psychopaedic Services in 1974 resulted in the government placing a moratorium on the building of residential institutions. The report found that a disproportionate emphasis that had been placed on the use of hospitals, and emphasis should instead be on the provision of facilities in the community that would assist in keeping people out of hospitals and provide the necessary care within the community (Hunt, 2000). The report also upheld a fundamental belief of the IHCPA (later know as the Intellectually Handicapped Children's Society or IHC) and stated that hospitals are places for the sick, and that the majority of people with mental handicaps are not sick, and although they require care, medical treatment is generally not necessary (Hunt, 2000). The focus of government committees was thus moved from considering large institutions as the only place for people with intellectual disabilities to exploring whether the community itself can provide a better place for people to live, be educated, trained and receive medical care (Hunt, 2000). The attitude of New Zealand society and the medical establishment was slowly being changed. It was no longer seen as acceptable for all people with an intellectual disability to be confined to an institution, and more acceptance and support was being given to the choice and right of parents to keep their children at home.

While attitudes regarding suitable accommodation for people with intellectual disabilities were slowly changing, it was another 12 years before the last institution closed. Government health agencies began the process of de-institutionalising Templeton Hospital in late 1994. Deinstitutionalisation was defined as the "process involving the expansion of a range of residential programmes with a mix of normal housing and specialized accommodation to create a more normal family living environment and the closure of the traditional institutional setting for the care of people with an intellectual disability. As far as possible, accommodation is provided in community settings" (Healthlink South, 1994 p2). At the time of its closure, Templeton Hospital provided care for up to 480 people, which included 30 people under the age of 17 years, 8 of whom were aged under 10 years old (HealthlinkSouth, 1994).

1.5 Current attitudes towards families and children with disabilities

As has been shown there have been significant changes in the attitudes of the government and society towards people with disabilities over the last 100 years. In the past, people were routinely admitted to hospitals or institutions, often without parental consent or agreement, as there was simply no other option. If parents chose to keep their child within the family home they were not provided with financial or practical support, and their child was not entitled to an education. In current times, the majority of children with disabilities live with their parents and family. The government provides financial assistance for equipment and many parents are entitled to a number of respite care days every year, in which the government pays another person to care for the child in order to provide the parents with a break from the continual caring requirements. Parents have access to organizations such as the IHC (now known as IDEA), and the Crippled Children's Society (now known as CCS) and many children have access to psychologists, occupational therapists, early intervention teachers, and speech and language therapists. In general, the change in attitude to allow children to remain in their homes has been positive. Children with disabilities are now able to be integrated into society and can live happy, healthy lives as part of a family and community. They have as much right to an education as any other child and play important roles in society as people are now becoming more accepting of children with disabilities, even if there is often a lack of understanding about the functioning of children with disorders such as autistic spectrum disorder (ASD) or Down syndrome. However, by taking part in society and community events, the children themselves play an important role in improving other peoples' understanding as misunderstanding generally arises from ignorance, and by helping children to become involved in society common misunderstandings surrounding disability issues can be ameliorated.

Caring for a child with a disability at home has thus been improved by the provision of services, and the government attitude is now one of complete community care for children yet from the parents' point of view, attitudes towards children with disabilities have begun to reverse. As has been shown, parents in the past generally had little choice but to send their child to an institution, and in the current society, parents generally have little choice but to keep their child at home. There are a number of group homes in the community, yet parents are not able to ask for their child to be placed in a group home, they must first prove that they are not able to cope with their child at home, and must go through a rigorous assessment before their child is able to live at a group home. Even the issue of schooling is becoming difficult. There are a number of special schools throughout New Zealand that are able to provide suitable education to children with various disabilities and levels of intellectual functioning. Children have access to various therapists and funding whilst at school, however the attitudes of integrating people fully into the community is becoming a hazard to the education of children with disabilities. Children with disabilities receive funding through the Ongoing and Reviewable Resource Scheme (Ministry of Education, 2005a), which provides funds for children to receive therapy and equipment. However, this is becoming harder to obtain, even for children with severe intellectual disabilities. The definition of special education in the Special Education Policy Guidelines is: "the provision of extra assistance, adapted programmes or learning environments, specialized equipment or materials to support children and young people with accessing the curriculum in a range of settings" (Ministry of Education, 2005b). Efforts are being made to provide all learners with resources and equipment; however Government preference is for all children to attend mainstream schools. This would result in the child's loss of valuable education, as teachers in a class of up to 30 pupils simply do not have time to spend working individually with one child.

Children who have disabilities can bring much joy and happiness to a family; however the strain of caring for them can have effects on other members of the family, not only for parents and siblings but also for extended family members. As caring for children with disabilities in the home has become increasingly normalized, parental stress has shifted from the child with the disability to all children in the family, and family coping in general (Baxter et al., 2000). Parents of children with disabilities generally report more stress than parents of typically developing children, and siblings of children with a disability may have an increased risk of developing psychological problems. The following chapters will explore research and issues surrounding the families of children with developmental disabilities, particularly exploring stress, family functioning, levels of support received, and sibling relationships.

Chapter Two

Definitions of Developmental Disabilities

The purpose of this study is to explore the levels of social support received by families of children with developmental disabilities and how this impacts on the psychological adjustment of typically developing children in the family, how they view their relationship with their brother or sister, and how both parents and siblings view the family environment. However, families who took part in this study have children with a range of disabilities, and it is important to first understand the differences between various disorders or disabilities and to understand how each can affect the family. The most common disorders present in the lives of families in this study are Autistic Spectrum Disorder and Down syndrome. Many of these children have also been diagnosed as having Attention-Deficit Hyperactivity Disorder. A small number of families have children with Angelman syndrome, Turners syndrome and intellectual disabilities (not otherwise specified).

2.1 Autistic Spectrum Disorder

Autistic Spectrum Disorder (ASD) is a form of pervasive developmental disorder. ASD is marked by three main characteristics. The central impairment is in social reciprocity. This means that the child does not have the skills needed for social perception, social knowledge or social functioning. Social perception includes picking up nonverbal aspects of behaviour such as body language. Social knowledge includes knowing about feelings and intentions of other people; and social functioning is the ability to relate to others, be aware of others emotions and to use language and nonverbal skills to engage other people during social interactions (Towbin, Mauk, & Batshaw, 2002).

The second major impairment is in communication skills. Children with ASD are generally severely delayed in language acquisition and the development of both expressive and receptive language is hindered. Speech that does develop may be idiosyncratic or echolalic (Towbin et al., 2002).

The third dominant impairment is abnormalities in behaviour. Children with ASD have limitations in capacities to play and pretend, and play behaviour is often limited to restricted, perseverative and stereotyped patterns and interests. Children with ASD often have extensive attention spans for ritual behaviours, for example flicking a piece of paper, yet they are usually incapable of focusing on interactions with other people (Towbin et al., 2002).

Children with this disorder are generally diagnosed as having autism, which is a term that, while it explains the child's disability, does not describe the different degrees of impairment demonstrated by children. The term Autistic Spectrum Disorder provides a better understanding of the disorder being expressed on a scale. At one end of the scale, children with ASD may display severe impairments across all areas of development, and at the other end of the scale children may have impaired social skills, yet communication skills may be more advanced. Children at this end of the scale are generally diagnosed as having Aspergers Syndrome, which is often viewed as a form of higher functioning autism. Thus children with ASD will display impairments in each of the above areas to some extent along the spectrum. While each child has a different manifestation of the disorder, each child has their own unique abilities and areas of weakness, and each child presents a challenge to their family.

The exact cause of ASD remains unclear, however it is generally accepted that it is the result of developmental brain abnormalities, with significant genetic influence (Towbin et al., 2002). Autistic Spectrum Disorder is a disorder that affects all areas of development and remains constant across the person's life. The outcome for the person depends largely on their language abilities and intelligence, however most adults with ASD remain dependent to some extent, yet many people with Aspergers have better outcomes than people with more severe forms of the disorder.

Living with a child with ASD is arguably more difficult than any other type of disorder. The presence of ASD can have a number of important impacts on the family life. Children with ASD can demonstrate a number of difficult behaviours, which are often hard to control. Parents and siblings can easily become worn out attempting to deal with them. The lack of communication ability exhibited by children with ASD is also very difficult to deal with, particularly as children are often very set in their ways and can become easily upset if something has disrupted their routine, and both parent and child can become easily frustrated if the parents cannot understand what the child wants or needs, and the child cannot express their feelings to their parents. Perhaps the most difficult aspect of living with a child with ASD arises during public outings as parents may become embarrassed at their child's behaviour, particularly as many people do not understand ASD and feel the parents should control their child.

2.2 Down syndrome

Down Syndrome is caused by a number of chromosomal abnormalities. The most common type is trisomy 21, or an extra 21st chromosome, and affects around 95% of all people with Down Syndrome. The second type affects around 4% of people with Down syndrome and is where the long arm of an extra chromosome 21 attaches to chromosome 14, 21 or 22. The third main type, mosaicism, affects 1% of people with Down syndrome and occurs when some, but not all cells have a defect (Roizen, 2002). Children born with Down syndrome generally have central hypotonia, where their limbs are floppy yet not weak, thus gross motor skills are delayed, and children do not generally sit until around 11 months of age, or walk until around 19 months of age. However, significant physical disabilities are rare as children are able to learn to run or ride bikes. Children with Down syndrome often display ‘normal’ social interactions but display varying levels of cognitive impairment. Language is generally delayed, and receptive language is better than expressive language. Children with Down syndrome are also delayed intellectually, as 85% have IQ scores ranging from 40 – 60, which means the majority of people with Down syndrome have mild to moderate intellectual disabilities (Roizen, 2002).

Children with Down syndrome are also at risk of developing various medical conditions, for example congenital heart disease, sensory impairments, orthopedic problems, dental problems and skin conditions (Roizen, 2002). The quality of life for people with Down syndrome has improved greatly since times when doctors would recommend parents institutionalise their children. Now, many people with Down syndrome are able to hold jobs and live independent lives, participating comprehensively in society.

As with ASD, living with a child with Down syndrome can present a number of challenges for their families. In particular there may be difficulties with communication. Children with Down syndrome are generally able to understand what is said to them, but can become easily frustrated if they are unable to express themselves, and people are unable to understand them. For parents, the most difficult thing to deal with may be the increased risk of the child developing health problems. For siblings, the main problem may be feelings of embarrassment at their brother or sister having a disability, or they may feel they do not receive as much attention from their parents. Issues relating to sibling relationships will be discussed in more detail in a later section.

2.3 Attention-Deficit Hyperactivity Disorder (ADHD)

Attention-Deficit Hyperactivity Disorder (ADHD) is a neurobiological syndrome and is assumed to be a congenital condition (Stein, Efron, Schiff, & Glanzman, 2002). Many families who participated in this study have a child who has a co-diagnosis of ADHD along with another diagnosis, but none of the children had ADHD as a primary diagnosis. The primary features of the disorder are inattention, hyperactivity, and impulsivity, which combine in various ways to create three different subtypes of ADHD – Predominantely Inattentive, Predominantly Hyperactive-Impulsive, and a Combined type (Wicks-Nelson & Israel, 2003). Symptoms of inattention can include failing to attend to details or having difficulty sustaining attention; hyperactivity symptoms include fidgeting with hands or feet and having difficulty playing quietly; and impulsivity symptoms include having difficulty waiting their turn and interrupting others (Wicks-Nelson & Israel, 2003). ADHD is generally diagnosed in early childhood as children display developmentally inappropriate levels of inattention, hyperactivity and impairments in functioning in school, home or social situations (Stein et al., 2002). Children with ADHD also display deficits in executive functions, for example sustaining and shifting attention, planning and self-monitoring (Stein et al., 2002). Children with ADHD generally underachieve at school, often as a result of their inability to pay attention to lessons, and they may be frequently removed from the classroom as a result of disruptive behaviour, causing them to fall further and further behind their peers. Children often demonstrate impairments in skills required for daily living, communication and social skills (Stein et al., 2002). Many children with ADHD exhibit social difficulties as they are talkative and are generally louder and more forceful than their peers, with behaviour often becoming noncompliant and disruptive, resulting in peers being less likely to want to form friendships (Wicks-Nelson & Israel, 2003).

The presence of ADHD has an impact on family life as parents can become excessively directive and intrusive (Wicks-Nelson & Israel, 2003). Discipline may revolve around shouting and punishment in an effort to get the child to listen to their parents, particularly as the child’s behaviour is often noncompliant and oppositional. Families of children who have ADHD have also been shown to display increased levels of parental stress, lower sense of parenting competence and a higher rate of parental separation and divorce (Wicks-Nelson & Israel, 2003).

Attention-Deficit Hyperactivity Disorder is most commonly treated with methylphenidate (Ritalin) which is a stimulant medication that can reduce aggressive, noncompliant and oppositional behaviours by increasing the arousal and activity of the central nervous system (Wicks-Nelson & Israel, 2003).

2.4 Other disorders/syndromes

Angelman Syndrome

Angelman syndrome is a genetic condition that features severe motor and intellectual retardation, including jerky movement, hypotonia, absence of speech and unusual facial characteristics (Towbin et al., 2002). Many children with Angelman syndrome display characteristics similar to autistic spectrum disorder, however Angelman syndrome is caused by a deletion in chromosome 15q11 – q13.

Turner Syndrome

Turner syndrome is a disorder which only affects girls and is caused by the loss of an entire chromosome, as girls are born with only one X chromosome, resulting in 45 rather than 46 chromosomes. Most girls with Turner syndrome have average IQs but have visual-perceptual impairments resulting in a predisposition to learning disabilities (Batshaw, 2002) .

Chapter Three
Support for parents of children with disabilities

Numerous studies have been conducted to investigate the functioning of families with a child with a developmental disability. A substantial proportion of this literature has focused on the stress experienced by these families, particularly whether families experience more stress than families of children with typically developing children. An important factor that has been investigated is the effect of social support on families with a child who has a disability. Social support has been shown to have a moderating effect on stress, and much research has been conducted to determine the extent of this effect with families with a disabled child. This literature review will focus on research on families with a child with a disability and will cover the stress experienced by families of children with disabilities, followed by a definition of social support and a review of the literature surrounding the benefits of social support for families.

3.1 Stress in families

Stress in families of children with autism has been well documented (Dyson, 1993; Krauss, 1993; Woolfson, 2004). Raising a child with a disability is arguably one of the greatest stressors any parent has to face. The chronicity of disorders such as Autistic Spectrum Disorder (ASD) or Down syndrome leaves parents with little hope that their child will ever be able to live a ‘normal’ life. Parents of children with ASD have been found to experience more stress and adjustment problems than parents of children with Down syndrome, who in turn reported more stress and adjustment problems than parents of typically developing children (Sanders & Morgan, 1997). Many parents are able to cope well with the demands and requirements of their child, however others will require supportive counselling by a professional who is able to listen to and help them with their concerns (Hornby, 1994). Raising a child with a disability can have a profound impact on the family, firstly as parents come to acknowledge that the ‘normal’ child they thought they had does not exist, and they are instead left with a child who may never be able to lead a normal life and who may exhibit behavioural problems. Parents thus have to first deal with the fact that their child is different to other children, and will require special attention throughout their lives. Some of the stressors that parents may face are the economic problems of providing for a disabled child, time demands of intervention therapies, possible social isolation due to a child’s mobility or behavioural problems and strained family relationships (Beckman, 1983; Woolfson, 2004).

During school years parents become more aware of their child’s limitations, particularly as there may be increasing evidence of discrepancies between their child’s physical size and their developmental capacity, thus the disability becomes more visible (Dyson, 1997). Parents may also have difficulty finding babysitters or suitable respite care providers, and may be unsure about how to deal with preadolescent problems (Dyson, 1997). However, despite these potential stressors, studies have found that many families are able to cope effectively and positively with these additional demands (Krauss, 1993). Dyson (1997) found that parental stress is not predictive of family dysfunction, and families may respond to the stress of caring for their child with resilience and adaptive functioning, and increased stress does not necessarily lead to a distressed or dysfunctional family.

Associated stressors such as the child’s ability, age, birth order or behaviour problems can have an impact on relationships between other members in the family, and can affect the marital relationship. However, the effects may be ameliorated in the presence of certain factors. Firstly, the child’s characteristics can have important effects. Studies have shown that mothers are generally no more stressed than fathers, yet fathers are generally more distressed by their child’s inability to speak, whereas mothers are more distressed by more visible symptoms, such as inappropriate or stereotypical behaviours (Konstantareas & Homatidis, 1989; Ricci & Hodopp, 2003; Frey, K.,Greenberg, M.T., & Fewell, R. R., 1989). Parents of children with less severe disabilities may thus experience less emotional distress as there are fewer characteristic or behavioural factors to influence their coping abilities. Fathers may also be more affected by the gender of their child than mothers, as fathers may be at greater risk of being unable to develop affective ties to their child, particularly if the child with a disability is a son (Krauss, 1993). Main stressors for both mothers and fathers can include having a prematurely born child, less belief in their own ability to control their child’s development, providing more control to professionals and perceiving their family as being unable to adapt (Krauss, 1993). Added to this for mothers is the level of helpfulness derived from social support networks (Krauss, 1993). While these factors can act as stressors for both mothers a fathers, for maternal employment status can act as a buffer of stress (Warfield, 2001), as mothers have another area to focus their attention and increase self-esteem as they are not solely spending time being a mother of a disabled child, but have another area to excel. However, this may also be viewed as a stressor if mothers are working full-time and may be left with little energy to deal with their child at home.

Respite care is another important factor that can act to reduce parental stress, as it can lead to improvements in the quality of family life (Factor, Perry & Freeman, 1990). Respite care is short-term, temporary, usually overnight or weekend, care for people with disabilities mostly living at home. Families in New Zealand are provided with a number of carer respite days every year which they may use to pay someone to care for their child. Despite this, a survey conducted in 2002 by the CCS found that 84% of parents and caregivers were dissatisfied with their lack of access to quality respite care services, and 91% reported that access to a respite care service was an important part of community oriented disability support services (Lemon, 2002). The main needs identified by caregivers are to be provided with release time; to be able to access emergency respite care; and to support caregivers to lead an ordinary life (Lemon, 2002). Users of respite care generally have children who are more severely disabled and more dependent than families of non-users (Halpern, 1985; Marc & MacDonald, 1988). Perceptions of respite care generally show that it has a positive impact on the family life, as one study found that 68% of respite care users agreed or strongly agreed that the family gets along better since receiving respite care services; and 52% of families agreed that respite care allowed nondisabled family members to spend more time with each other (Joyce, Singer, & Isralowitz, 1988). Much voluntary respite care comes from members of the immediate family such as grandparents, aunts, uncles and siblings who are able to provide emotional or social support (Sharpley, Bitiska, & Efremidis, 1997). While respite care can be accessed through professional services, it is also important for families to be able to access respite care from other family members and close friends. Families of typically developing children are generally able to rely on other family members to babysit and provide practical help; however this help is not as readily available for families of children with disabilities. The assistance received by family members is vitally important for the functioning of the family, particularly as it can help to reduce stress levels and assists families to develop coping strategies as there are other people to whom to turn if help is needed.

Parenting stress is an important factor to consider when providing services for the family, as it has been associated with lower parenting satisfaction, higher parental symptomatology, abusive behaviour and insecure child attachment (Smith, Oliver, & Innocenti, 2001). One study found that there were three main factors associated with parenting a child with autism. These were: concern over the permanency of the condition; poor acceptance of autistic behaviours by society or other family members; and the very low levels of social support received by parents (Sharpley et al., 1997). Stress and depression are two main factors that lead mothers of children with autism to seek social support (Boyd, 2002). This study also found that mothers are more likely to first seek support from families and friends, as sources of informal support are more effective at reducing stress than sources of formal support. Access to social support has been related to positive family and child outcomes in families of children with a disability (Rivers & Stoneman, 2003). Social support can come from various areas of society, for example from a spouse, grandparents, other family members, other parents, friends and professional agencies. Mothers tend to first seek support from other family members, as informal sources of support are believed to be more effective at reducing stress than formal sources (Boyd, 2002). Family assistance can be one of the most useful sources of support, as families may be more willing and able to provide instrumental and financial assistance. Family respite care and financial supports are some of the most frequently identified services that family support networks are able to provide (Herman & Thompson, 1995). For mothers of children with autism, the most useful source of formal support appears to be parent support groups, where they are free to discuss their concerns among other parents who understand the problems firsthand (Boyd, 2002). Parenting networks can also be important sources of support as they are able to discuss concerns with other parents who have been through the same issues themselves. Many countries, including New Zealand have services such as Parent-to-parent, which is a support group run by parent volunteers, and generally operates as a telephone contact helpline. Parents are able to ring the helpline and are then put in contact with another parent who has a child with a similar disability (Hornby, 1994).

3.2 Social support definition

There are various definitions of social support. Dunst, Trivette and Cross (1986a) defined social support as being a multidimensional construct that includes physical and instrumental assistance, sharing of information and resources, and as providing emotional and psychological support. The term may also refer to formal services received by professional organisations and less formal organisations, such as social clubs or churches, which the family feel is important to their lifestyle (Dunst, Trivette, & Cross, 1986b). Cobb (1976) defined social support as information belonging to one or more of three classes. Firstly, information which leads the person to believe that they are cared for and loved, secondly, information which leads to person to believe that they are esteemed and valued, and thirdly, information which leads the person to believe that they belong to a network of communication and mutual obligation. These definitions can be summed to define social support as a network of individuals who are able to provide information, resources, and emotional and psychological support through either formal, professional services, or through less formal mutual involvement within a family, friendship or social group.

The stress involved in raising a child with a disability can be exacerbated by a lack of social support and can have effects on how the family is able to function, and on the psychological adjustment of other children in the family. However, studies have shown that families who report higher levels of social support also report lower levels of stress (Beckman, 1991). This may be because families who have access to higher levels of social support may find that stress levels are ameliorated as the family has other people to turn to for respite care, someone to talk to or just the knowledge that someone else is willing to help. According to family systems theory, social networks and support provided to families both directly and indirectly influence the behaviour, attitudes, expectations and knowledge of parents and their offspring (Dunst, Trivette, & Cross, 1986a).

3.3 Benefits of social support

Social support is able to act to facilitate coping with crisis and adaptation to change (Cobb, 1976), and may act as a mediator of stress by influencing how well parents are able to cope with the demands of raising a child with a disability, as families who report higher levels of social support generally report lower levels of stress (Beckman, 1991; Boyd, 2002; Seybold, Fritz, & MacPhee, 1991). Parents who do not have effective support networks may have few people to provide respite care, thus will have very few breaks from the continual pressure of caring for their child, leading to increased pessimism, exhaustion and risk of burnout (Factor, Perry, & Freeman, 1990). Social support has also been found to be an important component in therapeutic processes, as patients who receive special supportive care following an operation require less medication for pain and are able to be discharged earlier than patients who do not receive special care (Cobb, 1976).

The effectiveness of support networks has been found to be a more important factor for parental self-esteem than the size of the network (Seybold et al., 1991), thus a small, actively helpful group of friends or family is more effective at increasing a parent's self-esteem than a larger, less active support group. Social support is able to mediate personal well-being and can improve parental attitudes towards their children (Dunst et al., 1986b). The presence of social support may lead to more positive perceptions of the family environment as it is linked to more stable functioning, a more positive perception of the child, and can enhance the parent-child relationship (Seybold et al., 1991). Dunst et al (1986b) reported that parents with more supportive social networks were less protective of their child, regardless of the child's diagnosis or severity of the disability, indicating that as levels of social support increase, parents feel less of a necessity to overcompensate by overprotecting their child. This study also found that children were more likely to make more developmental progress if their parents had supportive social networks. These findings suggest that not only does social support relieve some of the stress associated with raising a child with a disability, but it also gives them an opportunity to develop more positive relationships with their child. As parents are less protective they may be more willing to allow their child to experiment with their skills and provide them with more independence, which may explain why these children made greater developmental gains than children whose parents had less supportive social networks. However, the presence of more supportive social networks was related to children who had fewer physical limitations, were more socially acceptable to others, with fewer behaviour problems and with less difficult personality characteristics (Dunst et al., 1986b). This relation of child characteristics to the presence of social support suggests that the benefits gained through having a supportive network may be limited to those families with a less physically disabled, more socially acceptable child.

While it is acknowledged that social support is an important factor in reducing the stress of parents with children with disabilities, research has found that such families have less social support available to them than families of typically developing children (Dunst et al., 1986b). There are various reasons why social support is often not readily available to families. Firstly, the perceived stigma associated with the child displaying characteristics that deviate from societal norms by displaying stereotypical or unacceptable behaviour may mean that parents are less likely to seek help, or that other people are less likely to be willing to help. Perceived stigma has been found to be consistently related to less perceived support from other family members and more negative interactions with family (Mickelson, 2001).
The perceived stigma in this study related to the individual's personal feelings about the stressor, for example, embarrassment or shame, and their projections of these feelings onto others, whether or not they accurately reflect support network members' or society's feelings about the stressor (Mickelson, 2001). Thus while parents may feel that their child's characteristics will be rebuked by society and fewer people will be willing to help them, this may not actually be the case.

Social support has thus been shown to be an important factor in the functioning of families of children with disabilities. Families who have increased levels of support demonstrate less stress. The most effective support network is derived from help received by family and friends. However, the benefits of effective social support networks may be limited to families who have a less physically disabled, more socially acceptable child. In general, it is important for families to have an effective support system, regardless of the size of the network in order for them to be able to function effectively as a family.

Chapter Four
Sibling Relationships

Sibling relationships are among the longest relationships any child will be involved in. However, the relationship can be disrupted when a brother or sister has a disability. There are a number of effects having a brother or sister with a disability can have on typically developing siblings in the family. This section will first discuss the importance of sibling relationships, particularly as it helps children to learn social skills. This will be followed by a review of literature regarding sibling relationships when one child has a disability, and the effects the presence of a disability may have on the amount of caregiving the typically developing sibling is expected to give.

4.1 The importance of sibling relationships

Sibling relationships are one of the longest and most enduring of family relationships (Seligman & Darling, 1989). The birth of a younger brother or sister can be a difficult experience for preschoolers, however, by the time the baby is around 8 months old, siblings generally spend much time together and the infant can be comforted by the presence of their brother or sister in short maternal absences (Berk, 2001). During a child's second year he or she is often able to begin to imitate and actively join in play with their brother or sister (Berk, 2001). During early childhood siblings are an important and constant source of companionship and are often able to help with difficult tasks and provide emotional support (Berk, 2001; Seligman & Darling, 1989). During school years siblings are able to extend themselves to others outside the family, using the social skills they developed and practised together (Seligman & Darling, 1989). Sibling relationships generally change during adolescence as younger siblings become more self-sufficient and require less direction from their older brother or sister. Teenagers generally become more involved in friendships and spend less time with their siblings, who are a part of the family from which they are seeking to become independent (Berk, 2001). Siblings may be ambivalent towards one another yet still rely on each other as friends and confidants, and continue to provide encouragement and friendship into adult years (Seligman & Darling, 1989). While siblings may have less influence during the adolescent years, the quality of the siblings relationship remains stable – those who had a positive bond during early childhood years will retain high levels of affection and caring during adolescence (Berk, 2001).

Sibling interactions play an important role in the social life of children, particularly in the preschool years as siblings are able to model and learn social interactions from each other (Knott, Lewis, & Williams, 1995). As siblings spend large amounts of time interacting in the home, it is with a brother or sister that a child will experience their first extensive social interaction with another child (Abramovitch, Corter, & Lando, 1979). Older siblings have been found to be particularly powerful models and teachers for their younger siblings, as by around 18 months of age, the younger sibling imitates the older sibling more often than the other way around (Knott et al., 1995). Some of the ways in which older siblings act as a teacher for younger siblings are by teaching language, sharing skills, teaching imagination and how to play with various toys. Younger siblings gain vocabulary through listening to their brother or sister and spend time watching and imitating their sibling, often picking up toys abandoned by their sibling (Abramovitch et al., 1979). Older siblings can act as important role models for children during make-believe play as children provide rich, challenging stimulation to younger siblings (Berk, 2001). Research also suggests that siblings play a strong role in the development of conflict behaviour and in cooperative fantasy play (Dunn, 1988).

The birth of a younger sibling can be a difficult experience for other children in the family as the new baby will require much time from the parents and the older child may view the baby as a rival for parental attention. Parents may be able to set aside time to spend alone with the older child in order to reduce feelings of being deprived of attention and affection. Helping the older child to understand the baby's needs is also important in order for the child to realise that if the baby is hungry or wet, they need the mother or father's instant attention (Berk, 2001). As the child realises that their parents still have time for them, and as they understand the baby's needs they may feel less resentful towards the baby and more positive about developing a relationship. As the baby grows older and requires less of their parents' time, the children will likely spend increased amounts of time playing together, which can further improve and strengthen the bond between the children.

4.2 Sibling relationships when one child has a disability

Sibling relationships are an important aspect of childhood for children to learn social skills and to develop their first friendships. However, if the baby has a disability it will likely require continuous amounts of parental attention and may not be able to spend as much time playing with their brother or sister, due to cognitive or physical limitations. A positive sibling relationship may thus not be able to develop as the older child may continue to feel that their parents' time is taken away from them, and they may feel resentful that they are not able to play with their brother or sister as other children are able to play with their sibling(s).

During the school years, children may begin to realise how different their lives are to that of their peers (Strohm, 2002), and may be unsure how to react to teasing and questioning about their brother or sister. Typically developing siblings may miss a having a brother or sister with whom to share hopes, dreams, and a loving relationship (Meyer & Vadasy, 1994). As sibling relationships are one of the longest and stable of family relationships, it is possible for siblings to exert influence over one another (Seligman & Darling, 1989). The nature of a relationship between a nondisabled–disabled child dyad consists of different elements than that within a nondisabled-nondisabled child dyad, where children may play equal roles of modelling and learning, playmates and companionship. In sibling dyads where one sibling has a developmental disability, it is less likely that the siblings will be able to model and learn from each other, as children with developmental disabilities generally display a limited repertoire of play or social behaviours, they may have communication deficits and may not be socially responsive. Thus these siblings may not experience bonding moments that often arise from play sessions between non-disabled sibling dyads (Rivers & Stoneman, 2003).

Kaminsky and Dewey (2001) stated that little research has investigated siblings' perspectives on their relationship with a sibling with autism. They hypothesised that siblings of children with autism would report differences in their relationship compared to siblings of children with developmental delays, or of siblings of normally developing children, as a result of social deficits exhibited by children with autism. Their study subsequently found that siblings of children with autism reported less intimacy and nurturance towards their brother or sister with autism, and less prosocial behaviour in their sibling relationship than siblings of children with Down Syndrome, and of normally developing children (Kaminsky & Dewey, 2001). The development of a positive sibling relationship can be disrupted in sibling dyads where one child has Down Syndrome. General developmental delay and less emotional responsiveness in a child with Down syndrome may mean that they are a less responsive social partner for other children. Children with Down syndrome are often less active in initiating prosocial behaviours, instead tending towards imitating the behaviours (Abramovitch, Stanhope, Pepler, & Coter, 1987). A study by McHale, Sloan & Simeonsson (1986) found that on the average children have positive things to say about their relationship with a brother or sister, regardless of whether their brother or sister has a disability or not. The study also found that the sibling relationship between children with a brother or sister with a disability, and children with a brother or sister without a disability is very similar. However, for children with a brother or sister with a disability, more negative sibling relationships are associated with worries about their siblings' future, perceptions of parental favouritism and feelings of rejection towards the child.

Another important aspect of sibling relationships is conflict. All siblings engage in teasing and arguing, which can have a constructive purpose by teaching children how to manage and resolve disagreements (Meyer & Vadasy, 1997). However, this may also cause feelings of guilt when one child has a disability, as typically developing children may be blamed for causing conflict, which may prevent siblings from expressing their anger and aggression in a healthy manner (Meyer & Vadasy, 1997). Conflict is also an important part of development for the child with a disability, as a child who has learned to defend him or her self within the family will be better equipped to face life in the community without the protection of their family (Meyer & Vadasy, 1994).

4.3 Siblings and caregiving issues

Sibling dyads where neither sibling has a disability will generally be able to grow up with someone else to play with, teach, and learn from and to be a companion from early childhood through to adulthood. While these siblings may spend time helping each other with difficult tasks and watching each other if a parent is temporarily absent, and generally caring for each other, it is not likely that one will consistently be required to act as a caregiver for the other. However, if one sibling had a disability the dynamics of this dyad would change considerably. Siblings are generally expected to "grow up" sooner than other children as they may need to learn to look after themselves while their parents are caring for their brother or sister (Strohm, 2002). However, they may themselves also be required to spend time caring for their brother or sister. While this may lead the child to feel valued and useful, it may also interfere with their social development and ability to establish independence (Strohm, 2002). Female siblings are also more likely to be expected to provide caregiving than male siblings (Seligman, 1991). A child who is required to provide excessive caregiving to their brother or sister may feel angry, resentful, guilty for feeling this way, and may develop psychological problems (Seligman & Darling, 1989). The issue of siblings holding large amounts of responsibility for their brother or sister is important for professionals as the way siblings envision their own future may depend in part on whether they feel any resentment or anger towards their parents or sibling (Seligman & Darling, 1989).

4.4 Effect on attachment to a caregiver

The birth of a brother or sister with special needs can also lead to a disrupted attachment to primary caregivers. Attachment is the strong, affectional tie we feel towards people in our lives. As attachments develop we begin to feel pleasure and joy when interacting with the person, and are able to be comforted by their presence and can become distressed by their absence. There are four different types of attachment that can develop. Firstly, a secure attachment is one in which infants use the parent as a secure base from which to explore the environment and can become distressed in the parent's absence, actively seeking contact when the parent returns. Avoidant attachment is one in which infant can be unresponsive to the parent when they are present, are not distressed when the parent leaves, and are slow to greet the parent on their return. Resistant attachment is one in which infants retain physical closeness to their parent and fail to explore. The child may display angry, resistive behaviour when the parent returns following an absence and are difficult to comfort. The final attachment type is disorganised – disoriented attachment. This type displays the greatest insecurity as children display confused, contradictory behaviours on the parents' return (Berk, 2001). Children who develop secure attachments to caregivers who provide affection and security have been found to be higher in self-esteem levels, more socially competent, more cooperative and more popular than children who developed avoidant attachments (Berk, 2001).

Attachments begin to develop from the moment of the child's birth and by the age of 6 months to 2 years attachment to a familiar caregiver becomes clearly evident (Berk, 2001). This attachment process continues throughout early childhood and the level of the attachment assists the child to develop an internal working model, or set of expectations about the availability and accessibility of parental support during times of stress (Berk, 2001). The development of a positive, secure attachment to a parent or caregiver is thus important to assist the child to develop a sense of self, and be able to form future healthy relationships with other people (Strohm, 2002). However, the attachment process can become disrupted by the presence of a brother or sister with special needs. A child who has developed a secure attachment to their mother may begin to feel a sense of abandonment as their mother spends more time and energy with the child with special needs (Strohm, 2002). To develop a secure relationship, the child must learn that they can rely on their mother or other attachment figure to be there for them (Strohm, 2002), yet if the child has a brother or sister with special needs, this aspect of the relationship can be strongly threatened as the mother spends more time with their sibling, and has less energy to devote to other children in the family. Children may thus begin to develop a sense of abandonment and their sense of self may begin to suffer if they feel that their sibling receives more attention because they are more important, thus the smaller amounts of attention they receive may be because they are less important. A secure attachment between mother and child will be strong enough to be able to withstand misbehaviour or risk-taking, yet if the child has a sibling with a disability they may not feel that the relationship is strong enough to withstand such behaviour as their parents may appear more stressed or depressed and children may be less willing to rebel or test the limits (Strohm, 2002).

However, the presence of a brother or sister with a disability may also lead to increased levels of secure attachment between the child and their parent/s. Levy-Wassar & Katz (2004) found that children who had a brother or sister with an intellectual disability had a higher ratio or more secure than less secure attachments than siblings in the control group, suggesting that the presence of an child with an intellectual disability in the family does not necessarily lead to neglect and less secure attachments, but can be a catalyst for emotional growth (Levy-Wassar & Katz, 2004).

Chapter Five

Sibling Psychological Adjustment

In recent years there has been much research conducted on siblings of children with disabilities, but results regarding the psychological adjustment of siblings have been inconclusive. Most researchers agree that the presence of a brother or sister with a disability does not necessarily lead to psychological distress in siblings as other issues such as parental adjustment are also important. This section will discuss literature regarding the psychological adjustment of siblings of children with disabilities.

5.1 Issues for siblings

The presence of a disability in a family member not only impacts on the child's parents, but can create various stressors and issues for all members of the family, including other children. Even though the siblings of children with a disability may not be able to engage in a 'typical' sibling relationship, their relationship can still be positive and fulfilling. However, the presence of a brother or sister with a disability may result in children experiencing increased levels of stress and can have varying impacts on their own psychological well-being. Siblings of the child with a disability may have to cope with changes in family roles, such as structure and activities, feelings of guilt and shame, loss of parental attention and increases in parental stress (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004).

Family life when one child has a disability often revolves around the needs of that child, leaving less time for other children to spend with their parents, possibly leading siblings to believe that they are not as important as the child with the disability, which may then lead to both feelings of resentment and behavioural problems (Strohm, 2002). Young children in particular may have difficulty understanding why their brother or sister receives so much attention, as perceptions of attention are often linked to perceptions of love, thus a young child may feel that as their brother or sister receives more parental attention, they also receive more parental love (Strohm, 2002). Seligman and Darling (1989) found that some of the problems that may arise for typically developing siblings are feelings of guilt or shame and fear of 'catching' the disability. Siblings may feel a degree of survivor's guilt – i.e., that their brother or sister has a disability and they do not - and may feel guilt about their own feelings of ambivalence towards the disabled brother or sister (Meyer & Vadasy, 1994). Siblings may also experience a degree of role tension, when regardless of their birth order, their brother or sister with the disability becomes the youngest child socially, and other siblings are expected to care for him or her (McHale, Simeonsson, & Sloan, 1984).

One important issue is the need for siblings to be given information about their brother or sisters disability. Siblings may feel isolated if they lack the opportunity to talk about their feelings and a lack of understanding about their brother or sisters' condition or syndrome can subsequently lead to feelings of fear and anxiety (Strohm, 2002). It is important that parents are honest with their children in order to dispel any feelings of fear and uncertainty about their brother or sister, and to ensure other children in the family feel included in, not isolated from, the family. Providing the child with an understanding of their sibling's disability will also help them to understand that they are not at risk of developing the disability themselves. Children who are not provided with relevant information may be confused as to whether they will develop the disability, how to talk to other people about it, what it means for their own future and how to relate to their brother or sister (Seligman & Darling, 1989).

Having a sibling with a disability is, of course, not the only risk factor for children developing psychological problems. The effects that a child with a disability has on their sibling and other family members can depend on factors such as the family's socioeconomic status; size; religion; the extent of the child's disability; how parents handle the situation; whether the sibling with the disability is older or younger; and the level of caregiving the sibling is expected to provide (McHale et al., 1984; Seligman, 1991). These effects can vary depending on the characteristics of individual family members, as well as the family as a whole (McHale et al., 1984). Families of children with disabilities can be viewed as a microsystem in which the child, siblings and parents reciprocally influence one another, and how well the family is able to function depends on factors associated with each member within the microsystem (Hornby, 1994).

5.2 Risk of psychological problems

Various studies have been undertaken on the area of psychological difficulties in siblings of children with disabilities, and reported results have been inconsistent. While siblings of children with disabilities may be more at risk of developing psychological problems, whether siblings are helped or harmed by the presence of a brother or sister with a disability is a difficult question to answer, as there are many factors that lead to psychological difficulties, and these may occur indirectly of having a brother or sister with a disability (Seligman, 1991). Subjective or psychological well-being can be moderated by factors such as genetics, brain functioning, personality and health (Dykens, 2005). The type of disability present is an important factor when determining whether siblings may experience psychological distress. Siblings of children with Down syndrome generally demonstrate better adjustment than siblings of children with pervasive developmental disorders, such as autism, and both groups demonstrate poorer psychological adjustment than siblings of developmentally typical children (Rodrigue, Geffken, & Morgan, 1993).

One reason for this may be the difficult behaviours that can be displayed by people with autism. Siblings of children with autism may be the only people, besides parents and teachers, who are able to handle their brother or sister, which may lead to higher levels of stress as the siblings may be expected to provide additional care for their brother or sister in order to give their parents time to do things without worrying about their child (Bristol & Schloper, 1983). The size of the family can also have an impact on how siblings are able to adjust, as children who are part of a two or three child family may force one child to carry the parent’s hopes, wishes and aspirations about their children as they fulfil both their own and their sibling’s role in the family (Grossman, 1972). The research thus suggests that there are various unique predictors of adjustment in families of children with disabilities that differ from the predictors in families without children with a disability, as the age of siblings, and size of the family may play a less important role in the adjustment of families without a child with a disability.

Studies that have researched the psychological well-being and self-concept of siblings of children with disabilities have reported varying results. Hannah and Midlarsky (1999) compared the adjustment and competence of siblings who had a brother or sister with mental retardation with control siblings who had brothers or sisters with no disabilities. The results indicated that there were no overall differences for internalising disorders, externalising disorders, or for self-esteem based on group membership or gender. These findings were confirmed by Kaminsky and Dewey (2002), who reported that siblings of children with autism are not at inflated risk for adjustment difficulties or loneliness, however they also found that siblings whose parents attended support groups displayed fewer internalising and total adjustment problems on the Child Behaviour Checklist than siblings whose parents did not attend support groups. The reason for this is that siblings of children with autism whose parents attend support groups may have more access to information about autism and are more likely to interact with other families of children with autism, thus creating social support networks for the children which may facilitate healthy psychological adjustment (Kaminsky & Dewey, 2002). Another study also found that siblings of children with a less severely autistic child had fewer adjustment problems when more formal support is available to the family (Hastings, 2003). Varying effects have also been found based on the child's gender. Brothers of handicapped children have been shown to exhibit fewer fantasizing, deviant and isolated behaviours, and were less aggressive and hyperactive, and had fewer externalizing problems than brothers of nonhandicapped children (Dyson, 1989). However, boys with a brother or sister with an intellectual disability have demonstrated more difficulty in school functioning, and girls with a brother or sister with an intellectual disability were more likely to express any distress through internalization (Hannah & Midlarsky, 1999).

Dyson (1999) found that the psychosocial functioning of children remains stable over time, whether or not the child has a sibling with a disability. Children who had a sibling with a disability demonstrated greater stability in self-concept than children with a nondisabled sibling. This suggests that the presence of a child with a disability does not increase the presence of psychosocial difficulties in other children in the family. The psychosocial functioning of all participants was related to family psychological factors, for example parental stress, family social support and family functioning such as family relationships, emphasis on personal growth and the degree of family organization (Dyson, 1999). The psychological health of typically developing children in the family improved over time depending on the family's psychological processes, and declined when children were exposed to greater parental stress and less positive family relationships and support (Dyson, 1999). The findings from these studies suggest that while the presence of a child with a disability may have effects on the psychological adjustment of other siblings in the family, more important risk factors include family functioning and support. Thus the disability itself does not necessarily increase the presence of psychological malfunctions in other family members, other factors such as the type of disability, family stress, sibling gender and the level of caregiving provided by the sibling are all important factors that must be included when examining the risk of siblings developing psychological difficulties.

While it is important for parents to receive adequate support, it is also important that siblings have access to support groups, as this gives the child the opportunity to talk to other people their age who have a brother or sister with a disability in order to find out if their feelings are normal, and how other people cope with the additional stressors that may arise from having a siblings with a disability. D'Arcy, Flynn, McCarthy, O'Connor and Tierney (2005) found that sibling support groups, specifically Sibshops, have been found to be successful in bringing siblings together, providing them with opportunities to share any joys or concerns, and how other people handle various situations. They also provide the sibling with the opportunity to learn about their siblings' disability, which is often not discussed with the sibling, which in turn can lead to confusion and uncertainty about their brother or sister. Following attendance at a Sibshop, many siblings are able to describe their brother or sister's disability in terms of the child's needs (D'Arcy *et al*, 2005). The use of sibling support groups is thus important for siblings to learn about the disability, and to share their experiences with other people their own age, while hearing about other people's experiences and how to handle various situations. The support groups are especially important during the teenage years when peer contact is of paramount importance for their development (D'Arcy *et al*, 2005). Without this contact siblings may feel isolated from their peers as they may feel no one else can understand what they are feeling or going through, which in turn may begin to lead to psychological issues.

Research that has been conducted over the last fifteen years has thus demonstrated that children with a sibling with a disability are at no more risk of developing psychological problems than children without a sibling with a disability, however families with a child with a disability have various factors present which may act as unique predictors for the development of psychological difficulties. Research into families of children with disabilities has not yet been able to conclusively identify specific risk factors for siblings of children with disabilities as there are many possible factors which may lead to an increased risk of developing psychological difficulties. However, a main problem with the research is that it has largely focussed on the negative experiences of siblings, and much of the research which has shown a lack of negative effects has neglected to focus on the positive effects. The presence of a family member with a disability can have both positive and negative effects on other family members, and many families are not just able to cope with the challenge, they are able to thrive and grow (Dykens, 2005). Some families report positive transformations as having a child with a disability, while it may not be easy, can lead to a richer and fuller life (Dykens, 2005). Having a brother or sister with a disability can lead siblings to have increased empathy, love and understanding for those in need of protection or nurturance. Families can develop many positive outcomes as a direct result of having a family member with a developmental disability, and these positive outcomes are not measured by less stress or maladjustment, but instead by having enhanced well-being and character strengths (Dykens, 2005). Siblings who have a brother or sister with an intellectual disability may have been exposed to a more sensitive, warm and caring environment by their parents, and have had instilled in them an acceptance of human differences (Levy-Wassar & Katz, 2004). Thus while siblings may experience a range of negative effects as a result of having a brother or sister with a disability, they will also likely experience a range of positive effects that may not appear in research that focuses on negative aspects of the family life.

Chapter Six

Family Environment

Bronfenbrenner's ecological systems theory can be used to relate to the study of family support and sibling interactions. Support for parents is generally provided by immediate family members and friends, and to a lesser extent from the community. This support can directly or indirectly affect interactions within the microsystem, including parent-child interactions, and child-child interactions. This section will cover the theoretical background for the current study by describing the different levels of the environment, and how the amount of parental support received at the mesosystem level can have an impact on family interactions at the microsystem level.

6.1 Definition of a family

There are many different ideas about what constitutes a family. A family is historically considered to be a father, mother and their children. However, families can now consist of step-parents or step-siblings, grandparents and other extended family members, and foster children. If a family is to be viewed as a system, it can be defined as an "interdependent group of individuals who (1) have a shared sense of history; (2) experience some degree of emotional bonding; and (3) devises strategies for meeting the needs of individual family members and the group as a whole" (Anderson & Sabatelli, 2003). This definition implies that the family has multiple subsystems, for example a parent-parent subsystem, and a parent-child subsystem; has common purposes; and strategies are in place to undertake various tasks (Anderson & Sabatelli, 2003). For the purposes of this study, a family is considered to consist of the immediate members living in the home with the child with a disability.

6.2 Bronfenbrenner's ecological systems theory

Families of a child with a developmental disability face many stressors at all levels of interaction with family, friends, and the community. The attitudes of society, which may view a child as a blemish on the family's reputation, or as deviant, may have as much of an impact on the family as the child's actual abilities or handicap (Grossman, 1972). Urie Bronfenbrenner developed an ecological model using four subsystems to describe how families interact with external environments. Bronfenbrenner viewed the ecological environment as "a set of nested structures, each inside the next" (Bronfenbrenner, 1979, p3). The innermost level, the microsystem, consists of environments containing the developing person, such as the immediate family. The next level, the mesosystem consists of the range of settings within which the family participates, as well as the relationships between the settings. The third level suggested by Bronfenbrenner is an external setting called the exosystem. The developing person is not immediately present in this subsystem, however events occurring at this level can have an affect on their development. The fourth level is the macrosystem, which consists of society and cultural beliefs and laws (Bronfenbrenner, 1979). The ecological systems theory has a view on development that does not emphasise traditional psychological processes such as perception, motivation, thinking and learning, but emphasises what is perceived, desired and thought about; and views development as the individuals' conception of the environment, how they relate to it, and their ability to discover, sustain and alter its properties (Bronfenbrenner, 1979). Bronfenbrenner (1979, p21) thus defines the ecology of human development as "the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded".

Ecological systems theory is suitable for describing the environment experienced by typical families, however the various subsystems can be extended to include additional experiences and settings experienced by families of children with development disabilities that may not be experienced by families of typically developing children. The effects on parents of caring for a child with a disability can be influenced by the social environment, extended family, available support services and community attitudes (Hornby, 1994). The microsystem of families of children with a disability includes the family, child and other siblings. How well the family is able to function depends on factors associated with each member, for example, the type of disability, birth order of the child, personality of the child and any siblings, and closeness of the parental relationship and employment and health status (Hornby, 1994). The microsystem also includes attitudes and assistance from medical and health care workers, levels of acceptance from extended family, community acceptance and support, and social, psychological or practical help from other parents (Seligman & Darling, 1989).

These interactions within the microsystem are influenced by the external mesosystem, for example, the extended family can play an important role in how well the family is able to cope by providing support and assistance. Positive contact parents have with neighbours, work mates, friends and professionals can all promote healthy family functioning (Hornby, 1994). The levels of support and assistance from each of these levels can have an effect on the family's perceptions of their environment, and on how well they may be able to cope with any additional stressors that may arise.

Just as the microsystem is influenced by events and support within the mesosystem, the mesosystem is influenced by actions in the exosystem, particularly the way people with disabilities are portrayed by the media. The quality and availability of government services and support groups can be a significant factor in determining how well families cope (Hornby, 1994), as families who have increased levels of formal and social support may have more skills to handle any situations that may arise. The exosystem also includes financial and government supports, the availability of health care that may be required if their child has severe impairments, and the accessibility of an appropriate education for their child (Seligman & Darling, 1989).

Each of these levels of the environment are again influenced by the macrosystem, which refers to cultural and societal attitudes about disability (Hornby, 1994). These beliefs largely determine how society will treat the family, the availability of services, and what types of attitudes the media is likely to portray. The macrosystem also includes economic and political elements as politics will largely determine what level of professional support and programs will be available for a child with a disability (Seligman & Darling, 1989).

Mitchell (1985) described an extension of the ecological systems theory, developed specifically to include families of children with disabilities. The extension of this theory consists of the same subsystems, however has included potential problems of families of children with disabilities. The theory suggests that parents of children with developmental disabilities must work through a series of challenges. There are different tasks to resolve at each stage of the child's life. These tasks include:

- Deciding whether to keep the child or to seek institutionalization or adoption
- Accepting the reality of the disabling condition
- Establishing a positive parenting relationship with the infant
- Understanding and coming to terms with the reactions of family, friends and associates
- Becoming familiar with and using appropriate support services
- Making contact with other families with handicapped persons
- Coping with the reactions of the broader community
- Participating in decisions relating to special education
- Accepting prolonged dependence of the child
- Helping the child and the community to adapt to each other
- Accepting the right of the child to maximum independence, while recognizing dependency needs

- Participating in decisions relating to vocational placement/training

Whether or not these tasks are satisfactorily completed depends on the family's personal resources, on factors present in the family's microsystem, and on relationships between mesosystem settings, for example, the hospital, family doctor, and extended family and friends (Mitchell, 1985). Many of the tasks consist of parents establishing relationships with a growing number of mesosystem settings, including other families, support services and professionals (Mitchell, 1985). Whether or not parents are able to establish these relationships can depend on how other people view the family, and whether current attitudes focus on providing community care and assistance for the child and their family, or whether the family is expected to cope on their own. The availability of support services and professional help can also depend on whether government policy provides the family with financial assistance to be able to access the services.

Ecological systems theory can thus be summarised as a theory that examines the effect on the immediate family environment of factors operating in the external environment. This is important for the study of families of children with developmental disabilities as are there are a number of factors which can influence how families are able to function at the microsystem level. For example, the amount of support received can directly influence how families are able to cope – families who receive more support may experience less stress and more positive family relationships. Attitudes of society can also play an important role as these can determine how the child and family are received by the community. A society that feels children with disabilities should not be brought into the public arena will not be as willing to assist the family as a society that accepts people with disabilities and is more willing to assist the family. Government policies are also highly important as this can determine the level of professional support parents are able to receive. Governments who put a large amount of money into providing therapy and practical assistance will be more beneficial to the immediate family environment than a government that is not able or does not provide much financial assistance. The ecological systems theory is important for this study as the main aim is to examine the family environment of families who have children with developmental disabilities. As parents report the levels of support received and their perceptions of the family environment, external aspects of the environment can be examined in order to determine the effects this may be having on the immediate family environment.

The current study

This literature review has explored research that has been undertaken on various aspects of the family environment. It has explored the literature on stress in families of children with disabilities, particularly the benefits of social support for the family to be able to develop effective coping strategies. It has explained the importance of sibling relationships, and what can happen when one sibling has a developmental disability. This was followed by a review of literature on psychological adjustment of siblings of children with disabilities, which described how siblings do not generally appear to be at greater risk of developing psychological problems simply because of having a brother or sister with a disability. The next aspect that was explored was the theory that this study is based on – the ecological systems theory which describes families as functioning within a number of subsystems. The immediate family environment is affected by factors at external environments.

The literature review has led to a number of questions that can be further explored in order to gain a greater understanding of the functioning of families of children with developmental disabilities. This research will aim to study a number of aspects of the family environment. Firstly it will explore how a sibling's relationship with their brother or sister with the disability is affected by the amount of support parents receive, and how the relationship is affected by the sibling's level of self-concept. Secondly, the research will explore how the family environment affects the psychological adjustment of a typically developing sibling. The research will also explore how the level of support received affects the family environment. There are four main hypotheses that will be explored in this research:

1. Typically developing children whose parents report higher levels of support will report a more positive relationship with their brother or sister with a developmental disability
2. Siblings who report higher levels of satisfaction with their sibling relationship will report a higher level of self-concept
3. Typically developing siblings whose parents report higher levels of support will report a higher level of self-concept
4. Families who report higher levels of support will report a more stable family environment

The results of this study will be able to provide more information about the functioning of families who have children with developmental disabilities. This is important for the future of these families as it will provide an overview of their family environment, sibling's psychological adjustment and whether families are receiving adequate support. The results may indicate whether parents or siblings require further assistance, or whether the current levels of support are adequate, and if not what areas need to be improved to provide adequate services to these families.

Chapter Seven

Methods

7.1 Participants

Participants were 22 parents and 19 siblings of children with a developmental disability. Each family lives in Christchurch, New Zealand. Each participant volunteered to take part in the study. Parent participants were all mothers except for two fathers, and sibling participants included 11 sisters and 8 brothers, ranging in age from 8 years to 22 years with a mean age of 14.23 years.

Each participant is a parent or sibling of a child with various disabilities. The type of disability present in each family is shown in Table 1 below. The ages of the children with the disability ranged from 6 to 20 years, with a mean age of 13.22 years. The mean intellectual age of the children is 4.75 years.

Table 1: Type of disability

Disability type	N
Autism	5
Down syndrome	3
Down syndrome and autism	2
Aspergers	3
Autism and ADHD	2
Angelman Syndrome	1
Turners syndrome	1
CPT type II	1
I.H not specified	4

The children have various abilities, as shown in Table 2 below, which provides in indication of the level of care and assistance parents may have to provide. Half of the children are unable to communicate in sentences of four or more words, limiting their ability to communicate needs, and possibly increasing assistance required by parents. Nine of the children are unable to dress themselves, again increasing the assistance required by parents and other family members.

Table 2: Abilities of children with disabilities

Ability	**N = Yes**	**N = No**
Able to communicate	19	2
Uses sentences of 4+ words	11	10
Communicates needs to others	18	3
Able to read	7	14
Able to dress self	12	9
Able to feed self with spoon/fork	21	1

The income level for each family varied. Nine families had an annual income of $10 – 40,000; six families has an annual income of $41,000 – 70,000; and four families had an annual income of $70,000+. All fathers and mothers, with the exception of three mothers, are currently in paid employment. The remaining three mothers work full-time as at-home mothers.

7.2 Measures

Measures used were eight questionnaires or scales which are described below.

7.2.1 General Questionnaire

The General Questionnaire (Appendix A) was designed to gather data about family demographics (Kaminsky & Dewey, 2001). It consists of 13 questions about the members in the family, how many have a disability, family income; parental marital status; education level; and occupation.

7.2.2 Adaptive Behaviour Questionnaire

The Adaptive Behaviour Questionnaire (Appendix B) consists of 16 questions designed to gather specific data about the abilities of the child with the disability, and was adapted from the Vineland Adaptive Behavioral Scales (Kaminsky & Dewey, 2001). The questions include the child's chronological age, intellectual age, year at school, actual level performed at school, whether they receive special services at school and any additional support services received. The questions also cover whether the child can communicate through spoken or signed language, whether they can read, write their name, follow simple instructions, dress themselves completely, tie shoelaces without assistance, and feed themselves with a fork or spoon.

7.2.3 Family Support Scale

The Family Support Scale (Appendix C) consists of 18 items rated on a five-point scale ranging from not at all helpful (1) to extremely helpful (5) (Dunst, Trivette, & Jenkins, 1986). The scale measures the helpfulness of sources of support to families with a young child. Sources of support are measured across five factors. Firstly, Informal Kinship includes spouse/partners friends, own friends, other parents, own children, church. Spouse/Partner support includes spouse/partner, parents, spouse/partner's parents, relatives/kin. The Social Organization factor includes social groups/clubs, parent's groups, school/day care centers, co-workers. Formal kinship includes own relatives/kin and own parents. The final factor is Professional Services, which includes early intervention programs, professional helpers, and the family/child's physician. The different factors ensures that the scale is measuring different, independently available sources of social support (Dunst et al., 1986). The test-retest reliability of the scale, measured one month apart is $r = .75$ ($SD = .17$, $p<.001$) (Dunst, Trivette, & Deal, 1988).

7.2.4 Family Environment Scale

The Family Environment Scale (Appendix D) developed by Moos (1974) is a 90-item true-false questionnaire designed to examine interpersonal relationships; personal growth and system maintenance within families. Items are measured on 9 subscales across three dimensions. The Relationship Dimension includes cohesion, expressiveness and conflict. The Personal Growth Dimension includes independence; achievement orientation; intellectual-cultural orientation; active-recreational orientation and moral-religious orientation. The final dimension, System Maintenance, includes measures of organization and control (Moos, 1974).

7.2.5 Family Environment Scale, Children's Version

This scale measures aspects of the family using the same subscales as the Family Environment Scale, but was designed for children between the ages of 5 and 12 years. It is a pictorial, multiple choice scale consisting of 30 items. Each item has three equivalent pictures consisting of four cartoon figures representing a son, daughter, father and mother. Each picture is identical except for one feature that indicates the Family Environment Scale characteristic being questioned. The instructions ask "Which picture seems most like your family?", and children can select either picture A, B, or C (Moos, 1984). A sample of this scale can be found in Appendix E.

7.2.6 Short-form of the Questionnaire on Resources and Stress

The Short-form of the Questionnaire on Resources and Stress (Appendix F) was developed from the 285-item Questionnaire on Resources and Stress, which was developed to measure the impact of a developmentally delayed, disabled, or chronically ill child on other family members (Friedrich, Greenberg, & Crnic, 1983). The QRS-short form is a 52 item scale answered on a true/false basis. The items include questions such as: 'I worry about what will happen to ……when I can no longer take care of him/her' and 'It bothers me that ……. will always be this way'. The items cover four subscales – Parent and Family Problems; Pessimism; Child Characteristics; and Physical Incapacitation. Parent and Family Problems assess the respondent's perception of problems for themselves, other family members or the family as a whole (Friedrich et al., 1983). The Pessimism subscale assesses immediate and future pessimism about the child's prospects of achieving self-sufficiency (Friedrich et al., 1983). The Child Characteristics subscale examines the perception of the specific behavioural or attitudinal difficulties presented by the child. The Physical Incapacitation subscale examines perceptions of limitations in the child's physical abilities and self-help skills (Friedrich et al., 1983). A validation study conducted by Friedrich *et al* (1983) found that the QRS-SF has a reliability coefficient of .93.

7.2.7 Piers-Harris Children's Self-concept Scale

The Piers-Harris Children's Self-concept Scale (Appendix G) is an 80 item self-report questionnaire designed to assess how children and adolescents (aged from 8 to 18 years) feel about themselves. Each item is a simple descriptive statement, for example; 'I am a happy person', or 'I am often sad'. The scale is answered by indicating whether the item applies to them or not by circling yes or no. The items cover six subscales: Physical Appearance and Attributes; Freedom from Anxiety; Intellectual and School status; Behavioral adjustment; Happiness and Satisfaction; and Popularity (Piers & Harris, 1969). Test-retest coefficients for the scale range from .42 to .96, and internal consistency estimates for the total score range from .88 to .93 (Piers & Harris, 1969).

7.2.8 Satisfaction with Sibling Relationship Scale

The Satisfaction with Sibling Relationship Scale (Appendix H) is a 10 item scale that assesses how happy the children are with various aspects of their relationship with their brothers or sisters. The scale uses a 9-point Likert Scale where the child circles a number from 1 – 9, 1 being unhappy, 5 being ok, and 9 being happy. The scale asks questions about whether the child is happy with the amount of time spent with their brother or sister, how they have been getting along, how much time is spent caring for their brother or sister and how happy they are with how close they are to their brother or sister. This scale was received directly from, and used with, the permission of one of the authors, Susan McHale.

7.3 Procedure

Participants were recruited through two Special Needs schools in Christchurch. An information letter, consent form (Appendix I) and self-addressed envelope was sent home with children attending the schools. Parents and siblings who wished to take part in the study signed the consent form and returned it to me. Participants were then sent a packet of questionnaires directly. The packet included a copy of each questionnaire to complete, instructions for each questionnaire, and an information sheet explaining the purpose of the study (Appendix J). Participants completed the questionnaires in their own time and returned them to me when completed. Participants were given two weeks to complete the questionnaires, at which time they were sent a reminder letter if they had not yet returned the questionnaires.

Chapter Eight

Results

Data were analysed with the Statistical Package for Social Science, SPSS, 13th Edition. Correlational analyses were conducted between the total scores for the Satisfaction with Sibling Relationship Scale (SSRS) and the Family Support Scale (FSS); SSRS and the Piers-Harris Children's Self-concept scale (CSCS); the FSS and the CSCS; and the FSS and the Family Environment Scale (FES). Further correlational analyses were conducted between the FSS and the Questionnaire on Resources and Stress Short-form (QRS-SF); and the FES and the QRS-SF. The means scores for each of the scales are shown in Table 3.

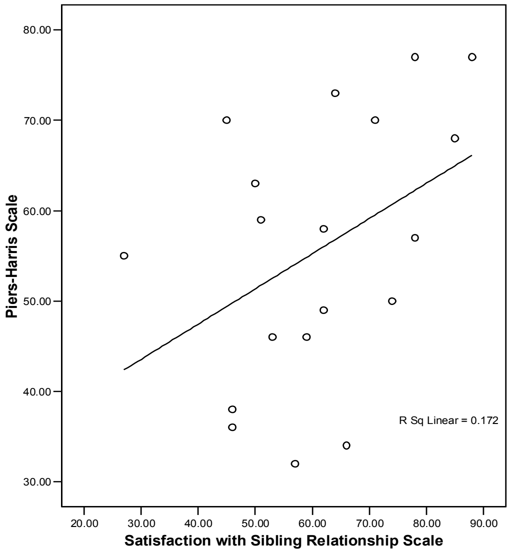
Table 3: Means and *SDs* for each scale

	N	Parent scores		Sibling scores	
		m	*sd*	*m*	*sd*
Family Support Scale	21	35.23	10.72		
Questionnaire on Resources and Stress	22	24.76	10.71		
Family Environment Scale	22	51.31	8.10		
Family Environment Scale – completed by siblings	11			42.90	9.66
Family Environment Scale – Children's edition	6			62.50	5.43
Piers-Harris Children's Self-concept scale	19			55.68	14.60
Satisfaction with sibling Relationship scale	20			60.20	15.73

Correlations between the Family Support Scale (FSS) and the Satisfaction with Sibling Relationship Scale (SSRS) were analysed in order to determine whether children whose parents report higher levels of formal and informal support are more likely to report a more positive relationships with their brother or sister with a developmental disability. No significant difference was found, r = .12 (.60). A regression analysis between family income and satisfaction with the relationship found that having an income level in the lower and higher ranges was more likely to predict a more positive relationship, Inc1 (0 – 30,000): t = -2.102 (.05); Inc3 (60,000 – 100,000): t = -2.463 (.02). There was no significant correlation between income in the middle bracket and satisfaction with the relationship.

Correlations between the SSRS and the Piers-Harris scales were analysed in order to determine whether siblings who report higher levels of satisfaction with their sibling relationship are more likely to demonstrate better psychological adjustment. A significant positive correlation was found: $r = .41$ (.03) 1-tailed (Figure 1).

Figure 1: Piers-Harris and Satisfaction with Sibling Relationship Scale



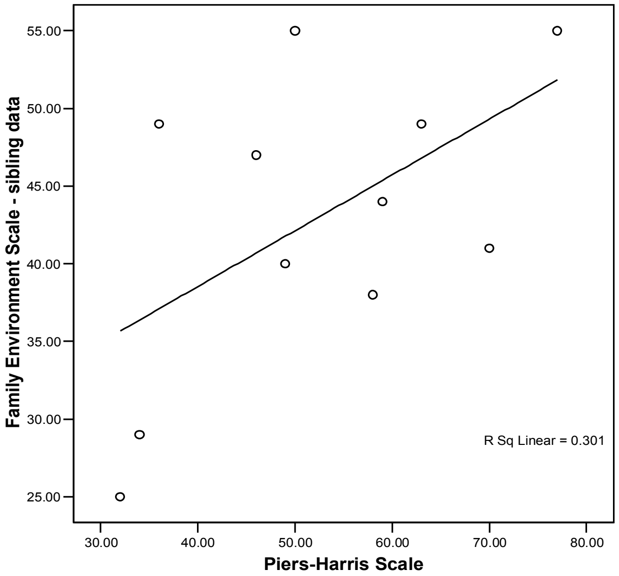
An examination of the results from the Piers-Harris scale with two other studies found that the results from the current study were well below the results from the other studies, and had a higher standard deviation (Table 4), indicating that participants in this study have a lower self-concept than other children of a similar age.

Table 4: Comparison of Piers-Harris results with other studies

	Current study	Dyson, 1996	Dyson, 1999
N	19	19	37
m	55.68	63.6	65.4
sd	14.60	8.1	10.0

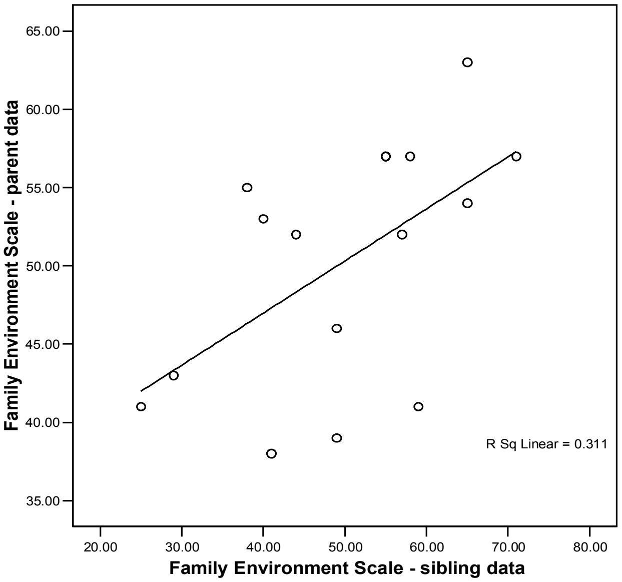
Siblings over the age of 12 years also completed the Family Environment Scale, and siblings under the age of 12 years completed the Family Environment Scale – Children's edition. These scores were correlated with the Piers-Harris scores. A significant correlation was found between the Piers-Harris scale and the FES score for siblings over the age of 12: $r = .549$ (.04) 1-tailed (Figure 2). There was no significant correlation between the Piers-Harris scale and the FES-Child's edition for siblings under the age of 12 years.

Figure 2: Family Environment Scale and Piers-Harris Scale



A further correlation was conducted between parent and sibling scores on the FES to determine whether both family members have similar views of the family environment. A significant correlation was found: *r* = .558 (.01) 1-tailed (Figure 3).

Figure 3: Family Environment Scale: Parent data and sibling data



Correlations between the FSS and the Piers-Harris scales were analysed to determine whether siblings whose parents report higher levels of support are more likely to report higher levels of self-concept. No significant correlation was found: *r* = .214 (.38) ns. The scores on the FSS were found to be clustered with no high or low outliers. This restricted range limits the analyses that can be conducted as the standard deviation and variance is very small.

Correlations between the FSS and the Family Environment Scale (FES) were analysed to determine whether families who report higher levels of support reported a more stable family environment. A significant correlation was found: *r* = .378 (.04), 1-tailed (Figure 4). This finding is to be expected, as families who receive more help would be expected to view their environment as more positive, however further analyses were conducted to examine whether support from various sources contributed to perceptions of different aspects of the family environment. Table 5 shows correlations between the subscales of both the FSS and the FES.

Figure 4: Family Support Scale and Family Environment Scale

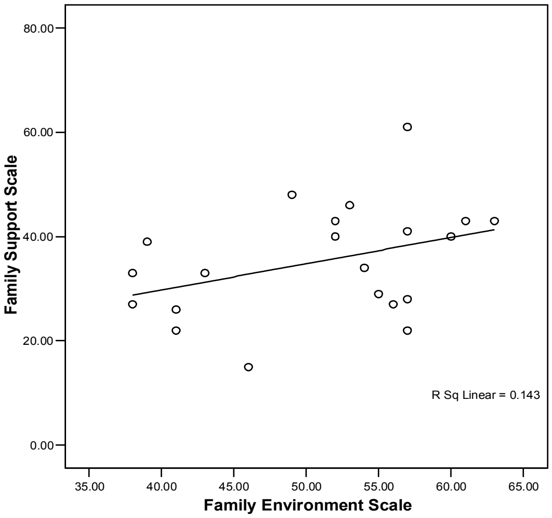


Table 5: Correlations between subscales of the FSS and the FES

	Formal Kinship	Spouse/partner	Social Organisations	Informal Kinship	Professional
Cohesion	-.407*	.136	.356	.196	.313
Expressiveness	-.065	.375*	.280	.124	.264
Conflict	.164	-.274	-.151	-.199	-.305
Independence	.102	.434*	.262	.349	.134
Achievement Orientation	-.336	-.203	-.240	-.107	-.040
Intellectual Cultural	-.411*	.040	.366	.197	.185
Active Recreational	-.183	.120	.364	.142	.348
Moral Religious	.172	.123	.011	.024	.153
Organisation	-.086	-.174	.104	-.184	.099
Control	.054	-.265	.018	-.185	.220

* correlation is significant at .05 level (1-tailed)

This correlation matrix indicates that there are significant relationships between some sources of support and some aspects of the environment. There is a negative relationship between amounts of formal kinship support and both cohesion and the intellectual/cultural subscale – as the support decreases, levels of cohesion within the family; and amount of intellectual or cultural activities participated in both decrease. The amount of spouse or partner support received has a positive correlation with expressiveness and independence. The amount of support received through informal kinship, social organisations and professional agencies does not have any significant correlations with any aspect of the family environment. Formal kinship and spousal support appear to be the most important factors for certain aspects of the family environment.

Correlations have also been found between different aspects of the family environment, as shown in Table 6.

Table 6: Correlations between subscales of the FES

	Cohesion	Expressiveness	Conflict	Independence	Achievement Orientation	Intellectual Cultural	Active Recreation	Moral Religious	Organisation
Expressiveness	.473**								
Conflict	-.728**	-.535**							
Independence	.338	.224	-.311						
Achievement Orientation	-.050	-.244	-.047	-.053					
Intellectual Cultural	.282	.419*	-.146	-.257	-.059				
Active Recreation	.635**		-.456*	.196	-.010	.400*			
Moral Religious	.160	.034	-.141	-.106	-.033	.117	.176		
Organisation	.467*	.115	-.366*	-.085	.016	.260	.469*	.632**	
Control	-.038	-.607**	.199	-.330	.224	-.169	-.224	.319	.336

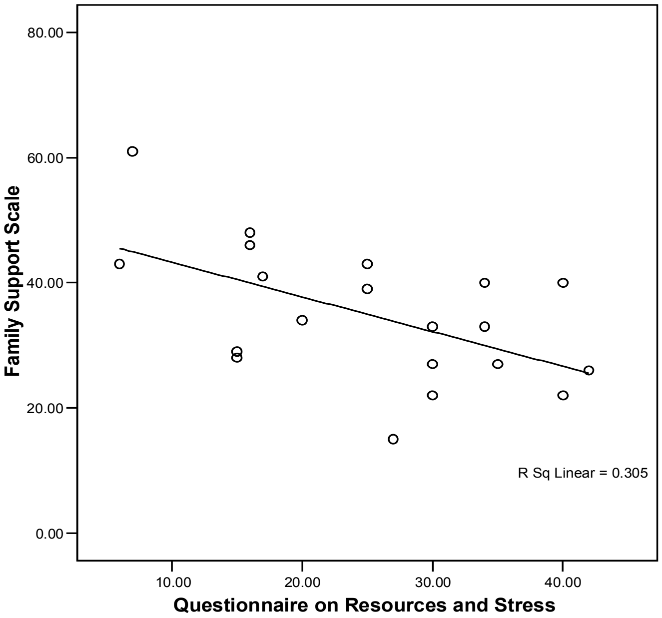
* correlation is significant at the .05 level (1-tailed)
* correlation is significant at the .01 level)1-tailed)

This correlation matrix demonstrates that there are many relationships between various aspects of the family environment. The strongest correlation is between conflict and cohesion. This is a negative correlation which demonstrates that as levels of cohesion decrease, levels of conflict increase. Another strong correlation is between moral-religious beliefs and organisation. Families who view themselves as more religious demonstrate higher levels of organisation.

I also conducted a regression analysis on the Family Support Scale with aspects of the family environment as predictors. The results showed that the best predictors from the Family Environment Scale of the level of support likely to be received are Organisation: t = -2.59 (.02); and Control: t = 3.06 (.01). This demonstrates that families who are more organised and who exert more control over family members also receive more external support.

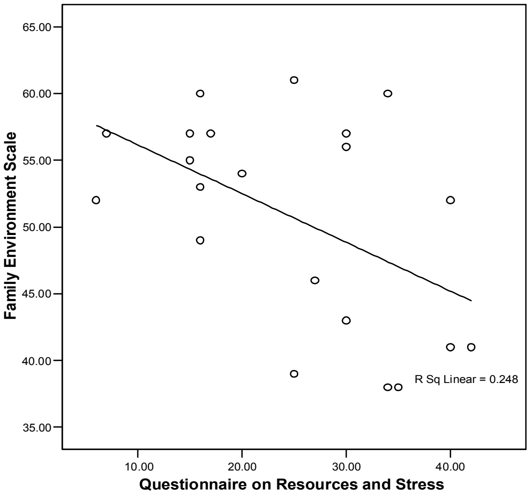
Correlational analyses were also conducted between the Questionnaire on Resources and Stress and the Family Support Scale and the Family Environment Scale. There is a significant negative correlation between the Family Support Scale and the Questionnaire on Resources and Stress, r = -.552 (.06) 1-tailed; (Figure 5), thus families who receive more support have fewer concerns on the QRS.

Figure 5: Family Support Scale and Questionnaire on Resources and Stress



A significant negative correlation was also found between the Family Environment Scale and the Questionnaire on Resources and Stress, r = -.49 (.01) 1-tailed; thus families who have a more positive perception of their environment have fewer concerns on the QRS (Figure 6).

Figure 6: Family Environment Scale and Questionnaire on Resources and Stress



A regression analysis was conducted on the Family Environment Scale with the subscales from the QRS as predictors (Table 7)

Table 7: Regression analysis of subscales of QRS

	β	*t*	Sig.
Parent Family	-.083	-.367	.719
Pessimism	-.717	-2.85**	.01
Child Characteristics	.064	.204	.841
Physical Incapacitation	.148	.702	.493

** significant at the .01 level

This demonstrates the Pessimism subscale is the best predictor for the score on the FES. Families who demonstrate higher levels of pessimism about the future have lower scores on the Family Environment Scale.

The results have thus shown a number of findings from this study:

1. Siblings who report a higher self-concept are more likely to report more satisfaction with the relationship they have with their brother or sister
2. Families who receive higher levels of external support are more likely to report a more positive family environment
3. Siblings who report more positive self-concept are more likely to report a more positive perception of the family environment. This finding was only significant for siblings over the age of 12 years
4. Families who receive more external support are more likely to report fewer concerns on the Questionnaire on Resources and Stress
5. Families who have a more positive perception of their environment are more likely to report fewer concerns on the Questionnaire on Resources and Stress
6. A sibling from a family with an income in the high or low bracket is more likely to report a more positive sibling relationship
7. Families who receive less support from kin are more likely to report lower levels of cohesion
8. Parents who receive more support from a spouse or partner are more likely to report increased levels of expressiveness and independence within the family
9. Families who report higher levels of pessimism on the Questionnaire on Resources and Stress are more likely to report less positive perceptions of the family environment.

Chapter Nine

Discussion

Given the small sample size and similar nature of families in this study the results must be interpreted with caution. Each of the families is from the same city, therefore will be receiving similar support from agencies and social organizations, and may be experiencing similar attitudes towards their child by members of the community. Each family has also chosen to send their child to a special needs school. One of the main aims of this thesis was to further explore the family environment of New Zealand families who have children with developmental disabilities. This included exploring the levels of support received by parents, perceptions of their family environment and factors which can affect these, satisfaction siblings have with their relationship with their brother or sister with a disability, and how having a brother or sister with a disability effects the self-concept of other siblings in the family. The study has found a number of interesting results which will be further examined in this section, particularly whether the hypothesis have proven to be true or not; possible reasons behind some of the results; and how the results can be linked to past research and the benefits the results may have for future research, and for families of children with developmental disabilities.

9.1 Relationship between support received and satisfaction with sibling relationships

The first hypothesis that was being explored in the current study was whether typically developing children whose parents report higher levels of both formal and informal support will demonstrate a more positive relationship with their brother or sister with the disability. The rationale behind this hypothesis was based on the theory that families who receive more external support will demonstrate more positive relationships within the family. This is based on Bronfenbrenner's ecological systems theory which describes different aspects of the family environment interacting with each other (Bronfenbrenner, 1979). Based on this theory it could be assumed that families who receive more support from the mesosystem will have closer relationships within the microsystem. However, the results from testing this hypothesis proved not to be significant, therefore this study found no relationship between the amount of support received by parents and the level of satisfaction with the sibling relationship. The participants in this study appear to be able to engage in positive relationships with their brother or sister that does not appear to be related to other family factors such as stress or level of support received by parents (Rivers & Stoneman, 2003). It would be expected that families who receive lower levels of support would rely more on other family members for assistance, thus potentially increasing stress levels of all family members, which may result in a breakdown of family relationships, particularly between the sibling relationship as older siblings may be expected to spend more time caregiving and may not be able to engage in play. This finding thus suggests that families have been able to adapt to the stresses of raising a child with a disability and are able to engage in positive relationships with other family members.

However, further analyses identified one interesting result – children from families with income in the lower ($0 – 30,000) and higher ($60 – 100,000) brackets demonstrated more satisfaction with the sibling relationship than children from families in the middle income bracket. Reasons for this finding are currently unknown, however it may be possible that families in the lower income bracket qualify for more funding for their child with the disability, therefore are able to access more assistance; and families in the higher income bracket may be able to afford to pay for extra assistance. Families in the middle income bracket may be neither eligible to receive further funding nor able to afford it themselves. This may mean a number of families are missing out on resources that other families are able to receive, thus may be relying on other family members for assistance which may then be having an impact on the satisfaction of the sibling relationship. However there was no significant relationship found between income level and amount of support received based on the Family Support Scale, yet this scale asks whether certain sources of support have been helpful when accessed, it does not ask how easy it is to access, or how often they are able to be accessed. Family stress has also been found to be related to the care of a child with special needs in middle-class families (Dyson, 1991), thus backing up the finding that family relationships may be influenced by income level.

9.2 Relationship between satisfaction with the sibling relationship and self-concept

The second hypothesis to be tested was whether siblings who report higher levels of satisfaction with their sibling relationship also demonstrate a more positive self-concept. The results showed that there was a positive correlation between the two scales, suggesting that more satisfaction with the relationship is related to a more positive self-concept. However the results could not indicate a direction for this relationship – that is whether participants who have a more satisfying relationship with their brother or sister have a more positive self-concept; or whether participants with a more positive self-concept are more likely to have a more satisfying relationship with their brother or sister. This finding suggests that siblings are able to feel positive about their relationship with their brother or sister, regardless of the presence of a disability, and does not appear to influence siblings' self-concept. This finding confirms previous studies which have found that siblings of children with disabilities do not feel any less positive about themselves; and do not have a higher risk of developing adjustment problems than siblings of children without disabilities (Hannah & Midlarsky, 1999; Kaminsky & Dewey, 2002).

However, the scores from the Piers-Harris scale in this sample were lower than that of other studies, suggesting that this sample has a lower mean self-concept than other populations. Regardless of the relationship found between self-concept and satisfaction with the relationship, it is possible that the lower scores indicate a relationship between self-concept and having a brother or sister with a disability. This may have resulted from a number of factors, for example, parental stress, family resources devoted to the child, and family isolation (Eisenberg, Baker, & Blacher, 1998). There is one factor in particular that may have an effect on the lower Piers-Harris scores. On the Family Support Scale, the majority of parents reported their other children to be a good source of support. Two parents reported other children not to be available, one parent reported them to be sometimes helpful, seven parents reported other children to be generally helpful, and 10 parents reported their other children to be very or extremely helpful. This may be having an effect on self-concept scores as they may have been forced to grow up sooner (Strohm, 2002), and to be provided with additional responsibilities before they are emotionally and psychologically ready for them, which has been found to interfere with social development and ability to establish independence (Strohm, 2002). Children who are expected to provide excessive caregiving may feel angry and resentful, which can potentially increase the risk of developing psychological problems (Seligman & Darling, 1989). This finding would need to be further examined to determine the siblings' own feelings about being asked to provide support to their parents.

Other factors have been suggested to play a role in sibling psychological adjustment, for example participant gender; gender match between the two siblings and age of the siblings; however even these factors do not have overly strong effects of adjustment (Hastings, 2003). It would be expected that a brother or sister with a severe disability would have an impact on social and emotional functioning of other family members, particularly as siblings must cope with changes in family structure and less parental attention (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Consistent with other studies, there was no difference in self-concept scores between males and females (Mates, 1990). Further research would need to be undertaken in order to determine whether the low self-concept scores are related to family factors or to external factors, in particular the sample would need to be compared with a sample of children who do not have a sibling with a developmental disability.

9.3 Relationship between levels of support received and sibling self-concept

The third hypothesis that was tested was whether children whose parents report higher levels of support will demonstrate a more positive self-concept. For this hypothesis there was no correlation between the two scales; thus suggesting that there is no relationship between sibling's self-concept and parental support; or that having more support focused on the family does not have an effect of the child's self-concept. This is inconsistent with previous research which has suggested that there is a possible link between social support received and psychosocial adjustment of siblings, particularly indicating that siblings whose parents receive more formal support have fewer adjustment problems (Hastings, 2003; Kaminsky & Dewey, 2002). Social support has been suggested to influence the adjustment of siblings for a number of reasons. Firstly, the presence of social support may act as a mediator as having a brother or sister with a disability may reduce the access to social support, which in turn may affect sibling adjustment. Secondly, social support may act to compensate for the presence of a disability. Thirdly, social support may act as a protective factor, particularly when the child has a more severe disability or more problem behaviour (Hastings, 2003). Despite these previous findings that social support is related to sibling psychological adjustment, this study has not supported these results. There are a number of possible reasons for this. Firstly, the scores on the Family Support Scale are relatively clustered, suggesting there are no high or low outliers thus support is received at a similar level across all participants. Secondly, the scores on the Piers-Harris scale had a wider range, and were low compared to other studies, suggesting that there are a number of factors that influence sibling self-concept. The level of support received does not appear to be one of these factors for this study. Thirdly, the small sample size and similar characteristics of the families may have influenced this finding. Each of the families is from the same geographic area, and has access to similar levels of support from professional agencies. This hypothesis would need to be re-tested with a larger sample size, from a wider geographical area before it could be rejected.

One factor that was found to be related to self-concept was the siblings' perceptions of the family environment. There was a positive correlation between self-concept scores and their perceptions of the environment, suggesting that as self-concept scores increase, their perceptions of the family environment increase. As with the finding between self-concept and satisfaction with sibling relationship, there is no known direction between this finding, that is whether a positive family environment leads to higher levels of self-concept, or whether higher levels of self-concept lead to a more positive perceptions of the family environment as they may able to see more positive aspects.

9.4 Relationship between levels of support received and perceptions of the family environment

The fourth hypothesis to be tested was whether families who report higher levels of support will also report a more positive family environment. Levels of support received have been found to be an important variable for family functioning (Herman & Thompson, 1995). This finding was supported in the current study as a significant correlation was found between these two factors, suggesting a relationship between support received and perceptions of the family environment. There are various sources of support that were found to correlate more strongly with factors of the family environment. A negative relationship was found between the amount of formal kinship support received and cohesion, suggesting that as the amount of support from kin decreases, levels of cohesion also decrease. Support from kin thus appears to be an important aspect in assisting families to function as a cohesive unit. The analysis also found that as levels of partner/spouse support increased, levels of expressiveness and independence within the family also increased. This shows that support from a spouse or partner is important as it demonstrates that the family is a unit and they are more likely to have higher levels of expressiveness and are able to allow independence. This may also mean that the child with the disability is allowed more independence. Support from a spouse or partner has been previously found to be a stronger predictor of adjustment than support from any other source (Mickelson, 2001). The presence of social support in families of children with disabilities has been found to be linked to more stable functioning, a more positive perception of the child, and can enhance the parent-child relationship, and influences the coping ability of parents (Gill & Harris, 1991; Seybold, Fritz, & MacPhee, 1991). These factors provide a strong suggestion as to why increased social support leads to a more positive family environment. Families who have access to more external support, whether they use the support or not, may be able to function more effectively as the knowledge that there is someone else who is able to help if needed may as important as the actual help received.

One factor that may be contributing to positive aspects of the family environment is the level of respite care reported. The majority of families reported that they received a number of respite care days per year, generally between 26 to 28 days. This means that the government pays for someone else to care for their child for the allocated number of days per year. Many of the families reported using organizations such as Mary Moodie, Life Links or IDEA, which were able to provide the families with respite care. The main purpose of respite care is to provide families with a break from physical and emotional demands of caring for the child and can benefit the family by reducing stress and improving family relationships (Joyce, Singer, & Isralowitz, 1988; Marc & MacDonald, 1988). Research has shown that respite care is generally only used by families who have limited support networks (Factor, Perry, & Freeman, 1990), however is one of the most frequently identified family support services (Herman & Thompson, 1995). In this study the levels of support received were similar across all participants, and there is no relation between level of support received and whether respite care is used, as the majority of families take advantage of being able to access respite care. The fact that parents reported using the above organizations as sources of respite care also suggest there is a difficulty in receiving respite care from family and friends.

Different factors from the Family Environment Scale were also examined to find any relationships. This analysis found a strong negative relationship between conflict and cohesion, suggesting that as levels of conflict increase, levels of cohesion decrease, therefore families who demonstrate high levels of conflict are less likely to demonstrate high levels of cohesion. There was also a strong positive relationship between being moral/religious and levels of organization, suggesting that families who are more religious or have higher moral standards also demonstrate high levels of organization. Families of children with disabilities have been found to show distinct styles of functioning, particularly emphasizing achievement and moral-religious beliefs (Dyson, 1991). The fact that families in this study generally had positive perceptions of their family environment suggests that they have been able to adapt to the stress of raising their child and have been able to adapt family functioning in order to improve or develop coping mechanisms (Dyson, 1991). While these families may experience more stress than families of typically developing children they are generally able to cope effectively and positively with the additional demands of parenting a child with a disability (Krauss, 1993).

A further interesting result was that families who have more support have fewer concerns on the Questionnaire of Resources and Stress; and families who have a more positive perception of the family environment also have fewer concerns on the Questionnaire on Resources and Stress. This finding specifically demonstrated that pessimism is an important factor in determining scores on the family environment scale; as families who reported higher levels of pessimism about the future for their child were more likely to have lower scores on the Family Environment Scale. The QRS examined areas of stress associated with the parent and family; child characteristics; pessimism and child’s abilities. Each of these factors, along with developmental stage and the environment are associated with levels of stress (Wolf, Noh, Fisman, & Speechley, 1989). Contrary to what may be expected, the age of the child did not have any influence on the score parents received on the QRS. The child’s age would be expected to impact on the score as there are various challenges associated with the child’s age and needs (Dyson, 1997), particularly as they reach the teenage years and parents may be looking towards their child’s future. The level of pessimism reported on the QRS appears to be a more important factor when examining the family environment than either the child’s age or type of disability. There are a number of factors which have previously been suggested to have an impact on parental stress, for example parent and family problems (Dyson, 1993) and the child's ability to communicate (Frey, Greenberg, & Fewell, 1989), however these factors do not appear to impact levels of parental stress for this study. Increased stress levels may have a stronger relation with the level of support received and specific caregiving needs of the child, and may not specifically lead to distress or dysfunction in families (Beckman, 1991). The level of stress experienced by parents is an important factor to consider as it has been associated with lower parenting satisfaction, abusive behaviour and insecure child attachment (Smith, Oliver, & Innocenti, 2001), all of which can affect the family environment.

9.5 Relation of findings to ecological systems theory

One of the aims of this thesis was to explore the relationships between the functioning of families of children with developmental disabilities and various levels of the environment. The findings have demonstrated that there are a number of factors within the family that can impact on different aspects of the environment. The level of support received has been shown to be an important factor for families as it correlates highly with perceptions of the family environment. The families who took part in this study can each be considered a group of individuals with a unique shared history; a degree of emotional bonding; with various functional strategies to meet the needs of individuals and the family as a whole (Anderson & Sabatelli, 2003). Each of these families has a different support network that may be contributing to positive family functioning. The results from this study have demonstrated that regardless of the fact that each of these families is raising a child with a disability; which may lead to increased stress levels; family members are able to engage in positive relationships with each other, and have positive perceptions of their family environment. This suggests that the families have developed specific strategies designed to cope with the additional stresses that may not be experienced by families of typically developing children. This raises the question of how these families have been able to develop effective strategies – has it arisen from within the family; through external support; or through another factor? To answer this question further research would need to be conducted specifically investigating family functioning, however possible reasons may be found through examining Bronfenbrenner's ecological system to determine what relationships and support have been found at different levels of the environment which may have contributed to the results of this study.

The first level of the environment is the microsystem and includes the parents, the child with a disability and other siblings (Bronfenbrenner, 1979). This study has suggested there are a number of positive relationships among family members. Siblings reported being satisfied with their relationships with their brother or sister; and both parents and siblings reported positive perceptions of the family environment.

These findings may be the result of various factors within the family, for example the type of disability; children's birth order; and employment (Hornby, 1994). Analyses of these factors with results from the various scales did not find any significant relationships. The family environment and level of support was similar regardless of type of disability; siblings' satisfaction with the relationship and self-concept was similar regardless of whether they were older or younger than their sibling with the disability; and all parents were in paid professional employment, with the exception of three mothers who worked as unpaid stay-at-home mothers. Employment has been found to act as either a stressor or a buffer of stress for mothers of children with disabilities (Warfield, 2001). In this sample, employment may act as a buffer of stress as it provides mothers with another outlet – they do not have to concentrate all energy onto their children but have a job which may contribute to their own levels of self-concept which in turn may assist them to cope in their role as a mother of a child with a disability.

This study has not found any significant factors that may play a role in family functioning at the microsystem level, however the fact that sibling scores on the Piers-Harris scale are relatively low suggest that there is one or a number of unknown factors that are contributing to this result. Further research would need to examine siblings specifically to determine whether the scores are normal for another New Zealand population, or whether it is limited to siblings who have a brother or sister with a disability.

The next level of the environment that is able to provide support and assistance to families is the mesosystem, which consists of neighbours, friends and professionals, such as education workers or health workers, all of whom can help to promote healthy family functioning (Hornby, 1994). Support from this level could be considered the most important factor to impact on the family environment. Extended family and neighbours can particularly play an important role in how well the family is able to function. However in this study, relatives and kin and neighbours were most commonly reported to be either not available or not at all helpful. Only seven participants reported relatives to be generally to extremely helpful. This can be compared to support from a partner or spouse. Four participants reported a spouse/partner to be sometimes helpful, and 15 participants reported a spouse/partner to be generally helpful to extremely helpful. Professional support was also viewed as helpful; four participants reported it to be sometimes helpful and 16 participants reported it to be generally helpful to extremely helpful. These findings suggest that for this sample the most important source of support from the mesosystem is from professional services, and the least helpful source is from relatives and neighbours. This raises further questions as to why people who may be closest emotionally to the family appear to be the most distant when it comes to providing practical assistance. The fact that professional services have been most commonly reported to be generally or extremely helpful suggests that New Zealand services are working efficiently and effectively to provide families with the support that is needed, for example by providing the family with financial assistance, therapists, equipment and counselling. The level of assistance from professional sources is important for the family environment as professionals who are sensitive, understanding and knowledgeable can help to promote healthy family functioning (Hornby, 1994). This finding is a good sign that New Zealand policies have altered substantially over the last 20 – 30 years, and families are being provided with the professional support needed. This is not only important to the families of children with disabilities, more important than this is the fact that the children themselves are being provided with the support necessary in order to assist them to reach their full potential.

Of greater concern is the finding that families are generally not able to rely on assistance from relatives and kin. Extended family can play an important role in determining how well families cope with the additional stresses of raising a child with a disability and supportive and understanding family members has a significant positive influence on family functioning, whereas if there is little contact the family lacks an important source of support (Hornby, 1994). Families of typically developing children would generally be able to rely on family and friends to help for example, with babysitting; however for families of children with disabilities this support is not as easily accessible. The reasons for this finding are as yet unknown, there are a number of potential reasons, for example family and friends may not know how to help or they may be unwilling to take care of a child with difficult behaviours; yet it is also possible that the families themselves are unwilling to ask family and friends for help as they may see it as their problem to handle.

The issues raised here should be investigated further to determine their specific effects on the family environment. As has been shown in various studies, social support is an important factor to assist with functioning within the family, as parents with effective support networks exhibit lower levels of pessimism, have a lower risk of exhaustion and burn-out, and report lower levels of stress (Beckman, 1991; Boyd, 2002; Seybold et al., 1991). These families who have reported lower level of support from friends and family at the mesosystem level may thus be at increased risk of experiencing stress and exhaustion within the microsystem level. Parent support groups have also previously been found to be an important source of formal support for mothers, and siblings of children with autism whose parents are involved in support groups may be able to gain information about the disorder which in turn may facilitate healthy psychological adjustment (Boyd, 2002; Kaminsky & Dewey, 2002), however in this study very few parents reported support groups to be helpful or even to be available. This raises further questions about whether support groups are available, or whether parents do not know about them, or simply do not choose to attend. Further research could explore the availability of support groups and how this impacts on family functioning and on the psychological adjustment of siblings.

The next levels of the environment which may influence family functioning within the microsystem is the exosystem, which includes mass media and the education system; and the macrosystem which includes attitudes, beliefs and values inherent in society (Hornby, 1994). These factors have not been investigated in this study, however an investigation of these aspects of the environment may provide some reasons as to why family and friends are less helpful than professional support services. In particular, the beliefs and attitudes of society may have a role to play in why people do not appear to be inclined to provide support to families of children with developmental disabilities.

9.6 Services available to Christchurch families

As has been shown, the results of this study have suggested that there is a strong link between the level of support received and perceptions of the family environment. The results demonstrated that there is a lack of support available to families. The source of support most commonly reported as being helpful was from professional agencies, and the source of support least commonly reported as being helpful was from family and friends. This suggests that professional organizations in Christchurch are effectively providing information, support and assistance to families of children with developmental disabilities. There are a number of professional organizations available to families in Christchurch. Firstly, the Disability Support Services through the Ministry of Health is able to conduct a needs assessment to determine what support, assistance or equipment is required by the family. Early interventions programmes can be accessed through the Ministry of Education, or through the Champion Center. The Ministry of Education is able to provide a range of services, for example speech-language, psychologists, and education support workers (MinistryofEducation, 2005). The IHC (now known as IDEA) is able to provide families and children with home support, relief care, holiday and after school programmes, and sibling support, as well as running staffed homes or flats in the community (IHCNewZealand, 2005). NZCCS Canterbury & West-Coast runs a support group called Side by Side which is available for parents and family members of children with disabilities. There are also a range of support groups that can be accesses, for example ADD support groups, Autism New Zealand Inc., Child Help Line, the New Zealand Down syndrome association and the Royal New Zealand Foundation for the Blind (Lewis & Tudor, 2003). A study conducted by NZCCS Canterbury & West Coast in 2002 found that 84% of parents and caregivers were not satisfied with their access to respite care services (Lemon, 2002), however this appears to have been remedied in recent years as this study found that the majority of parents reported using respite care. Despite the fact that there are a number of support groups available, many parents reported them to be not available or to be not helpful, however it is currently unknown as to whether the parents do not know about the support groups, or whether they have in fact found them to be unavailable.

9.7 Conclusions

This study has identified a number of interesting findings about the functioning of and support received by families of children with developmental disabilities. This has provided some insight into the functioning of these families, but has not been able to find answers as to why some of the results have arisen. The first main finding is that the sibling participants generally report high levels of satisfaction with their relationship with brother or sister with a disability. The level of satisfaction with the relationship does not appear to have any relation to the level of support received by parents. There is a relationship between the level of satisfaction with the relationship, and the level of self-concept. In other words siblings who are more satisfied with the relationship also have higher levels of self-concept. However they have also reported comparatively low levels of self-concept, which may be a factor of having a brother or sister with a disability, or there may be other unknown factors.

Another important finding is that families who have higher levels of support also have more positive perceptions of the family environment. One particular finding from this is that families in general report professional services as being very helpful, whereas family and friends are generally reported not to be very helpful. The study showed that support from family is important as families who reported higher levels of support from kin reported higher levels of cohesion within the family. Families who report fewer concerns on the QRS also reported a more positive family environment. The level of pessimism reported on this scale had the strongest influence on the family environment.

In general, this study has found that families of children with developmental disabilities are able to function effectively. Siblings have reported positive relationships, both parents and siblings have reported positive perceptions of the family environment, and families report receiving adequate support from professional services, and from spouses/partners. However the level of support received from family and friends appears to be a concern. This may in turn have an influence on how families are able to function. Siblings have also reported low levels of self-concept, the reasons for which are currently unknown. This study has thus found that regardless of support from family and friends being not as easily accessible as support from professional services, families appear to have adapted to cope with the additional stresses of raising a family that includes a child with a developmental disability.

9.8 Limitations of the study

There are three main limitations to this study. Firstly, the sample size consisted of only 21 families, including 21 parent participants and 19 sibling participants. The small sample size means the results should be interpreted with caution. A larger sample size would include more diverse families and provide a wider range of scores and more information as to the reasons behind the findings.

The second limitation is the geographic area of the participants. The families were recruited through two schools in Christchurch, and each family lives within the main Christchurch area, thus has access to similar support services, and is likely to experience similar attitudes by the community towards their child with a disability, which may affect how the family perceives the amount of support received; their family environment; and possible self-concept reported by siblings.

The third limitation to this study arises from the scales used, specifically the scale to measure satisfaction with the relationship. This scale was suitable to measure the satisfaction, however it does not ask about the type of behaviours exhibited by the siblings towards each other. This may need to be measured to provide further information on the type of relationship exhibited between the sibling dyads. The Family Support Scale was suitable to measure the level of support available, but it does not ask how easy it is to access the support, or to explain why various sources were not available. These details could provide further information as to the actual reasons behind why family and friends were not found to be highly supportive.

9.9 Implications for practice

This research has a number of implications for professionals working with families and children with disabilities. Firstly, the study has found that siblings have lower levels of self-esteem than has been found in other studies. Practitioners may need to provide more workshops or assistance for siblings in order to increase the amount of information siblings receive about their brother or sisters' disability. Practitioners may also need to work with the siblings; or refer them to another professional; to address any self-esteem or other issues experienced by the individual.

The second important finding is that families have reported receiving adequate levels of professional support. This finding can reassure professionals that they are doing their job well and providing the family with appropriate levels of support and assistance. Linked to this finding are the parents' reports that there is a lack of support from extended family and friends. Practitioners may be able to attempt to resolve this discrepancy by organizing programmes for extended family and friends to provide them with specific information about the child's disability and to give them an understanding of how it can affect the immediate family, along with practical suggestions of how to provide support, for example by offering to care for the child while the parents take a break.

The results also found that parents who had higher levels of pessimism had a less positive perception of the family environment. Practitioners could work with families to address the factors that may be causing parents to feel pessimistic about the future, which may help to improve the family environment.

In general, this study has found that practitioners and professionals are providing families with good levels of support; however the implications described here provide a number of additional areas where children and their families may need extra support.

9.10 Directions for future research

This study has been able to answer a number of the original research questions, however further questions have arisen that could provide more information about the functioning of families of children with developmental disabilities. Future research could be undertaken based on the following three questions:
Why did the sibling participants report relatively low levels of self-concept?
What strategies have families developed to cope with the additional stresses?
Why are family and friends generally not available to provide support?

Chapter Ten

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Appendices

Appendix A: General Questionnaire

Appendix B: Adaptive Behaviour Questionnaire

Appendix C: Family Support Scale

Appendix D: Family Environment Scale

Appendix E: Family Environment Scale, Children's version

Appendix F: Short-form of the Questionnaire on Resources and Stress

Appendix G: Piers-Harris Children's Self-concept Scale

Appendix H: Satisfaction with Sibling Relationship Scale

Appendix I: Information letter and consent form

Appendix J: Information letter

Appendix A

General Questionnaire

Please answer the following questions about your family.

1. What is your nationality and /or ethnic background?

____

2. Please complete the following information about members of your household.

Name Gender Date of Birth

Father____

Mother____

Child____

Child____

Child____

Child____

Child____

3. Have any children in your family been diagnosed with autism, Down's Syndrome, a language disorder, learning disability, developmental problem, attentional problem, or a chronic illness

Yes__________ No__________

4. If yes, what is the specific illness or type of problem, and which child (ren) is/are affected? Please also complete the attached Adaptive Behaviour Form.

Name Type of problem

____

____

____

5. Are any of your children adopted?

Yes__________ No__________

6. If yes, specify which child (ren) is/are adopted?

Name

____

____

7. What is your annual family income?

_____ below 10,000
_____ 10,000 – 20,000
_____ 21,000 – 30,000
_____ 31,000 – 40,000
_____ 41,000 – 50,000
_____ 51,000 – 60,000
_____ 61,000 – 70,000
_____ 71,000 – 80,000
_____ 81,000 – 90,000
_____ 91,000 – 100,000+

FOR MOTHER:

8. What is your present marital status? (please check all that apply)

_____ Married
_____ Living with someone
_____ Divorced
_____ Separated
_____ Never married and not living with someone
_____ Widowed

9. Please indicate the highest level of education that you completed

a) no high school
b) Some high school
c) High School Diploma
d) Some post-secondary, but no diploma or degree
e) Post-secondary diploma
f) University Degree

10. What is your occupation?

____

FOR FATHER:

11. What is your present marital status? (please check all that apply)

_____ Married
_____ Living with someone
_____ Divorced
_____ Separated
_____ Never married and not living with someone
_____ Widowed

12. Please indicate the highest level of education that you completed
a) no high school
b) Some high school
c) High School Diploma
d) Some post-secondary, but no diploma or degree
e) Post-secondary diploma
f) University Degree

13. What is your occupation?

____

Appendix B

Adaptive Behaviour Questionnaire

1. What is the name and age of your child with Down's Syndrome, Autism or other developmental disability?

Name Age

______________________________________ ____

______________________________________ ____

2. What is this child's IQ, mental age, and/or degree of disability (if known), please specify

____

____

____

3. What year is your child in at school?

____

4. At what year level or age level does your child currently perform at in school?

____

5. Have you received any special services from the school system for this child such as placement in special classes, teacher aides. Please specify

____

____

6. Have you received any other types of support services for this child, such as respite services, assistance of a professional caregiver in the home etc. Please specify

____

____

7. Can your child communicate with others through spoken language (or sign language)?
Yes______ No_____

8. Does your child use sentences of four or more words?
Yes_____ No_____

9. Can your child communicate his/her wants or needs to others?
Yes_____ No_____

10. Can your child read?
Yes_____ No_____

11. If your child can read, at what year level are they currently reading at?

____

12. Can your child print/write his or her first name?
Yes_____ No_____

13. Can your child follow simple instructions given to them by a parent?
Yes_____ No_____

14. Can your child dress his/herself completely?
Yes_____ No_____

15. Can your child tie shoelaces into a bow without assistance?
Yes_____ No_____

16. Can your child feed him/herself with a fork or spoon?
Yes_____ No_____

Family Support Scale

Appendix C

Listed below are people and groups that are often helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please *circle* the responses that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following Been to you in terms of raising your Child(ren):	Not Available	Not at All Helpful	Some-Times Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partners kin/relatives	NA	1	2	3	4	5
5. Spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Neighbours	NA	1	2	3	4	5
10. Other parents	NA	1	2	3	4	5
11. Co-workers	NA	1	2	3	4	5
12. Parents groups	NA	1	2	3	4	5
13. Social groups/clubs	NA	1	2	3	4	5
14. Church members/minister	NA	1	2	3	4	5
15. My family or child's physician	NA	1	2	3	4	5
16. Early childhood intervention program	NA	1	2	3	4	5
17. School/day-care center	NA	1	2	3	4	5
18. Professional helpers (social workers, therapists, teachers etc.)	NA	1	2	3	4	5
19. Professional agencies (public health, social services, mental health)	NA	1	2	3	4	5
20.________________________	NA	1	2	3	4	5

Family Environment Scale **Appendix D**

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all of your marks on the separate answer sheet. If you think the statement is *True* or *Mostly True* of your family, circle T (True). If you think the statement is *False* or *Mostly False* of your family, circle F (false).

You may feel that some of the statements are true for some family members and false for others. Circle T if the statement is *true* for most members. Circle F if the statement is *false* for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly.

Remember, we would like to know what your family seems like to *you*. So *do not* try to figure out how other members see your family, but *do* give us your general impression of your family for each statement.

1. Family members really help and support one another
2. Family members often keep their feelings to themselves
3. We fight a lot in our family
4. We don't do things on our own very often in our family
5. We feel it is important to be the best at whatever you do
6. We often talk about political and social problems
7. We spend most weekends and evenings at home
8. Family members attend church, synagogue, or Sunday School fairly often
9. Activities in our family are pretty carefully planned
10. Family members are rarely ordered around
11. We often seem to be killing time at home
12. We say anything we want to around home
13. Family members rarely become openly angry
14. In our family, we are strongly encouraged to be independent
15. Getting ahead in life is very important in our family
16. We rarely go to lectures, plays or concerts
17. Friends often come over for dinner or to visit
18. We don't say prayers in our family
19. We are generally very neat and orderly
20. There are very few rules to follow in our family
21. We put a lot of energy into what we do at home

22. It's hard to "blow off steam" at home without somebody getting upset
23. Family members sometimes get so angry they throw things
24. We think things out for ourselves in our family
25. How much money a person makes is not very important to us
26. Learning about new and different things is very important in our family
27. Nobody in our family is active in sports, Little League, bowling, etc.
28. We often talk about the religious meaning of Christmas, Passover, or other holidays
29. It's often hard to find things when you need them in our household
30. There is one family member who makes most of the decisions
31. There is a feeling of togetherness in out family
32. We tell each other about our personal problems
33. Family members hardly ever lose their tempers
34. We come and go as we want to in our family
35. We believe in competition and "may the best man win"
36. We are not that interested in cultural activities
37. We often go to movies, sports events, camping etc.
38. We don't believe in heaven or hell
39. Being on time is very important in our family
40. There are set ways of doing things at home
41. We rarely volunteer when something has to be done at home
42. If we feel like doing something on the spur of the moment we often just pick up and go

43. Family members often criticize each other
44. There is very little privacy in our family
45. We always strive to do things just a little better the next time
46. We rarely have intellectual discussions
47. Everyone in our family has a hobby or two
48. Family members have strict ideas about what is right or wrong
49. People change their minds often in our family
50. There is a strong emphasis on following rules in our family
51. Family members really back each other up
52. Someone usually gets upset if you complain in our family
53. Family members sometimes hit each other
54. Family members almost always rely on themselves when a problem comes up
55. Family members rarely worry about job promotions, school grades, etc.
56. Someone in our family plays a musical instrument
57. Family members are not very involved in recreational activities outside work or school
58. We believe there are some things you just have to take on faith
59. Family members make sure their rooms are neat
60. Everyone has an equal say in family decisions
61. There is very little group spirit in our family
62. Money and paying bills is openly talked about in our family
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace
64. Family members strongly encourage each other to stand up for their rights
65. In our family, we don't try that hard to succeed
66. Family members often go to the library
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school)
68. In our family, each person has different ideas about what is right and wrong
69. Each person's duties are clearly defined in our family
70. We can do whatever we want to in our family
71. We really get along well with each other
72. We are usually careful about what we say to each other
73. Family members often try to one-up or out-do each other
74. It's hard to be by yourself without hurting someone's feelings in our household
75. "Work before play" is the rule in our family
76. Watching TV is more important than reading in our family
77. Family members go out a lot
78. The Bible is a very important book in our home
79. Money is not handled very carefully in our family
80. Rules are pretty inflexible in our household
81. There is plenty of time and attention for everyone in our family
82. There are a lot of spontaneous discussions in our family
83. In our family, we believe you don't ever get anywhere by raising your voice
84. We are not really encouraged to speak up for ourselves in our family
85. Family members are often compared with others as to how well they are doing at work or school
86. Family members really like music, art and literature
87. Our main form of entertainment is watching TV or listening to the radio
88. Family members believe that if you sin you will be punished
89. Dishes are usually done immediately after eating
90. You can't get away with much in our family

Appendix E

Family Environment Scale – Children's Edition

The following questionnaire asks about what your family is like. Each picture contains two parents and two children – a boy and a girl. Your family may be different to this, but pretend that each picture has your family in it.

I would like you to look at the pictures, and choose one that looks most like your family. Each picture has the letter A, B, or C next to it. Please circle the letter of the picture you have chosen on the answer form. For example, in question one, you may choose picture A, so you would circle the letter A next to number 1 on the answer sheet.

If you think your family isn't like any of the pictures, just think which one they are most like, or try and imagine your family in that situation and what they might do.

Please answer every question and remember that I would like to know YOUR opinion on what your family is like, so please be honest.

Appendix F

A Short-Form of the Questionnaire on Resources and Stress

This questionnaire deals with your feelings about a child in your family. There are many blanks on this questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please begin. Remember to answer all of the questions.

1. ________ doesn't communicate with others of his/her age group T F
2. Other members of the family have to do without things because of ________ T F
3. Our family agrees on important matters T F
4. I worry about what will happen to ________ when I can no longer take care of him/her T F
5. The constant demands for care for ________ limit growth and development of someone else in our family T F
6. ________ is limited in the kind of work he/she can do to make a living T F
7. I have accepted the fact that ________ might have to live out his/her life in some special setting (eg institution or group home) T F
8. ________ can feed himself/herself T F
9. I have given up what I have really wanted to do in order to care for ________ T F
10. ________ is able to fit into the family social group T F
11. Sometimes I avoid taking ________ out in public T F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress T F
13. It bothers me that ________ will always be this way T F
14. I feel tense whenever I take ________ out in public T F
15. I can go visit with friends whenever I want T F
16. Taking ________ on a vacation spoils pleasure for the whole family T F
17. ________ knows his/her own address T F
18. The family does as many things together now as we ever did T F
19. ________ is aware who he/she is T F
20. I get upset with the way my life is going T F
21. Sometimes I feel very embarrassed because of _______ T F
22. ________ doesn't do as much as he/she should be able to do T F
23. It is difficult to communicate with ________ because he/she has difficulty understanding what is being said to him/her T F
24. There are many places where we can enjoy ourselves as a family when ________ comes along T F
25. ________ is over protected T F
26. ________ is able to take part in games or sports T F
27. ________ has too much time on his/her hands T F
28. I am disappointed that ________ does not lead a normal life T F
29. Time drags for ________, especially free time T F
30. ________ can't pay attention very long T F
31. It is easy for me to relax T F
32. I worry about what will be done with ________ when he/she gets older T F
33. I get almost too tired to enjoy myself T F

34. One of the things I appreciate about ________ is his/her confidence T F
35. There is a lot of anger and resentment in our family T F
36. ________ is able to go to the bathroom alone T F
37. ________ cannot remember what he/she says from one moment to the next T F
38. ________ can ride a bus T F
39. It is easy to communicate with ________ T F
40. The constant demands to care for ________ limit my growth and development T F
41. ________ accepts himself/herself as a person T F
42. I feel sad when I think of ________ T F
43. I often worry about what will happen to ________ when I no longer can take care of him/herT F
44. People can't understand what ________ tries to say T F
45. Caring for ________ puts a strain on me T F
46. Members of our family get to do the same kinds of things other families do T F
47. ________ will always be a problem to us T F
48. ________ is able to express his/her feelings to others T F
49. ________ has to use a bedpan or nappy T F
50. I rarely feel blue T F
51. I am worried much of the time T F
52. ________ can walk without help T F

"The Way I Feel about Myself" Appendix G
The Piers-Harris Children's Self-Concept Scale

Here are a set of statements that tell how some people feel about themselves. Read each statement and decide whether or not it describes the way you feel about yourself. If it is *true* or *mostly true* for you, circle the word "yes" next to the statement. If it is *false* or *mostly false* for you, circle the word "no". Answer every question, even if some are hard for you to decide. Do not circle both "yes" and "no" for the same statement.

Remember that there are no right or wrong answers. Only you can tell us how you feel about yourself, so we hope you will mark the way you really feel inside.

1. My classmates make fun of me………………. yes no
2. I am a happy person……………..…………… .yes no
3. It is hard for me to make friends…….......... .yes no
4. I am often sad………………………………...yes no
5. I am smart……………………………….....yes no
6. I am shy…………………………………………yes no
7. I get nervous when the teacher calls on me....... ..yes no
8. My looks bother me……………………………..yes no
9. When I grow up, I will be an important person...yes no
10. I get worried when we have tests in school…... yes no
11. I am unpopular………………………………….yes no
12. I am well behaved in school…………………...yes no
13. It is usually my fault when something goes wrong….yes no
14. I cause trouble to my family…………………...yes no
15. I am strong……………………………………...yes no
16. I have good ideas………………………………yes no
17. I am an important member of my family………yes no
18. I usually want my own way……………………yes no
19. I am good at making things with my hands……yes no
20. I give up easily…………………………………yes no
21. I am good in my school work…………………yes no
22. I do many bad things………………………….yes no
23. I can draw well………………………………...yes no
24. I am good in music……………………………yes no
25. I behave badly at home………………………..yes no
26. I am slow in finishing my school work………..yes no
27. I am an important member of my class………..yes no
28. I am nervous…………………………………....yes no
29. I have pretty eyes………………………………yes no
30. I can give a good report in front of the class…..yes no
31. In school I am a dreamer…………..…………..yes no
32. I pick on my brother(s) and sister(s)…………...yes no
33. My friends like my ideas………………………yes no
34. I often get into trouble……………………….....yes no
35. I am obedient at home…………………………yes no
36. I am lucky…………………………………….. yes no
37. I worry a lot……………………………………yes no
38. My parents expect too much of me……………yes no
39. I like being the way I am………………………yes no
40. I feel left out of things………………………...yes no

41. I have nice hair………………………………. yes no

42. I often volunteer in school……..…………… .yes no

43. I wish I were different……….………......... .yes no

44. I sleep well at night…………………………..yes no

45. I hate school…...…………………………….....yes no

46. I am among the last to be chosen for games…………yes no

47. I am sick a lot……………………………...... ..yes no

48. I am often mean to other people...……………..yes no

49. My classmates in school think I have good ideas…. yes no

50. I am unhappy……………………………..….... yes no

51. I have many friends...…………………………..yes no

52. I am cheerful…………………………………...yes no

53. I am dumb about most things……….…………..yes no

54. I am good-looking…………………………...yes no

55. I have lots of pep...……………………………..yes no

56. I get into a lot of fights...………………………yes no

57. I am popular with boys………………………...yes no

58. People pick on me………..……………………yes no

59. My family is disappointed in me………………yes no

60. I have a pleasant face..…………………………yes no

61. When I try to make something, everything seems to go wrong……………………………….…………yes no

62. I am picked on at home……………..………….yes no

63. I am a leader in games and sports….…………...yes no

64. I am clumsy……….……………………………yes no

65. In games and sports, I watch instead of play…..yes no

66. I forget what I learn…………………………..…..yes no

67. I am easy to get along with…………...………..yes no

68. I lose my temper easily………………………...yes no

69. I am popular with girls…………………………yes no

70. I am a good reader……………………………..yes no

71. I would rather work alone than with a group…..yes no

72. I like my brother/sister…………………………yes no

73. I have a good figure…...………………………yes no

74. I am often afraid……..………………………....yes no

75. I am always dropping or breaking things...……yes no

76. I can be trusted……………………………….. yes no

77. I am different from other people………………yes no

78. I think bad thoughts……………………………yes no

79. I cry easily……………..………………………yes no

80. I am a good person…..………………………...yes no

Appendix H

Satisfaction with the Sibling Relationship Scale

I'd like to know about how happy or unhappy you are with different things that are going on between you and your brother or sister. Sometimes children feel pretty happy about things with their brother or sister, sometimes they feel pretty unhappy with things about their brother or sister, and sometimes they feel somewhere in between. I would like you to please answer the following questions. There are no right or wrong answers, I'd just like you to tell me, as honestly as you can, how you've been feeling about your brother or sister in the last month or so. Underneath some questions you will see some numbers, I'd like you to circle one of the numbers that will tell me how you feel.

The numbers will look like this:

1	2	3	4	5	6	7	8	9
Unhappy				Ok				Happy

For example, question one asks "How happy or unhappy are you with the amount of time you spend with your brother or sister?" If you are very happy with the amount of time, please circle number 9. If you are unhappy with it, please circle number 1. You may feel the amount of time spent together is just ok, so please circle number 5. The numbers in between mean that sometimes things make you feel just ok, not happy or unhappy, so if you feel somewhere between 'ok' and 'happy', choose one of those numbers to circle.

Other questions ask whether you would like to spend more or less time doing something with your brother or sister. Underneath those questions you will see:

Less No Change More

Please circle one of these words, depending on whether you would like to spend less time with your brother or sister, or more time. Circle No Change if you like the amount of time spent with your brother or sister.

Please remember that I would like to know how YOU feel, so be as honest as you can, and please answer every question. If you do not know what to answer for a question, imagine yourself and your brother or sister in that situation and tell me how you might feel.

Thank-you for taking the time to answer the questions!

1a. Think about how much time you and your brother or sister spend together. How happy or unhappy are you with the amount of time you spend with your brother or sister?

1	2	3	4	5	6	7	8	9
Unhappy				Ok				Happy

1b. Would you like to spend more or less time with your brother or sister?

Less No Change More

2a. Think about how you and your brother or sister have been getting along – for example, whether you fight or do nice things for each other. How happy or unhappy are you with how you and your brother or sister have been getting along?

1 2 3 4 5 6 7 8 9
Unhappy Ok Happy

2b. Do you think you should try to get along better with your brother or sister, or is it that your brother or sister should start trying to get along better with you? (Circle the statement below which you think is most true)

I should try better My brother or sister should try better

3a. Think about the amount of time you spend taking care of your brother or sister. How happy or unhappy are you with the amount of time you take care of your brother or sister?

1 2 3 4 5 6 7 8 9
Unhappy Ok Happy

3b. Would you like to spend more or less time taking care of your brother or sister?

Less No Change More

4a. Think about how close you are to your brother or sister. How happy or unhappy are you with how close you are to your brother or sister?

1 2 3 4 5 6 7 8 9
Unhappy Ok Happy

4b. Would you like to be more close or less close to your brother or sister?

Less No Change More

5a. Think about the amount of time you and your brother or sister spend playing or doing fun things together. How happy or unhappy are you with the amount of time you do fun things with your brother or sister?

1 2 3 4 5 6 7 8 9
Unhappy Ok Happy

5b. Would you like to spend more or less time playing with your brother or sister?

Less No Change More

6a. How happy or unhappy are you with how your parents treat you compared to how they treat your brother or sister? This means whether they get mad at you or yell at you or make you do things and how much they do that with your brother or sister.
1 2 3 4 5 6 7 8 9
Unhappy Ok Happy

6b. Do you think they should start to treat you better, or should they start to treat your brother or sister better? (Circle the statement below which you think is most true)

Treat me better Treat my brother or sister better

7a. How happy or unhappy are you with how much you get to be the boss when you're with your brother or sister. This means how much you get to decide what you do together and how much you're the leader.

1	2	3	4	5	6	7	8	9
Unhappy				Ok				Happy

7b. Would you like to be the boss with your brother or sister more often or less often than you do now?

Less No Change More

8a. How happy or unhappy are you with how much you and your brother or sister are alike? This means that you like to do the same things and that you feel the same way about things most of the time.

1	2	3	4	5	6	7	8	9
Unhappy				Ok				Happy

8b. Would you like to be more like your brother or sister or less like your brother or sister?

Less No Change More

9a. How happy or unhappy are you with how much attention you get from your parents compared to how much your brother or sister gets? This means how much your parents talk to you, spend time with you, do things for you, buy things for you and things like that.

1	2	3	4	5	6	7	8	9
Unhappy				Ok				Happy

9b. Do you think your parents should start to pay more attention to you or should they start to pay more attention to your brother or sister. (Circle the statement below which you think is most true)

More attention to me More attention to my brother or sister

10a. One more question, how happy or unhappy are you with being __________'s brother or sister?

1	2	3	4	5	6	7	8	9
Unhappy				Ok				Happy

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Appendix I

23 June 2005

My name is Sharyn Gousmett, I am a teacher aide at Allenvale School. I am currently studying towards a Masters qualification in Psychology at the University of Canterbury. As part of my study I am undertaking research into families of children with developmental disabilities. I am interested in two main aspects of family interaction. Firstly, I will study the levels of support received by parents, and their perceptions of the family environment. Secondly, I will study the relationship between a typically developing sibling and their brother or sister with a developmental disability, and their perceptions of the family environment. The participants required for the study are one parent and one sibling, over the age of 7 years, of a child with a developmental disability. The study will require participants to complete a number of questionnaires. Parents will complete a General Questionnaire asking for information on the family; a family environment scale; a questionnaire on resources and stress; and a family support scale. Siblings will complete a family environment scale; a child's self-concept scale; and a sibling relationship scale. The questionnaires will require 30 – 45 minutes of each participant's time.

My aim in completing this study is to add to research on families of children with developmental disabilities, and I ultimately hope that my study will be used to improve support provided to families.

All information provided as part of this study will remain completely confidential, and will be viewed only by myself, and my supervisors, Neville Blampied and Garry Hornby at the University of Canterbury. All participants are able to withdraw from the study at any time.

Please also be aware that I am a teacher aide at Allenvale School, thus I may know your child, however no information on your child will be used as part of this study, and no other staff member at Allenvale School will be allowed access to any information gathered.

If you and one of your children would like to take part in the study, please sign the enclosed consent forms, and return it to me in the attached prepaid envelope. If your child closest in age to your child with a developmental disability does not wish to participate, it is fine if another child would like to take part in the study. If you would like further information on this study, please feel free to contact me at the above address, phone number, or via email.

Thank-you for your time,

Sharyn Gousmett

Parent Consent Form

1. I have read the attached information sheet and understand the requirements of the study
2. I would like to participate in the research study conducted by Sharyn Gousmett, and supervised by Neville Blampied and Garry Hornby, at the University of Canterbury.
3. I give consent for my child _____________________ to take part in the study
4. I understand that I may withdraw myself, my child, and all information from the study at any time
5. I understand that all information obtained will remain confidential and the written study will not identify myself or my family
6. I understand that Sharyn Gousmett is employed as a teacher aide at Allenvale School, thus may know my child who attends this school.

____
Name

Role in the family: (Please circle one)

Mother	Father
Stepmother	Stepfather
Caregiver	Other ____________

Address: ___________________________
____
____
____

____
Signature

____
Date

Sibling Consent Form

1. I have read the attached information sheet and understand the requirements of the study

2. I would like to participate in the research study conducted by Sharyn Gousmett, and supervised by Neville Blampied and Garry Hornby, at the University of Canterbury.

3. I understand that I may withdraw myself and all information from the study at any time

4. I understand that all information obtained will remain confidential and the written study will not identify myself or my family

5. I understand that Sharyn Gousmett is employed as a teacher aide at Allenvale School, thus may know my brother or sister who attends this school.

______________________________ ______________________
Name Age

Gender: Male Female

Address: ____________________________

____

____

____

______________________________ ______________________
Signature Date

Appendix J

Information Sheet

Thank-you for agreeing to participate in this research. This study has been reviewed and approved by the Human Ethics Department at the University of Canterbury.

Enclosed are the questionnaires for each participant to complete. The questionnaires for parents to complete are:

1. The General Questionnaire
2. The Family Support Scale
3. The Family Environment Scale
4. The Questionnaire on Resources and Stress

The questionnaires for children to complete are:

1. The Satisfaction with the Sibling Relationship Scale
2. The Piers-Harris Children's Self-Concept Scale
3. The Family Environment Scale, Children's Edition (for siblings aged under 12 years) OR The Family Environment Scale (for siblings aged over 12 years).

The questionnaires should take 30 – 45 minutes to complete. Please answer every question. Specific instructions for each questionnaire can be found attached to the front of the questionnaire.

If you or your child would like some assistance to complete the questionnaires, please feel free to contact me on (03) 343 2445, or email me at slg28@student.canterbury.ac.nz. Parents, if your child would like you to assist with the questionnaires, please read the questions to him or her, and allow them to mark their own answers on the answer forms.

Once you have completed the questionnaires, please return all answer forms to me in the attached prepaid envelope.

If participation in this project causes you to feel any distress, you are urged to see your regular family doctor, counsellor, or other mental health worker.

If you would like to discuss the project further please contact me at the above number or email. Alternatively, contact my supervisors at the University of Canterbury, Neville Blampied, ph (03) 364 2199, or Garry Hornby, ph (03) 364 2987 ext. 4906.

Thank-you again for assisting with my study. I hope that you have enjoyed taking part, and that this research will eventually be used to benefit families of children with developmental disabilities.

Sincerely,

Sharyn Gousmett