Quality of Life for Caregivers of a Child aged 6 - 16 years with Autistic Spectrum Disorder and/or an Intellectual Disability: A Comparative Study

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ABSTRACT

Quality of life for caregivers of children with autistic spectrum disorder and/or an intellectual disability was compared to quality of life for those caring for a normally developing child. Participants were caregivers of children between 6 - 16 years of age who were divided into two groups: Caregivers of disabled children (Group 1, *n* = 60) and caregivers of normally developing children (Group 2, *n* = 13). The research investigated differences of overall quality of life between groups. Within Group One the influence on quality of life for caregivers was investigated in relation to the child's behaviour, level of support the child requires to complete activities of daily living, caregivers marital status, caregivers socio-economic level, and caregivers satisfaction with perceived supports. The Quality of Life Index and the Nisonger Child Behavior Rating Form were used to determine quality of life and problem behaviours. Results showed a difference in overall quality of life between groups. Child's behaviour was found to have a significant relationship with caregiver's quality of life. Satisfaction with perceived supports had a weak relationship to caregiver's quality of life. No statistically significant relationship was found between caregiver's quality of life and the child's activities of daily living requirements, caregiver's marital status or caregiver's socio-economic status. Quality of life for caregivers of developmentally disabled children was shown to be lower than the general population. New Zealand is currently in a state of flux in regards to addressing and refining disability support services. Research that further investigates these results may enhance service delivery and result in better outcomes for those supporting children with a disability.

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Chapter One

The face of disability support services in New Zealand has seen numerous changes over the last few decades. These changes have resulted in current practices having a greater focus on people with a disability being provided natural supports at home or within the community. Families now carry the immense challenge of caring for their family members, and navigating government support services independently. There is only a small amount of research that has been conducted in New Zealand to identify the impact these changes have had on families (Huakau & Bray, 2000; Kingi & Bray, 2000; The Donald Beasley Institute Inc, 1997). Identifying caregiver's needs to help sustain and support them in their roles has lead to the development of current government initiatives. These include the introduction of Whanau Ora and Local Area Coordinators. Each of these are currently being piloted, fine tuned and further developed before they take effect across the nation.

Internationally there is a recognition that changes to social expectations, and a new drive towards deinstitutionalisation, has had a highly significant impact on families. The majority of international studies regarding quality of life (QoL) show similar outcomes despite conceptualisation differences. Past research has used terms such as: caregiving burden, stress, coping abilities, well-being, and quality of life (Emerson, 2003; Jorgensen, Parsons, & Jacobs, 2009; National Health Committee [NHC], 2009). Despite the differing terminology each have an underlying similarity in the measurement of the emotional and physical costs incurred by the caregiver when raising a child with a disability.

The current study builds upon previous research by comparing the quality of life between caregivers of a child with a disability and those caring for a child without a disability. The aim of this research was to investigate any differences in QoL between those caring for a child with autistic spectrum disorder (ASD) and/or an intellectual disability and those caring for a child without a disability. The results of this research may provide valuable information regarding the impact of caring for a child with a disability. Results may also highlight what factors have the potential to directly contribute to quality of life. Comparative research in the area of disability is timely given the current focus on addressing service gaps within the sector.

History of Disability Services In New Zealand

Disability services within New Zealand have a long history, involving many changes not only to policy, but also in regards to societal expectations. As far back as the 1900s government bodies were introducing policies specifically to address the needs of those with an intellectual disability. Primarily polices were developed to address the educational needs of children with an intellectual disability, this was then followed by holistic policies that addressed all aspects of the individual’s life (NHC, 2004).

Institutions first became an available resource for parents of a disabled child in 1929 (NHC, 2004). These institutions were known as psychopaedic hospitals and addressed educational and accommodation needs. It was common practise until the late 1960s to encourage parents to place their disabled child in institutionalised care (Bonardi, 2009). One of the first community lead support groups was the Intellectually Handicapped Children's

Parents Association (Milner, 2008; NHC, 2004). This group evolved from a group of Wellington based parents who sought to educate their children within the community, and care for them at home. This organisation is still extremely relevant in providing current disability support, and is now known as IDEA Services (Bonardi, 2009).

During the late 1960s societal views began to change and there was a shift of focus from institutional care to community based care practises (Bonardi, 2009; Milner, 2008; NHC, 2004). The first step of deinstitutionalisation occurred in 1988 when Kingseat Hospital transferred 61 residents into the community (Milner, 2008; NHC, 2004). During the next 10 years over 10,000 individuals would be moved from institutions into community based care (NHC, 2004). When the Kimberley Centre in Levin closed its doors in 2002, this marked the end of institutionalisation within the New Zealand disability sector (Milner, 2008; NHC, 2004).

Services for those with a disability became the responsibility of the health sector between 1993 to 1995, prior to this responsibility had sat with the Department of Social Welfare (Bonardi, 2009; NHC, 2004). In 1999, a Minister for Disability Issues was designated (NHC, 2004). This prompted the development of the New Zealand Public Health and Disability Act 2000, which in turn lead to the development of the New Zealand Disability Strategy (Bonardi, 2008; NHC, 2004). The New Zealand Disability Strategy was published in April 2001 by the Ministry of Health. Its goal was to ensure an inclusive society for all people living in New Zealand (Ministry of Health, 2001). An inclusive society was defined as "a society that highly values our lives and continually enhances our full participation" (Ministry of Health, 2001, p. 5). It sought to change the way disability is viewed, and to change terminology from disability to impairment (Ministry of Health, 2001, p. 1):

> "Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is a process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have."

The Ministry of Health's aims to change the terminology used when addressing disability issues, or individuals who identify as having a disability has been limited in its success. Society has a general acceptance that the two terms are interchangeable, with disability the more common form of expression.

The New Zealand Disability Strategy listed 15 objectives (see Appendix A for the full list of objectives) to reach the goal of an inclusive society, each with their own set of action points for success. These objectives aimed at ensuring equal inclusion, without prejudice, for all people living in New Zealand. The two key points of this strategy that directly relate to the current study are Objectives 13 and 15. A full list of the action points for Objectives 13 and 15 can be found at Appendix B.

Objective 13 focuses on addressing the necessity for support services to incorporate easy transition into adulthood and adult services. This is to be achieved through ensuring each child's basic needs are met in a dignified manner, including their right to a fair education, relationship development and access to the community and leisure activities. It also highlights the need to have children's voices heard, acknowledged, and promoted in regards to the development of appropriate support services.

Objective 15 identified that natural support, regardless of who was providing this support, should be valued and acknowledged (Ministry of Health, 2001). The Ministry of Health defines natural supports in the service specifications for Regional/National Intellectual Disability Secure Services as including friends, immediate and extended family, community groups or courses, neighbours and places of employment (Ministry of Health, 2010). Caregivers of children with a disability are included in the definition of natural supports. In 2008 the Ministry of social Development produced a document, The New Zealand Carers' Strategy and Five-year Action Plan, that focused on addressing the needs of carers as outlined in the New Zealand Disability Strategy (Ministry of Social Development, 2008).

To help meet the goals of the New Zealand Disability Strategy, action points were developed to guide disability services within New Zealand. Service providers contracted with the Ministry of Health to provide disability support services use the New Zealand Disability Strategy to provide appropriate service provision. These services are deemed to be client-focused, and aim to achieve the overarching goal of the Disability Strategy (Ministry of Health, 2001). One area that is gaining considerable interest within New Zealand is ensuring support for caregivers. Caregivers within New Zealand have become the backbone of community based supports. They provide the day to day care that those with a disability require. However, given that most supports are client-focused, the carers needs are often not successfully addressed.

Disability statistics in New Zealand. Disability statistics in New Zealand have been officially collated since 1996 (Office of Disability Issues and Statistics New Zealand, 2009). The figures expressed in this thesis were gathered during the New Zealand 2006 household Disability Survey. All figures in the statistical tables have been rounded up to the nearest 100 by Statistics New Zealand. The 2006 survey found approximately 90 000 children, between the ages of 0 -14 years had some form of disability (Office of Disability Issues and Statistics New Zealand, 2009, 2010).

The Office of Disability Issues and Statistics New Zealand (2009) had a broad definition of disability, classifying disability into the categories of: special education, chronic condition or health problem, psychiatric/psychological, speaking, intellectual, hearing, seeing, use of technical equipment and other. Disability in these areas was deemed to occur if the person felt their condition was expected to last six months or more, and it impacted on their ability to complete regular everyday activities.

Table 1.1 shows gender frequencies of disability in New Zealand. Those aged 5-14 years have a higher frequency of reported disability than children aged 0-4 years. A possible explanation is the lack of early diagnosis and the increased likelihood of disease, illness or accident taking place later in the child's life. Additionally, as the child ages differences in development may become more apparent which results in a referral for specialist testing and diagnosis. Approximately 59% of children with some form of disability identify as male. Similar results can be seen in Australia with 51% of disabled children aged 0-14 years old identifying as male (Australia Bureau of Statistics, 2003).

Table 1.1

Ages, Gender and Ethnicity of Children with a Disability in New Zealand

	Māori	Non-Māori	Total
Male			
0-4 years	3 100	5 000	8 100
5-9 years	6 300	13 100	19 400
10-14 years	7 700	18 400	26 100
Female			
0-4 years	2 200	4 700	6 900
5-9 years	4 300	9 700	14 000
10-14 years	4 700	10 900	15 600

Note. Numbers may not sum to the stated totals because numbers are rounded to the nearest 100. Adapted from "2006 Household Disability Survey" (Office of Disability Issues and Statistics New Zealand, 2009).

Table 1.2 provides information regarding the family structure of children with and without a disability in New Zealand. A higher proportion of one parent households occur when a child with a disability is included in the family. Differences may be due to increased stress raising a child with a disability can cause on a relationship. Alternatively it may reflect the reality that some parents struggle to raise a child with a disability. This struggles can, at times, represent the end of a relationship.

Table 1.2

Percentage of Disabled and Non-Disabled Children by Family Type

Family Type	Disabled Child %	Non Disabled Child %
Two parent household	63	72
One parent household	28	18
Other	8	9

Note. Numbers may not sum to the stated totals because numbers are rounded to the nearest 100. Adapted from "2006 Household Disability Survey" (Office of Disability Issues and Statistics New Zealand, 2009).

Socio-economic status is presented in Table 1.3, including the differences in income between families caring for a child with a disability and those caring for non-disabled children. These figures show a higher prevalence of reduced incomes for those caring for a child with a disability with 36% of families with a disabled child earn $50, 000 or less, compared to only 28% of families with non-disabled children. It is likely that the increased needs of the children restricts the ability for parents to successfully enter the workforce at a meaningful remuneration level.

Table 1.3

Socio-economic levels of families with and without a disabled child in New Zealand

	Percentage of households	
Income	Disabled Children	Non-Disabled Children
Less than $15 000	6	4
$15 000 - $ 30 000	13	9
$30 001 - $50 000	17	15
$50 001 - $70 000	16	16
$70 000 or more	27	39
Not elsewhere included	21	17
Total	100	100

Note. Adapted from "2006 Household Disability Survey" (Office of Disability Issues and Statistics New Zealand, 2009).

The Office of Disability Issues and Statistics New Zealand (2009, 2010) included children diagnosed on the autistic spectrum as having a chronic health problem. When compared to other disability types, 39% of children identified as having a chronic health problem. In comparison, 19% of children identified as having an intellectual disability. It should be noted that participants were asked to select one disability type only, and therefore those with co-morbid conditions were only recorded once based on their primary disability.

The current study focused on caregivers of children aged between 6 - 16 years of age. Specific statistics could not be gathered for this age group. However, the statistics shown provide us with some understanding of the prevalence of disability within New Zealand.

Quality of Life

The definition of QoL has slowly evolved over previous decades resulting in general agreement in regard to what it encompasses. Perhaps the most well known definition is that taken from the World Health Organisation's Quality of Life Questionnaire (WHOQOLQ). This was developed in 1996 and offers the following definition of QoL within its Introduction, Administration and Scoring Handbook (p. 5):

> "Quality of life is defined as individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."

The key term 'individual perceptions' calls attention to differences that are evident in each individual’s quality of life. The premise of individualisation has long been promoted as essential in the understanding of QoL. An awareness that individual perceptions hold the key to individual meaningfulness is paramount to QoL studies.

The term QoL is known to most people around the globe; however, history indicates a lack of global agreement on its definition. Even the general population shows little awareness of the discrepancies that exist in its everyday expressions and understanding of QoL (Ferrans, 1990). Recent literature tends to support QoL as a multi-dimensional concept that needs to ensure information is gathered from a number of specific domains (Ferrans & Powers, 1992; Schalock, 2004; Verdugo, Schalock, Keith, & Stancliffe, 2005). These domains range from: physical, psychological, social and spiritual (Hanson, 2001); health and functioning, psychological/spiritual, social and economic, and family (Ferrans 1996); interpersonal relations, social inclusion, personal development, physical wellbeing, self-determination, material wellbeing, emotional wellbeing, and rights (Schalock, 2004; Verdugo et al., 2005) and; physical functioning, social functioning, psychological functioning, overall life satisfaction, and perceptions of health status (Naughton & Shumaker, 2003). This ensures that many aspects of an individual's life are addressed and measured. This supports the theory that QoL is heavily influenced by multiple interacting sources (Bramston, Chipuer, & Pretty, 2005) and that the concept of QoL needs to ensure inclusion of all relevant variables (Schalock, 2004). Despite the perceived agreement on the multi-faceted nature of QoL, divergence remains regarding definitions of QoL between individual research projects. Academic journal searches conducted on scholarly search engines using the key phrase 'Quality of Life' produces thousands of results, and very often there is little commonality between the articles produced (Koot, 2001).

The definition of QoL involves more than the recognition of multiple life domains. Past research also discusses the relevance of subjective and objective indicators in measuring QoL. Subjective indicators are closely linked to the individual's perceptions of life and their life experiences (Browne & Bramston, 1998). Levels of life satisfaction are heavily influenced by individual experiences and expectations within a person's day-to-day life (Verdugo et al., 2005). Objective indicators are those which can be readily measured, such as socio-economic and marital status (Browne & Bramston, 1998). Debate remains regarding the importance of subjective and objective indicators, including which of the two yields the most valid results. Despite this debate most researchers promote the use of both subjective and objective indicators to help determine overall QoL (Browne & Bramston, 1998; Cummins, 2005; Verdugo et al., 2005). Generally there is a weak relationship between subjective and objective indicators, making it difficult to predict one based solely on information from the other (Cummins, 2005). This increases the importance of collecting both types of data when measuring for QoL. Decisions regarding which indicator to focus on primarily sits with what the researcher is hoping to measure. Evaluations of health programmes and the outcomes of such programmes may be better to utilise objective indicators as a means of QoL calculation. The use of subjective means may outweigh objective indicators for those wishing to discover how an individual feels within themselves on a day to day basis (Schalock, Bonham, & Verdugo, 2008).

It is imperative that researchers recognise the importance of weighting the subjective indicators level of importance to the individual when determining overall QoL (Welham, Haire, Mercer, & Stedman, 2001). Two people can indicate equal dissatisfaction with an area of their life. However, one person may indicate this area has little importance to them, while the other says it has a high level of importance. The person who indicates they are dissatisfied with an area of life that is highly important, is likely to have a lower QoL than the individual who is dissatisfied with an area of little importance. Individual levels of importance are heavily influenced by life expectations and the hopes that people harbour for themselves. When these hopes and expectations do not match reality it is likely that the individual's QoL will be affected (Skevington & O'Connell, 2004). Weighting systems in QoL measures removes the presumption that individual's perceptions, cultural identity, life experiences and overall sense of ownership towards their expressed feelings is universal. It is not plausible to accept that all individuals will place equal importance on all items (Kind, Hsu, Wang, Yao, & Tang, 2003).

Health-related QoL (HRQoL), and family QoL (FQoL) are two popular areas of research. HRQoL questionnaires are generally separated into two distinct categories, disease specific and generic. Disease specific QoL includes questions relating to specific disease symptoms, whereas generic questionnaires focusing on general health related issues (Spieth, 2001). These can also be used as a method of rating treatment outcomes, evaluating health services and generally improving the care of individuals throughout their disease progression (Fayers & Machin, 2000; Phillips, 2006; Spieth, 2001). FQoL is a relatively new concept that has emerged within the QoL literature. It has gained increased momentum with the societal shift away from institutionalised care for children with a disability and the impact this may have on FQoL (Werner et al., 2009). FQoL focuses on addressing and identifying QoL for the family unit as a whole, resulting in the additional burden of defining and conceptualising the term family. Today's multi-faceted view of what a family should encompass is one of the difficulties researchers need to address when studying FQoL (Park et al., 2003). Additional difficulties facing the development of FQoL questionnaires include the data collection from multiple family members that can then be presented in a manner that truly reflective of each individuals QoL as well as the family's QoL as a whole (Wang et al., 2006). Despite these differences, both HRQoL and FQoL have a heavy basis in the conceptual definition and measurement of individual QoL.

DSM-IV-TR Definitions

Mental Retardation. The DSM-IV-TR classifies intellectual disability as Mental Retardation. Mental Retardation requires an individual to have an IQ of 70 or under as measured on a IQ test, with an approximate measurement error of 5 points. The individual must also show difficulties with their adaptive functioning within two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health or safety (American Psychiatric Association [APA], 2010). Evidence of both of these criteria must be present before the age of 18 years. The American Association of Mental Retardation identifies the level of intellectual disability based on the amount of support the individual requires with daily tasks. There are four levels of support: intermittent support, limited support, extensive support, and pervasive support (American Association of Mental Retardation, 2002). The personality characteristics of a person with mental retardation varies depending on the individual, co-morbid conditions, and functional deficits. Within New Zealand the term Mental Retardation is no longer used due to is derogatory implications, and has been replaced with Intellectual Disability. Despite the difference in terminology the diagnostic criteria remain the same.

Pervasive Developmental Disorder. Pervasive Developmental Disorders are a broad term given to autistic spectrum disorder , rett's disorder, childhood disintegrative disorder, asperger's disorder and pervasive developmental disorder not otherwise specified (APA, 2010). Each of these shows a high level of impairment in numerous areas of development such as:

social interactions, communication, repetitive and stereotypic behaviours, interests and activities (APA, 2010). Within New Zealand the DSM-IV-TR diagnostic criteria is loosely adhered to by paediatricians. Difficulties with diagnoses occur due to limited access to qualified psychologists who are publicly funded. This can result in misdiagnosis which has on-going impact on individuals and their families when trying to access funded support services. Additionally within New Zealand's popular media and paediatric health system autistic spectrum disorder is used to broadly categorise those diagnosed with autistic disorder or asperger's disorder. Rett's disorder and childhood disintegrative disorder are commonly seen to sit outside this diagnosis. The lack of clear understanding of DSM-IV diagnostic systems produces fragmented service provision that is relative to the level of expertise and knowledge within each disability support organisation.

Possible Factors Influencing Quality of Life

QoL has many factors and variables influencing and interacting with its core concepts and as such cannot be researched independently. Research shows that mothers caring for a child with an intellectual disability are economically disadvantaged, have less social and psychological support, have an increased chance of suffering a stressful life event, and are more likely to be functioning in an 'unhealthy' family (Emerson, 2003). Additional factors to measuring QoL can include, but not be limited by; developmental delay, behavioural traits, socio-economics, marital status, functional support needs, and satisfaction at the level of formal and informal support within these areas. Each of these factors are relevant to this research, and as such, require further explanation and development.

Does disability matter? A number of studies have investigated whether disability type has an impact on caregivers QoL. Lewis et al (2006) investigate the differences between those caring for a child with fragile X syndrome, those caring for a child with co morbid autism and fragile X syndrome, and those caring for a child with Down syndrome. This study found no differences in levels of depression, life satisfaction and coping skills of the mothers when the three groups were compared. This differs from other studies which have highlighted differences between those caring for a child with Down syndrome compared to those caring for a child with autism (Lewis et al., 2006). Furthermore research has also shown higher scores of depression among those caring for a child with autism, when compared to those caring for a child with an intellectual disability without autism (Mungo, Ruta, Genitori D'Arrigo, & Mazzone, 2007; Olsson & Hwang, 2001). Mungo et al. (2007) reported lower QoL for parents of children with a pervasive developmental disorder when compared to parents of children with an intellectual disability, cerebral palsy, and non-disabled children. When compared to Cornelia de Lange syndrome or autism, those parenting a child with Down syndrome reported less depression and stress, and higher QoL (Blancher & McIntyre, 2006; Richman, Belmont, Kim, Starin, & Hayner, 2009).

Comparisons in relation to parenting stress or QoL between normally developing children, and those with a disability are less common. Lee et al (2009) found that when compared to parents of children without a disability, those raising a child with high functioning autism had lower levels of QoL and higher stress levels, especially with regard to their physical and mental health. High functioning autism was defined as children diagnosed with asperger syndrome, high-functioning autism, and pervasive developmental disorder not otherwise specified (Lee et al., 2009). This is supported by the results of the Carer Health Effects Study conducted in 1999 which found that those in a caring role had a 63% higher mortality rate than those in the non-caring comparison group (NHC, 2009).

Few research projects have been completed in New Zealand to investigate the quantitative impact of care giving in New Zealand. Jorgensen, Parsons and Jacobs (2007) undertook an investigation into carer wellbeing in New Zealand. The study measured stress and depression among carers throughout New Zealand. It was found that those caring for children, or adults under the age of 30 years had the highest stress level scores and carers aged between 30-39 years of age had the highest depression scores (Jorgensen et al., 2009). In addition to this, it was discovered that those caring for children with ASD were among the highest mean scores for depression and stress, regardless of the carers own age. Of the 300 people interviewed in the study, 59% rated moderate to severe levels of stress, and 66% indicated they suffered from depression (Jorgensen et al., 2009). One weakness of this study was the inclusion of whole of life disabilities. This resulted in 75% of those with a disability being over the age of 19 years making assumptions on the impact for caregivers of children with a disability difficult. In addition to this disability type was broad with attention deficit disorder and attention deficit hyperactive disorder included alongside autistic spectrum disorder. This thesis aims at addressing these issues by refining the participant inclusion criteria to allow for analysis within a specific group of caregivers.

Prior research has identified that caregivers of disabled children identify as having higher risks regarding stress, depression, and general health concerns and these are being attributed to prompting long term out-of-home placements (Carpinter, Irwin, & Rogers, 2000; Ministry of Social Development [MSD], 2007a ; Murphy, Christian, Caplin, & Young, 2006). These results provide policy makers the opportunity to carefully consider the position of caregivers within New Zealand when designing and implementing supports. Addressing aspects of the parenting role that exacerbate stress or depression levels, and lower QoL has the potential to ensure quality family relationships that support all family members. This provides the opportunity to ensure that care givers health remains the top priority in enabling individuals with a disability to remain within their family homes (MSD, 2007b; NHC, 2009).

Relationship between behaviour and quality of life. Previous studies have indicated the prevalence of emotional and behavioural support needs amongst children with an intellectual disability as between 31-41% (Baker et al., 2003). Children with a disability and co morbid high behavioural or mental health needs are often referred to as having a dual diagnosis. The ability to correctly identify an additional mental health condition in relation to the intellectual disability can be difficult due to the potential for misdiagnosis. The intellectual disability itself, can prevent the child from accurately participating in test administration and/or clinical assessment. Care must be taken when assessing for additional diagnoses as behavioural traits may be a result of the developmental disability, rather than a mental health concern (McIntyre, Blacher, & Baker, 2002; Richman et al., 2009). Dual diagnosis has its own implications with regard to caregiver QoL, when maladaptive behaviour is present studies show an increase in parental stress and depression (Baker et al., 2003; Epstein, Saltzman-Benaiah,O'Hare, Goll, & Tuck, 2008; Hastings et al., 2005; Lecavalier et al., 2006) whilst decreasing parental marital quality and psychological wellbeing for caregivers (Higgins, Bailey, & Pearce, 2005; Wieland & Bajer, 2010).

Maladaptive behaviour can include behaviour that is dangerous or harmful to the individual or those around the individual. It can include damage sustained by objects, and property caused by the individual. Additionally it encompasses any behaviour that results in the individual not being able to successfully integrate into societal norms and expectations, therefore creating a social barrier between them and those around them (Bruininks, Thurlow, & Gilman, 1987). Given these factors, it is unsurprising that those parents of children with a disability coupled with high behavioural needs indicate lower levels of life satisfaction, and higher levels of parenting stress and depression.

Past research clearly indicates a link between reduced caregiver QoL, and a child's high behavioural needs (Lecavalier, Leone, & Wiltz, 2006; Maes, Broekman, Dosen, & Nauts, 2003; McIntyre et al., 2002; Richman et al., 2009). Behavioural challenges have been reported to have a larger impact on caregivers reported stress levels than the impact of decreased cognitive functioning (Baker et al., 2003, Lecavalier et al., 2006). This may be due to the multifaceted nature of behavioural needs having numerous implications to the way in which family life is conducted. Parents report the social stigma attached to different behaviour at times prevents them from community involvement including; attending concerts, going on vacation, completing activities of daily living such as supermarket shopping, or even visiting friends (Higgins et al., 2005; Mactavish, MacKay, Iwasaki, & Betteridge, 2007; Schilling & Schinke, 1984). These restrictions only further heighten parenting stress and reduce QoL over time if behavioural intervention is not applied and supported, within all domains of the child's life, by trained professionals.

Relationship between activities of daily living and quality of life.

Research indicates parental stress is exacerbated as parents strive to ensure the family's needs are met. This is further enhanced when caring for a child with high support needs. Children who require high levels of support to complete their activities of daily living, can have a significant impact on parents coping skills. In addition, these needs are constant with little to no respite opportunity for parents. Parents do not have an unlimited amount of physical, emotional or psychological energy (Janisse, Barnett, & Nies, 2009) and this is readily depleted when caring for those with high needs (Sales, 2003).

The physical and emotional demands of caring for a child with a disability are often higher than caring for a non-disabled child (Tadema & Vlaskamp, 2009). Often these demands are unlikely to change as the child fails to meet developmental milestones and support needs remain high over the child's lifespan (Tadema & Vlaskamp, 2009). Carers identified that they face an exhausting challenge in caring for children with high needs, that is on-going with little to no practical support to ensure their safety and wellbeing (Carpinter et al., 2000). They often do not seek medical or psychological support until they have reached crisis point (NHC, 2009). With changes to social policies, parents are aware that their caregiving responsibilities are likely to continue indefinitely, and support networks are often strained or even non-existent in some areas (Cummins, 2001; Sales, 2003). The lack of national consistency regarding disability support services in New Zealand further increases the difficulties families face. Caregivers are well aware that they are likely to continue carrying the majority of the responsibilities with regard to the care their child requires from birth and through adulthood.

Relationship between socio-economic and marital status and quality of life. Research regarding the relationship between QoL for caregivers of a child with a disability and its interaction with socioeconomic status and marital status is mixed. Some studies investigating differences between parents in regards to QoL, stress, depression, and wellbeing show significant differences in results for mothers and fathers. These differences indicate higher levels of stress, and depression and lower levels of QoL and wellbeing for mothers (Allik, Larsson, & Smedje, 2006; Hastings et al., 2005; Little, 2002; Mungo et al., 2007; Olsson & Hwang, 2001; Tehee, Honan, & Hevey, 2009; Yamada et al., 2007). In comparison a smaller number of studies have shown little to no differences between maternal and parental QoL (Epstein et al., 2008; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Wang et al., 2006). The relationship between QoL and parental role is apparent despite the marital status of the mother, and may be explained by the different parenting roles, and responsibilities, undertaken by mothers when compared to fathers (Epstein et al., 2008; Hastings et al., 2005).

Olsson and Hwang (2001) reported an interaction between sole parenting and depression, however the study was limited by not investigating if this was directly related to parenting a child with a disability. Other studies have researched the impact of parenting a child with a disability on family cohesion and family QoL. Altiere and von Kluge (2009) reported agreement between maternal and parental figures in regards to family structure and effectiveness at dealing with life stressors. In concordance with this, Wieland and Baker (2010) found both maternal and paternal reports on marital quality to be similar when parenting a child with a disability. Wieland and Baker's study in 2010 concluded with a discussion that variances in marital satisfaction were more evident when the couple were raising a child with a disability. Kersh et al (2006) produced a body of research questioning the impact of marital relationships on caregivers wellbeing. The study highlighted a concern that marital quality was lower for those participating in the study in comparison to the general population. However, this study did not take into account differing physical, emotional and behavioural needs that a child with a disability may require.

Socio-economic status, and the resulting resource availability are reported to have an impact on individuals health and wellbeing (Hatton & Emerson, 2009; Kersh et al., 2006). Socio-economic status has been found to act as a moderator between QoL for caregivers and problem behaviours in children (Emerson, 2003; Hatton & Emerson, 2009). It has also been reported to have a strong positive relationship with depression (Kersh et al., 2006). Olsson and Hwang (2001) however reported no interaction between socio-economic status and depression. Given the small amount of research in this area, and the conflicting results, additional future research in this area would be beneficial.

Relationship between perceived satisfaction with support services and quality of life. Social support as a mitigating factor in relation to QoL is not a new concept. Social support itself is a highly complex construct, with structural and functional measures (Helgeson, 2003). Social support for parents caring for child with disabilities can take many forms, both informal and formal. Formal supports relate to funded initiatives to help alleviate parental stress and caregiver burden through providers contracted with the government. Informal support relates to support from family, peers, and the wider community. The perceived usefulness, reliability and flexibility of these supports can impact on caregivers wellbeing and QoL (Helgeson, 2003; Meadan, Halle, & Ebata, 2010; Schilling & Schinke, 1984; Tadema & Vlaskamp, 2009). Those who report higher levels of perceived social support from friends, family, support organisations, and their communities as a whole show lower levels of stress and higher levels of QoL compared to those who report low levels of perceived social support (Helgeson, 2003; Schilling & Schinke 1984; Tehee et al., 2009). Parents have reported a perception of less support, both natural and funded, when parenting children with autism, yet they also view the child as having greater needs than a child with Down syndrome (Pisula, 2007).

These findings bring context to a study completed by Cummins (2001) which undertook a review of the subjective wellbeing of those caring for a family member with a disability. The review raised the question of whether social policy makers have ever truly considered the impact of raising a child with a disability from the caregivers perspective. Cummins (2001) and Sales (2003) both questioned the social 'ideal' of having children with severe disabilities at home as having a place in current society where families are smaller, and often there is less social support for caregivers.

Carers other concerns with support services related to financial burdens, isolation from peer and social groups, lack of time and attention to focus on other siblings, lack of information provision regarding funded and unfunded services, and the inability to source appropriate respite facilities (Carpinter et al., 2000; Jorgensen et al., 2009). These areas of concern need to be addressed to ensure positive outcomes for individuals with a disability and their caregivers.

Research Questions

There has clearly been a considerable amount of research regarding the impact on caregivers who are caring for a child with a disability. Research methods and constructs have varied to such a degree that comparisons of results are difficult to determine. In addition little research has been done nationally to investigate the comparison between QoL for caregivers of children with a disability and those caring for a child without a disability.

Previous research highlights the need for further investigation into the impact of behaviour, socio-economic status, marital status, and social support on caregivers QoL. Therefore this research will focus on these areas of study to investigate any similarities or disparities with previous research.

The research questions for the study are:

1. Will overall QoL will be lower for those caring for a child with a disability when compared to those caring for a child without a disability?
2. Will caregivers of a child with a disability, who also identify as having high problem behaviours, have lower QoL than those caring for a child with a disability who identify as having low problem behaviours?
3. Will caregivers of children with a disability, where the child requires high support with basic activities of daily living have a lower QoL than those who indicate their child requires low support with basic activities of daily living support?
4. When caring for a child with a disability will socio-economic status and marital status influence QoL levels? Will those earning a higher income and identifying as married report higher QoL, than those with lower levels of income and parenting alone?
5. Will caregivers of children with a disability who report higher satisfaction with the disability support services they receive have higher QoL than those who report being dissatisfied with the supports they receive?

Chapter Two

Method

Research Design

Research in New Zealand focusing on QoL for caregivers of children with a disability is scarce. No research with a New Zealand focus was found that solely addressed QoL for caregivers of children with a disability compared to caregivers of children without a disability. This research attempts to address this gap in research to try and identify any key concerns or additional factors that may be impacting on QoL.

To enable a comparison of QoL between caregiver groups, the study consisted of two defined participant groups. Those in Group One were care givers of a child with a disability. Those in Group Two were caregivers of a child without a disability and were to be recruited by the person in Group One. Identical measures were completed by both groups to allow for a direct comparison between groups. The use of a comparison group had the potential to provide invaluable information regarding caregivers QoL discrepancies. Results from the questionnaire may be able to be directly compared to the general population. Separating the two groups was the presence or absence of caring for a child with ASD and/or an intellectual disability. Differences could then be better attributed to caring for a child with a disability. Without the comparison group inferences regarding QoL being influenced due to caring for a child with a disability could not be ascertained.

Participants

Of the 76 responses to the questionnaire, 73 were complete responses and were not duplicates. 60 participants identified as being in Group One - caregivers of a child with a disability, compared to 13 participants who identified as being in Group Two - caregivers of a child without a disability.

Female caregiver response numbers were higher than male responses, with 91.7% females in Group One, and 92.3% females in Group Two. Child's gender frequencies were different between the two groups, with 70% being male in Group One and 23.1% being male in Group Two. Ethnicity was fairly consistent between groups with the majority in each group identifying as New Zealand European, the exact ethnicity frequencies can be seen in Table 2.1.

Table 2.1

Ethnic frequency of caregivers and children in Group One and Group Two

	Caregivers		Children	
Ethnicity	Group One	Group Two	Group One	Group Two
New Zealand European	47	11	46	10
Maori	7	0	6	0
New Zealand European and Maori	2	0	3	1
New Zealander	0	1	0	0
Other or Unknown	4	1	5	2
Total	60	13	60	13

In Group One the mean age for caregivers was 42.2 years with a standard deviation of 6.6, and the mean age of the child was 11.2 years, with a standard deviation of 3.3 years. Group Two's caregiver mean age was 38.5

years with a standard deviation of 7.1, and the mean age of the child was 9.6 years with a standard deviation of 2.3.

Socio-economic status was similar between both group with the majority of participants in the More than $50 000 category, 55% for Group One and 38.5% for Group Two.

Table 2.2 shows higher frequencies of participants in the Manawatu/Wanganui, Wellington, Auckland and Waikato regions within Group One. The reduced number of participants in Group Two means that distribution is fairly evenly spread between regions.

Table 2.2

Comparison of frequencies for participants area of residence for Group One and Group Two

Area	Group One	Group Two
Auckland	9	1
Waikato	9	3
Bay of Plenty	6	1
Hawkes Bay	3	1
Manawatu/Wanganui	12	2
Wellington	10	2
Tasman	1	0
Canterbury	7	2
Southland	3	1
Total	60	13

With marital status 75% and 69.2% for Group One and Group Two respectively were married. In Group One 5% were in a defacto relationship compared to 7.7% in Group Two. The remaining 20% and 23.1% in Group One and Two were single or divorced, with one participant in Group One leaving the question blank.

Three or less children, in addition to the child that the questionnaire focused on, accounted for the total number of children in the family for 93.3% of Group One and 100% of Group Two. Of the other siblings in Group One, 35% identified as also having a disability. Medical conditions were identified as present for 45% of Group One caregivers and 15% of Group Two caregivers. In addition 48% of participants in Group One reported having suffered from depression or another mental health condition, with just under half of this number reporting the condition as current. In contrast Group Two only identified 15% as having suffered from depression or a mental health condition, and no one in this group identified the condition as current.

Measures

Various measures were combined to produce a final questionnaire to address the research questions postulated at the beginning of this thesis (see Appendix C for the full questionnaire). Background information included demographics, identification of the child's activities of daily living needs, funded supports being received and satisfaction with these supports. Ferrans and Powers (1985) Quality of Life Index was used to measure QoL for participants, and the Nisonger Child Behavior Rating Form was used by caregivers to identify problem behavioural tenancies and/or traits in the children.

Demographics. Demographic questions were asked to determine any influence these factors may have on QoL and to ensure an equal distribution of demographic features both between and within groups. Demographic areas of interest included: age, gender, ethnicity, socioeconomic level, area of residence, marital status, disability, family structure, medical conditions, and mental health concerns.

Activities of daily living. Participants were asked to identify which activities of daily living their child required assistance to complete. Tasks included: getting in and out of bed, showering, dressing/undressing, grooming, toileting, continence, menstruation, medication, eating, drinking, and health management. Level of assistance required in each of these areas was not requested or identified within the scope of this research.

Funded supports. Participants were asked to indicate what funded supports they currently accessed for their child, and how satisfied they were with these services. Funded support options included: Local Needs Assessment Service Coordination Services, Disability Support Groups, Enable New Zealand, Regional Children's Health, and Other. Level of satisfaction was recorded on a 5-point rating scale ranging from Very Dissatisfied (0) to Very Satisfied (5).

Qualitative responses. Participants were invited to comment on anything they believed would help improve their QoL. This was added as a means of determining possible future research questions within the realm of supporting care givers within New Zealand.

Quality of Life Index (QLI). The QLI was developed in 1985 by Ferrans and Powers to address a gap in quality of life measurement. There is a generic version of the measure as well as numerous disease/illness specific versions. The measure has now been translated into Arabic, Chinese, Danish, French, Hebrew, Italian, Lithuanian, Norwegian, Polish, Portuguese, Russian, Spanish, Thai and Turkish. The measure uses the following definitions within its conceptualisation (Ferrans & Powers, 1992, pg 29):

> "….quality of life was defined as a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her."

> "Satisfaction…suggests a cognitive, judgemental experience which fits…with the idea that quality of life is determined by judgement and evaluation of life's conditions."

Whilst this may be seen as a more simplistic version of the WHOQOLQ it incorporates the same ideal that QoL is an individual phenomena that is heavily reliant on individual perceptions, expectations and the level of difference between ideals and reality.

Reliability and validity. The QLI generic version consists of two question sets each comprised of 32 subjective indicators. The first set measures how satisfied a person is with certain areas of their life, and the second set measures how important each of these areas are to the individual (Ferrans, 1996; Ferrans & Powers, 1985, 1992). These questions are then further broken down into four domains: health and functioning, socioeconomic aspects, psychological/spiritual aspects, and family (Ferrans & Powers, 1992). The four domains were determined using factor analysis. Of the 32 questions in each set, 12 loaded with health and functioning, 9 loaded with socioeconomic, 7 loaded with psychological/spiritual wellbeing, and 4 items loaded with family (Ferrans & Powers, 1992). Loadings also show evidence of a higher order factor with regards to QoL (Ferrans & Powers, 1992). The items included in the QLI are displayed under their separate domains in Table 2.3. We can see from this table that the methodology follows closely to others by using multi-dimensional domains that encompass a large array of areas.

The purpose of measuring individuals' life satisfaction against importance rating is designed to enhance accuracy within the test scores. The underlying theory is that items that are highly satisfactory and highly important will contribute to greater QoL. Conversely items that have low satisfaction levels, but high importance will impact negatively on QoL. Those items that have high satisfaction, but low importance will be relatively neutral in terms of their contribution to QoL (Ferrans & Powers, 1985, 1992). The scoring mechanism reflects this by putting greater weight on high satisfaction/high importance responses compared to high satisfaction/low importance ratings (Ferrans & Powers, 1985, 1992).

Table 2.3

Domains and subsets of the Quality of Life Index questionnaire

Domain	Subset
Health and Functioning	Usefulness to others
	Physical independence
	Ability to meet family responsibilities
	Own health
	Pain
	Energy
	Stress or worries
	Control over own life
	Leisure time activities
	Potential for a happy old age/retirement
	Ability to travel on vacations
	Potential for a long life
	Sex life
	Healthcare
Psychological/Spiritual	Satisfaction with life
	Happiness in general
	Satisfaction with self
	Achievement of personal goals
	Peace of mind
	Personal appearance
	Faith in God
Social and Economic	Standard of living
	Financial independence
	Home
	Neighbourhood
	Job/Unemployment
	Friends
	Emotional support from others
	Education
Family	Family happiness
	Children
	Relationship with spouse
	Family health

Note. Adapted from " Development of a conceptual model of quality of life" by C.E. Ferrans 1996, *Scholarly Inquiry for Nursing Practice: An International Journal, 10* (3) p.295.

When compared to a single item life satisfaction measure convergent validity was measured between .65 and .77 for overall scores and .63 for health and functioning, .55 for socioeconomic, .88 for psychological/spiritual, and .44 for family (Ferrans & Powers, 1985, 1992). Test-retest reliability showed correlations between .81 - .87 (Ferrans & Powers 1985). Cronbach alpha scores of .93 have been recorded on two different trials (Ferrans & Powers, 1985, 1992). Individual subscale Cronbach alpha scores were: .87 for health and functioning, .82 for socioeconomic, .90 for psychological/spiritual, and .77 for family (Ferrans & Powers, 1992).

Ferrans (1996) also conducted tests to determine if the measure was transferable to other cultures and ethnic groups. The results were consistent with the original test group, adding weight to its transferability to other populations. In cases where a language other than English was the native tongue, words need to be adjusted to ensure the appropriate meaning was conveyed and comprehended (Ferrans, 1996). In the current study the wording on Question 20 was changed replacing the word ‘apartment’ with ‘flat’ and on Question 28 ‘your faith in God’ was changed to ‘Your spiritual/cultural wellbeing’. These changes were to ensure the language was reflective of terminology used in New Zealand in order to help prevent any confusion from participants. Question 34 'your ability to care for your child' was added to the family domain specifically for this research given that the focus was on caregivers of children.

Measurement. The QLI has five final scores comprised of the four domains, and one overall total QoL score. Each of these five scores is obtained by first subtracting 3.5 from the satisfaction responses for each question within its subsection, then multiplying this number by the raw importance response. The resulting number for each question within the individual subsections are then added together. To determine a consistent score within each subscale this number is then divided by the number of responses in that subscale. To remove the possibility of negative numbers 15 is now added to the total. This produces a possible score of 0 - 30 within each subscale and the total overall QoL. A score of 0 indicates low QoL, while a score of 30 indicates high QoL.

Nisonger Child Behavior Rating Form (NCBRF). The NCBRF is designed to assess behaviour in children with an intellectual disability (Aman, Tassé, Rojahn, & Hammer, 1996). It is very closely linked to the Child Behaviour Rating Form (CBRF), which was used as a basis for its conception. Changes were made to the instructions and new questions were added (Aman et al., 1996). The full NCBRF includes a rating form for parents and teachers. In the present study, only the parent form was used.

Reliability and validity. The rating scale was trialled on 369 participants who had accessed the Nisonger Centre for Mental Retardation and Developmental Disabilities in the USA. In this trial, coefficient alphas for the Social Competence Scale were .82 for Compliant/Calm and .73 for Adaptive Social (Aman et.al., 1996). Coefficient alphas for each of the subscales within the Problem Behaviors section were as follows: Conduct Problem .93, Insecure/Anxious .89, Hyperactive .90, Self-Injurious Behavior/Stereotypic .81, Self-Isolated/Ritualistic .77, and Overly Sensitive .80 (Aman et al., 1996). Pearson correlations between the parent rating form, and the teacher rating form were all significant at a .01 level, indicating acceptable inter-rater reliability (Aman et al., 1996). Concurrent validity was assessed using the Aberrant Behavior Checklist, and significant correlations were found with all subscales at the $p < .01$ level (Aman et al., 1996).

Normative age and gender distributions were evaluated using the same population described above. The Insecure/Anxious, Hyperactivity, and Self-

Isolated/Ritualistic subscales showed a relationship to age with mean scores in these areas increasing as children aged (Tassé, Aman, Hammer, & Rojahn, 1996). Interactions between gender and age were shown to be significant on subscales Conduct Problem and Insecure/Anxious (Tassé et al., 1996). Factor analysis has also been completed with a sample of children with ASD and further supported the construct validity (Lecavalier et al., 2004).

Measurement. The test is divided into two sections: Positive Social (10 items) and Problem Behaviors. All questions are rated using four step Likert scales. The Positive Social section ranges from 0 (=not true) to 3 (=completely or always true). Within this category there are two subscales; *(1) Compliant/Calm and (2) Adaptive Social*. Six subscales are included in the Problem Behaviors section, *(1) Conduct Problem, (2) Insecure/Anxious, (3) Hyperactive, (4) Self-Injurious Behaviour/Stereotypic, (5) Self-Isolated/Ritualistic, and (6) Overly Sensitive.* The response ratings in this section range from 0 (=did not occur or was not a problem) to 3 (= occurred a lot or was a severe problem) (Rojahn, 2008). Higher scores indicate a higher frequency of the behaviour occurring.

Procedure

Letters were sent to a number of Disability Support Groups (Appendix D) throughout New Zealand requesting their assistance in advising potential participants about the study. Of those groups willing to participate in the recruitment process, information was delivered via email, in newsletters, via websites and in journals depending on the groups preferred method of communication. The information sent through the support groups was either the full, or a shortened form of the Information Sheet (Appendix E). Due to the lack of response to the information published through support groups a second recruitment drive was undertaken. This involved the use of mass media to advise people of the study and encourage them to participate. Requests were sent to a number of local newspapers and radio stations within New Zealand (Appendix F). From this a small number of newspaper articles, and radio announcements were made. Following the media drive schools with a high concentration of special needs students were approached to hand out questionnaire packs to families who would meet the research criteria (Appendix G).

Group One and Group Two had access to the questionnaire in two different formats. Primarily participants were encouraged to use the on-line questionnaire which was designed and maintained by Harvey Jones, Programmer/Analyst, Massey University. The on-line questionnaire was complemented by an identical paper version that participants could access if they preferred. The paper version could be requested either through email or via cell phone. The email address and cell phone number were dedicated specifically to the research topic and were checked regularly. Those families who received the questionnaire through their child's school were automatically provided with two paper copies of the questionnaire, one for them and one for their pair. Any paper based versions included reply paid envelopes for participants convenience. The use of two methods of data collection was designed to ensure that no participants were disadvantaged or prohibited from the study due to technical limitations.

Raw data collected online was managed by Harvey Jones who sent it in an Excel format to the researcher. Raw data collected via mail were posted to Massey University were they were distributed to me as they arrived.

Ethics

This study was completed following the Massey University Research Code of Ethics application process. Approval for the study was sought and granted from the Massey University Human Ethics Committee: Southern A. As such, all procedures were carefully examined to ensure the safety of the participants and the researcher.

Informed consent. Informed consent was considered to be obtained upon submission of the questionnaire, either online or by post. Participants were provided with an information sheet explaining the research and listing contact details for myself and my supervisor should they have further questions before deciding on participation in the research.

Anonymity and confidentiality. Participants were not required to use their name or contact details on the questionnaire. Participants chose their own matching 'code names' for themselves and their Group Two partner. All verbal or written requests for paper based versions of the questionnaire were in no way able to be connected with future questionnaire submissions. All final results were presented in a manner that no respondent could be identified by a second party.

Overview of Data Analysis

The aim of the research was to address questions relating to the differences in QoL between Group One and Group Two. Additional aims were to investigate the relationship between QoL for those in Group One and child's behaviour, marital status, socio-economic status, social support and activity of daily living needs. Descriptive and inferential statistics were used to investigate these aims. All numerical data was analysed using PASW Statistics version 18 for Windows.

Given the complex nature of caregiving, and the personal perceptions of the caregiver role, qualitative feedback was included in the results as appropriate to add an additional viewpoint.

Chapter Three

Results

To ensure ease of understanding and interpretation each section of the results will be introduced with the research question to which they pertain. Additional participant comments will be included at the end of the results section. To ensure confidentiality and anonymity participants comments will not be referenced. Comments may be abbreviated, or adapted to ensure no first or last names are mentioned within the context of their comment.

Variables

Demographic information. Female caregiver response numbers were higher than male responses, with 91.7% females in Group One, and 92.3% females in Group Two. Child's gender frequencies were different between the two groups, with 70% being male in Group One and 76.9% being female in Group Two. A higher number of respondents identified as New Zealand European in both Group One (n = 47) and Group Two (n = 11). The mean age of respondents in Group One was 42.2 years, and in Group Two was 38.5 years. The mean ages of the children of interest were 11.2 years in Group One and 9.6 years in Group Two.

Disability type for the children of caregivers in Group One fell predominately under the category of ASD with these care givers making up 61.7% of the total Group One respondents. Only 8.3% identified as rett's, 5% identified as aspergers , and 20% identified as Other. Other included diagnoses of Velo-Cardio-Facial Syndrome, Dyspraxia, Dravet's Syndrome, Tuberous Sclerosis, Phelan-McDemid Syndrome, Intellectual Disability Not Otherwise

Specified, Neurofibromatosis Type 1, Optical Learning Disorder, rare chromosome disorder, Cerebral Palsy and Angelmann Syndrome.

Frequencies of health conditions within Group One were a lot higher than the frequencies in Group Two. 45% of respondents in Group One identified as personally having a medical condition compared to only 15.4% in Group Two. Similarly 48.3% of Group One respondents reported having been diagnosed with depression or other mental health condition, with 79% of these people reporting this diagnosis as current. In comparison 15.4% of Group Two respondents reported ever suffering from depression or other mental health condition, and no one in Group Two reported this diagnosis as current.

Does disability matter? The first research question sought to investigate differences in QoL between the two groups. Figures 3.1, 3.2, 3.3, 3.4, & 3.5 show boxplot comparisons of the Total Quality of Life Score, and individual subscale scores on the QLI between Group One and Group Two.

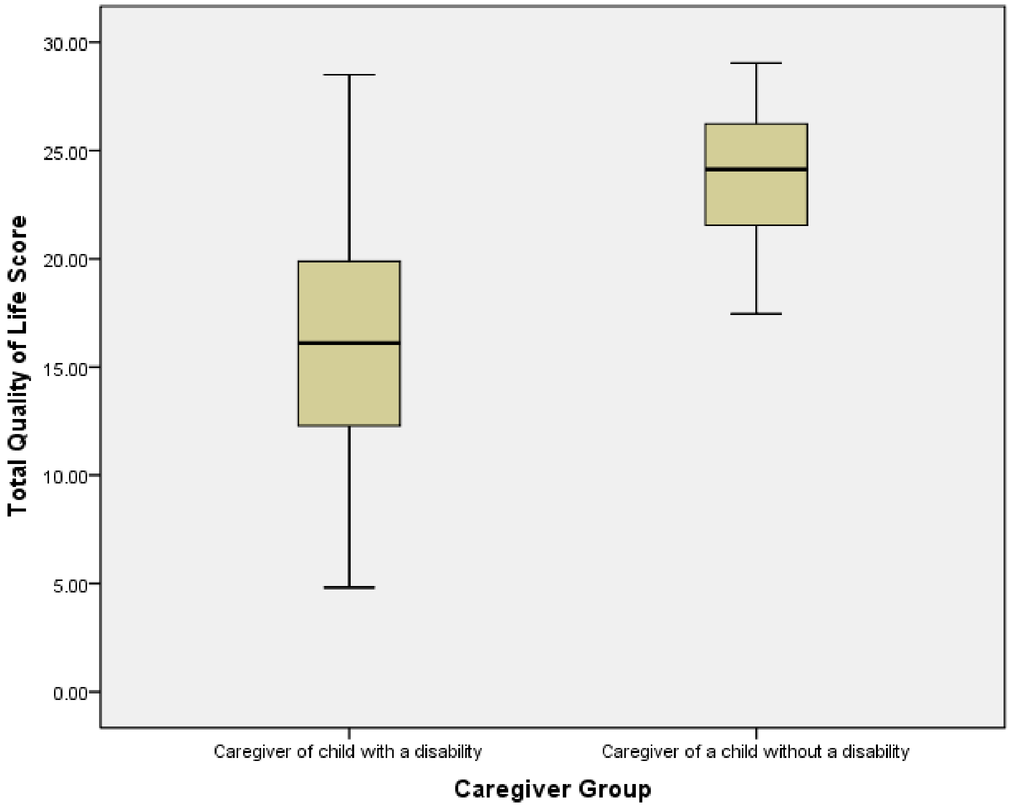

Figure 3.1. A comparison of the total Quality of Life Index scores between Group One and Group Two.

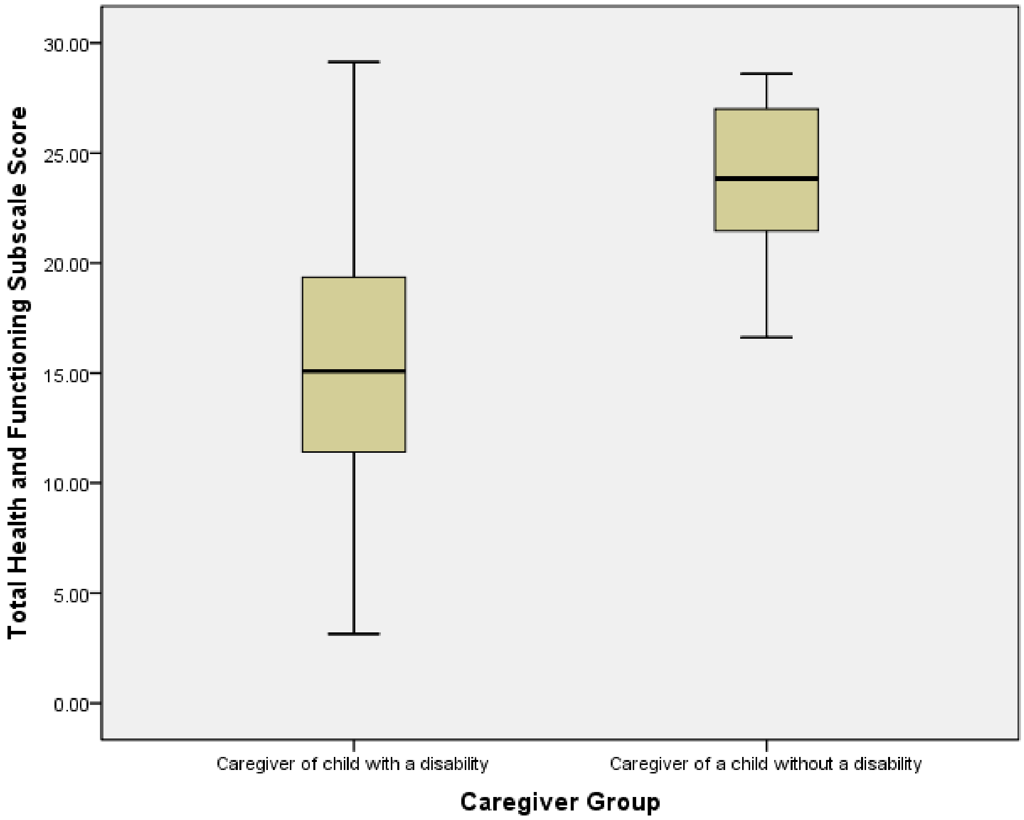

Figure 3.2. A comparison of the total health and functioning subscale scores for Group One and Group Two.

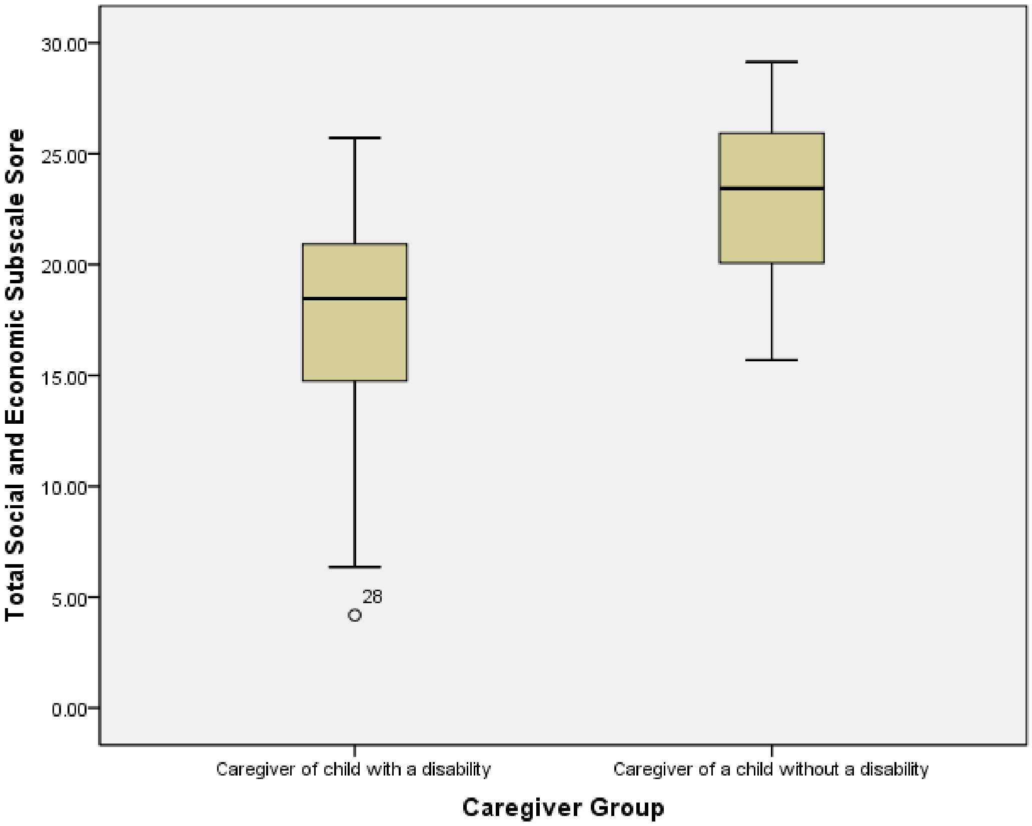

Figure 3.3. A comparison of the total social and economic subscale scores for Group One and Group Two.

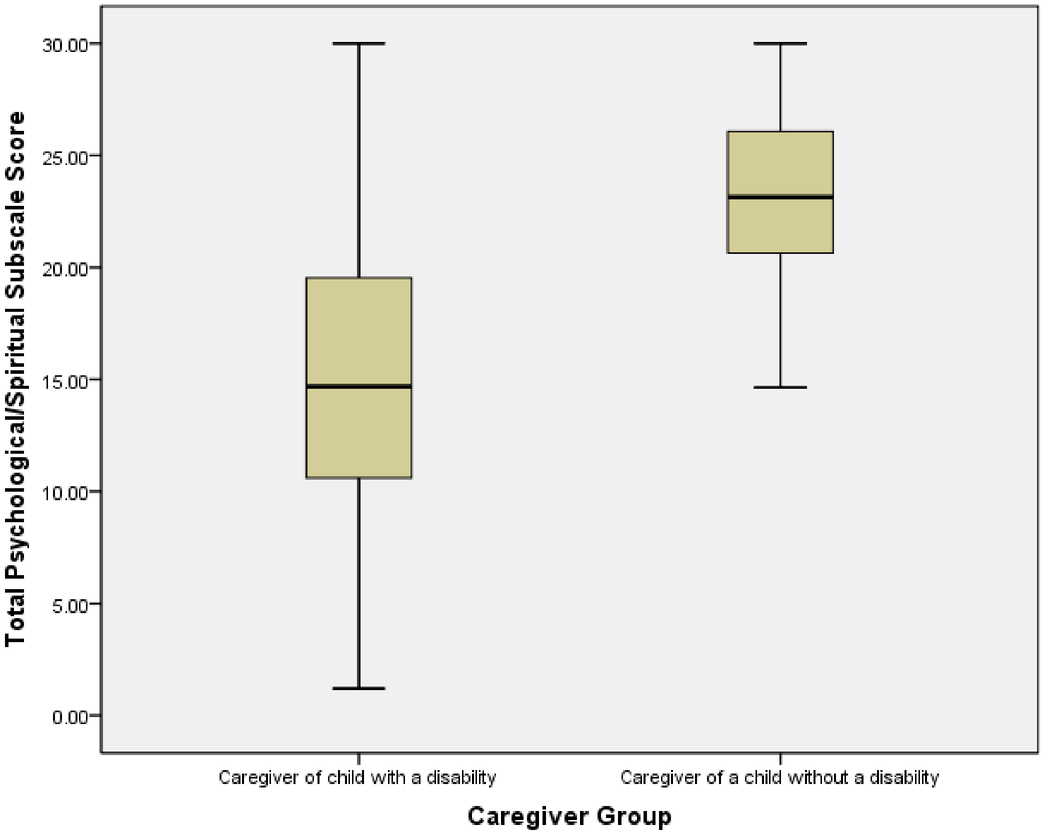

Figure 3.4. A comparison of the total psychological/spiritual subscale scores for Group One and Group Two.

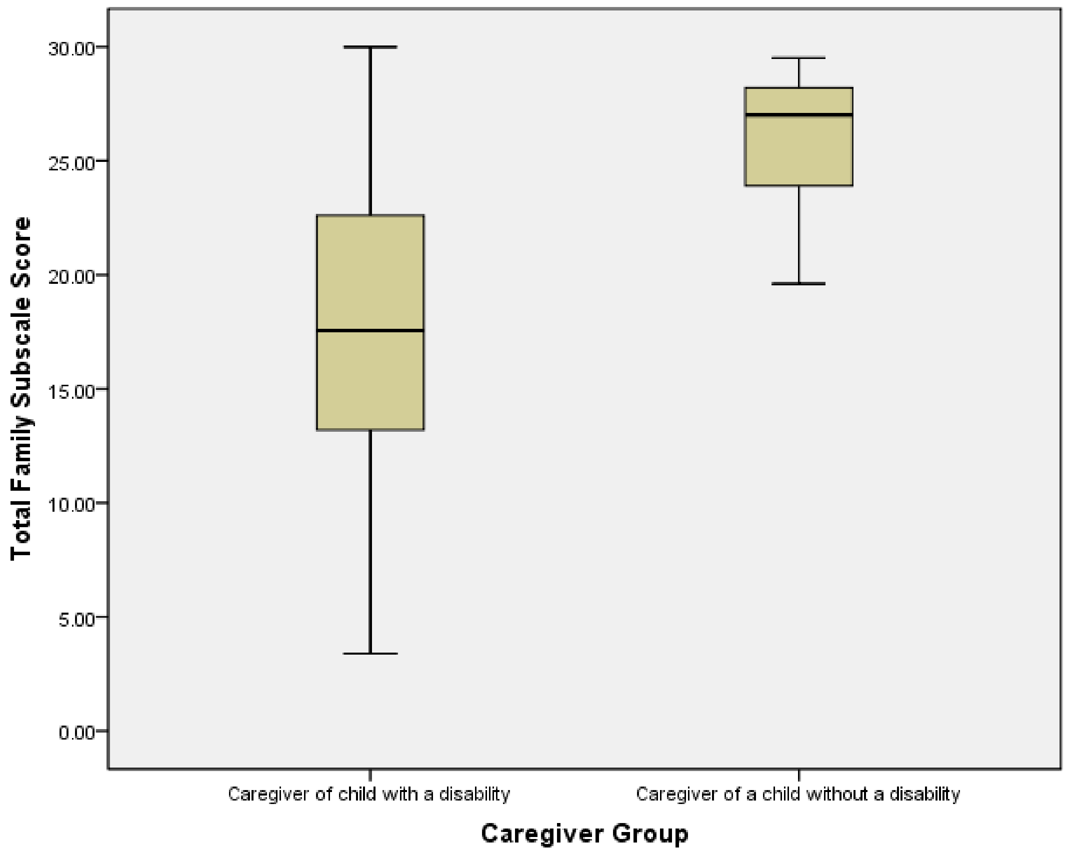

Figure 3.5. A comparison of the total family subscale score for Group One and Group Two.

Figures 3.1 - 3.5 show the differences between the two groups in relation to total subscale and overall scores. Table 3.1 adds further support to these differences, indicating the mean scores for each section between groups. Within Health and Functioning the lowest score in Group One was 3.14 compared to 16.62 in Group Two. Social and Economic had a lowest score of 4.19 for Group One and 15.69 for Group Two. Psychological/Spiritual resulted in a lowest score of 1.21 in Group One and 14.64 in Group Two. The Family subscale returned a lowest score of 3.40 in Group One and 19.60 in Group Two. Overall the lowest scores for each group were 4.82 and 17.45 for Group One and Group Two respectively.

Table 3.1.

Means and Standard Deviations between Group one and Group Two for the Quality of Life Index Subscales and Overall Score

Scale	Group One		Group Two	
	Mean	Standard Deviation	Mean	Standard Deviation
Health and Functioning	15.16	6.18	23.67	3.68
Social and Economic	17.59	4.70	23.04	3.97
Psychological/Spiritual	14.97	6.54	23.08	4.27
Family	17.63	6.07	25.99	3.17
Overall QoL	16.00	5.35	23.75	3.27

An independent-samples t-test was used to compare the mean overall QoL scores between Group 1 and Group 2. A significant difference in scores was found for Group 1 (*M* = 16.00, *SD* = 5.40) and Group 2 (*M* = 23.75, *SD* = 3.27; *t* (71) = -5.00, *p* = .000, two-tailed).

Relationship between behaviour and quality of life. Research shows that a child's behaviour may be related to caregivers QoL. The following results seek to confirm pervious research by investigating the relationship between behaviour and caregivers QoL. The parent's version of the Nisonger Child Behaviour Rating Form was used to measure child's behaviour and the QLI results were used to measure QoL. Responses from participants in Group One and Group Two were combined for this analysis. The theory behind combining the two groups for this analysis was underpinned by the notion that behaviour rather than disability was the focus of attention. Combining the two groups allowed for a comparisons across the groups of the general interactions between behaviour and QoL. Whilst no direct comparison between the two groups was undertaken, descriptive statistics were split between the two groups. The splitting of descriptive statistics allows for greater understanding when investigating the relationships between QoL and behaviour in further analysis, and highlights within which group these relationships are likely to be more dominant.   Descriptive statistics are shown in Table 3.2 which describes the means for Group one and Group Two within each subsection.

Table 3.2.

Means for Group One and Group Two within the Nisonger Child Behavior Rating Form subsections.

	Mean	
Subsection	Group One	Group Two
Positive Social		
Compliant/Calm	6.63	11.62
Adaptive Social	3.80	9.00
Problem Behaviour		
Conduct Problem	17.88	7.15
Insecure/Anxious	11.70	4.54
Hyperactive	12.28	4.46
Self-injury/Stereotypic	3.52	0.08
Self isolated/Ritualistic	7.55	1.77
Overly Sensitive	7.13	3.31

Persons r was used to calculate the relationship between QoL scores and each individual behaviour subscale. The results from this are displayed in Table 3.3. Predominately the relationships between QLI scores and NCBRF scores were of a medium strength, with positive strengths related to positive behaviours, and negative strengths relating to problem behaviours. Four variables displayed a large relationship strength. They were: Total Health and Functioning Quality of Life and Total Self-isolated/Ritualistic Behaviour ($r = -.55$, $n = 73$, $p < .0005$); Total Quality of Life and Total Self-isolated/Ritualistic Behaviour ($r = -.54$, $n = 73$, $p < .0005$); Total Psychological/Spiritual Quality of Life and Total Conduct Problem Behaviour ($r = -.53$, $n = 73$, $p < .0005$) and; Total Quality of Life and Total Conduct Problem Behaviour Score ($r =- .52$, $n = 73$, $p < .0005$). Four other variables displayed a small relationship strength. They were: Total Family Score and Self-injury/Stereotypic Behaviour ($r = -.24$, $n = 73$, $p < .0005$); Total Social and Economic Score and Overly Sensitive Behaviour ($r = -.24$, $n = 73$, $p < .0005$); Total Social and Economic Score and Total Self-injury/Stereotypic Behaviour ($r = -.25$, $n = 73$, $p < .0005$) and; Total Family Score and Hyperactive Behaviour ($r = -.29$, $n = 73$, $p < .0005$).

Table 3.3.

Correlations using Persons r between quality of life scores and behaviour subsection scores

		Total Quality of Life Score	Total Health and Functioning Subscale Score	Total Social and Economic Subscale Sore	Total Psychological/Spiritual Subscale Score	Total Family Subscale Score
Total Compliant/Calm Behaviour Score	Pearson Correlation	.473**	.479**	.376**	.457**	.339**
Total Adaptive Social Behaviour Score	Pearson Correlation	.446**	.463**	.352**	.391**	.346**
Total Conduct Problem Behaviour Score	Pearson Correlation	-.516**	-.463**	-.470**	-.527**	-.438**
Total Insecure/Anxious Behaviour Score	Pearson Correlation	-.479**	-.493**	-.313**	-.445**	-.428**
Total Hyperactive Behaviour Score	Pearson Correlation	-.421**	-.378**	-.400**	-.452**	-.294*
Total Self-Injury/Stereotypic Behaviour Score	Pearson Correlation	-.331**	-.332**	-.251*	-.329**	-.237*
Total Self-Isolated/Ritualistic Behaviour Score	Pearson Correlation	-.538**	-.545**	-.416**	-.485**	-.439**
Total Overly Sensitive Behaviour Score	Pearson Correlation	-.386**	-.386**	-.243*	-.398**	-.331**

Note. **. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Relationship between activities of daily living and quality of life. These results focus on the question of whether the level of support children require for activities of daily living impacts on caregivers overall QoL score. Results for Activities of Daily Living were only conducted within Group One. Group Two frequencies were not investigated due to the assumption that children within this group would require standard, age-appropriate support in the different areas. With regard to this only one respondent in Group Two indicating providing support to their child in the areas of grooming, toileting, medication, eating and health management.

Frequencies of support for activities of daily living within Group one are displayed in Table 3.4. These are shown as the percentage of participants providing support in each area, from a total of 60 respondents. In regards to the percentage of parents providing menstruation assistance the 15% is relative to the total number of respondents (60). However, of this 60 only 17 have female daughters. Taking this into account, the percentage of caregivers in Group One assisting female children with menstruation would be 50%.

Table 3.4

Percentages of parents in Group One providing assistance with Activities of Daily Living to their children

	Percentage of caregivers providing assistance
Activity of Daily Living Task	Group One
Getting in and out of bed	30
Showering	60
Dressing and/or undressing	65
Grooming tasks	78
Toileting	45
Managing continence	42
Managing menstruation	15
Managing medication	72
Eating	47
Drinking	33
Maintaining and managing health	78

In determining the impact of activities of daily living on caregivers QoL scores the raw data was manipulated to provide results that were of a higher quality and robustness. Due to the low number of responses for each category within the activities of daily living each category was coded as 0 = no and 1 = yes. These were then added together and grouped as Low support needs = a total score between 0 - 3 (*M* = 16.76, *SD* = 4.75); Medium support needs = a total score between 4 - 7 (M = 16.84, SD = 5.47) and; High support needs = a total score between 8 - 11 (*M* = 14.13, *SD* = 5.44). Of the 60 respondents in Group One, 15 reported a low level of support requirements, 27 reported a medium level of support requirements, and 18 reported a high level of support requirements. An one-way between groups analysis of variance was completed to determine the possible impact of high levels of support needs on caregivers Total QoL score. Levene's test for homogeneity of variances had a non significance value of .69 indicating no violation of homogeneity assumption. However, no statistical differences were found between the three groups and Total QoL scores.

Relationship between socio-economic status, marital status and quality of life. Investigation of the effects of marital status and socio-economic status on Total QoL was conducted using a two-way between-groups analysis of variance. Participants were separated into two marital groups according to their questionnaire responses (Non-partnered: single, widowed or divorced and; Partnered: married or defacto). Participants (*n* = 1) who left his section blank were removed from the analysis. Socio-economic groups remained identical to those used in the questionnaire (Under \$20, 000; \$20, 000 - \$30, 000; \$30, 000 - \$40, 000; \$40, 000 - \$50, 000; \$50, 000 and above). A two-way ANOVA showed no statistically significant effect with regards to the relationship between marital status and socio-economic status, *F* (3, 49) = 2.384, *p* = 0.08. However, a statistically significant main effect was found for socio-economic status , F (5, 49) = 2.881, p = .023). Levene's Test of Equality of Error Variances showing a significance value of .001 prevented further investigation of these relationships.

Relationship between perceived satisfaction with support services and quality of life. Support for any family can be formal or informal in nature, with formal supports often being government funded and informal supports relating to family, friends and the wider community. These supports may be transient or static in nature, and the amount of support they provide is often based on our expectations and perceptions as much as on the qualitative support given.

Various formal supporting agencies are available to individuals who have a disability and their family. The most commonly accessed groups are the regional Needs Assessment Service Coordination (NASC) agencies, individual Disability Support Groups such as Parent to Parent and Altogether Autism, Regional Child Health units to access specialists such as paediatricians and occupational therapists, and environmental support agencies such as Enable New Zealand or Accessable. The frequencies that these were accessed, and the level of satisfaction at the services received are shown in Table 3.5.

Table 3.5

Number of caregivers in Group One accessing support groups and level of satisfaction

		Level of Satisfaction				
Support Group	Total Frequency	Very unsatisfied	Mostly unsatisfied	Satisfied	Mostly Satisfied	Very Satisfied
NASC	34	7	6	14	5	3
Disability Support Group	38	7	3	11	12	11
Environmental support	11	7	3	4	0	1
Regional children's health	35	6	10	14	6	6
Other	24	2	5	7	5	2

Note. Caregivers who did not respond to this section of the questionnaire were assumed to not be receiving any supports. Level of satisfaction and Frequency number may not be equal as some individuals responded they are not eligible, therefore not receiving supports, for some services but indicated their level of satisfaction at their ineligibility.

To ensure ease of analysis regarding the relationship between satisfaction in support services and QoL the data was first transformed. This was done by first removing all those participants who did not receive disability support services. The remaining participants (*n* = 56), were given a value of 1 for each support group they accessed. These were then added together to give a total score of 1-5 depending on the number of services accessed. Satisfaction scores were weighted as Very Dissatisfied = 1; Mostly Dissatisfied = 2; Satisfied = 3; Mostly Satisfied = 4; Very Satisfied = 5. These were then added together for each participant to result in a total satisfaction score for all support services accessed. An average satisfaction score was obtained for each participant by dividing the total satisfaction by total number of support services being accessed (*M* = 3.05, *n* = 56). A weak positive correlation was found between level of satisfaction with support services and total QoL using Pearson product-moment correlation coefficient (*r* = .266, *n* = 56, *p* < .05).

Qualitative Responses

All of the following comments were made by participants in answer to the question "Please comment on two or three things which you believe would further enhance your quality of life". The comments listed are not a total rendition of all comments made. Participants comments have been abbreviated at times, and all names used were removed to ensure anonymity.

A number of comments related to a lack of good respite services or availability which lead to caregiver burnout:

> "...respite is our biggest issue as there are times I feel unable to cope...unlike other parents or children will be cared by us for the rest of our lives, they don't get to leave home"

> "Respite care before the meltdown occurs - this would avoid long term relationships being damaged further"

> "...finding good respite carers is difficult. They are like precious diamonds"

> "Being able to find an appropriate care giver who we trust to look after our child. Not many willing who have the necessary skills"

> "My child has respite days but no one will have him"

> "Access to appropriate, reliable respite carer - we have no family able to do it and we don't meet the criteria for a lot of respite services"

Comments regarding acceptance for the child within the community was another focus of participants responses:

> "Compassion and empathy from community about children who are different"
>
> "Understanding of the condition at school and in society"
>
> "Removing the power from school principles to stand down and suspend children illegally by claiming certain ASD type behaviours represent gross misconduct when they don't"
>
> "There are lots of people out there who put children down for what they have got and it's not fair"

The third comment which featured most frequently focused on professionals within the disability sector, and disability support services in general:

> "Good, caring, non-judgemental counselling for self and child"
>
> "Better information choices of treatment, support services available at diagnosis...more resources reaching root level"
>
> "I feel that doctors have their minds made up before you even see them and are not prepared to look outside the box by getting better diagnosis which could mean a better life for family and the child"

"Understanding employers who could be flexible about my hours"

"Equipment and resources should not have to be fought for...family should be financially compensated for not being able to earn a living"

"After school activities for the child to participate in within a supported environment"

"...better linked up services...sick of telling my story 100 times to 100 people all ending in no treatment or support"

"...The bureaucracy seems to grow at a frightening rate with more hoops for tired parents to try and hurdle"

"...children with degenerative conditions...have to be subjected to interviews every year to go over the same sad facts"

"Professionals who did their jobs competently - I am so sick of fighting the system to get inadequate levels of support for our son"

Two additional comments are worth mentioning, one indicates the extreme difficulties facing families, and children with disabilities. The second comment highlights the positive side of parenting a child with a disability.

> "My eldest child slit their wrists because they couldn't handle their siblings autism...my second eldest tried to hang himself at school as he hate his autism"

> "...although our son causes us more stress and drama than we thought humanly possible (he is very violent) he has also taught me many things I could not have learnt any other way. I am much more tolerant, accepting and less judgemental of others. I have rediscovered my spiritual side..."

Chapter Four

Discussion

The results indicate that QoL is lower for those caring for a child with a disability when compared to those caring for a child without a disability. Problem Behaviour was found to have a moderate relationship with QoL, supporting the theory that caring for children with high behavioural needs results in lower QoL for caregivers. No relationship was found between the level of support required for children's activities of daily living and caregivers QoL scores. Socio-economic status and marital status were found to have no combined impact on QoL scores. However, socio-economic status on its own did show some relationship with overall QoL scores. Satisfaction with support services, and the impact this had on QoL scores, showed a weak positive relationship.

Analysis, Limitations, and Future Research

Does disability matter? Differences in mean QoL scores between Group One and Group Two indicate that caring for a child with a disability has a negative impact on QoL for caregivers. Overall QoL scores were significantly different between the two groups, supporting previous research that QoL for caregivers can be influenced by the presence of a disability in the child (Emerson, 2003; Lee et al., 2009; Mungo et al., 2007). The differences in QoL between the two groups may be due to a number of variables that take effect when caring for a child with a disability. Some of these variables are addressed in this study, however numerous other variables impact and influence individuals QoL. Not all of these could be addressed or explored in the current research. Caring for a child with a disability can be fraught with numerous challenges that are foreign to non-disabled children and their families. The results show the differences in QoL between the two groups, yet no concrete evidence is available to indicate what is it about caring for a disabled child that impacts on QoL. Caregivers talk about the continuous burden of providing additional support to family members with a disability. The numerous emotions caregivers pass through following a diagnosis may have an everlasting impact on QoL. As the loss of original hopes and dreams they may have had for their child are replaced. New hopes and dreams are restricted and dictated by societal expectations and political decision making. All of this in conjunction with the normal day-today reality of caring for their child clearly takes a toll on individuals QoL.

Limitations. Those in Group One were unable to be compared within the group, due to uneven groups of disability type. The majority of respondents indicated ASD as the primary disability for their children. Therefore detailed analysis regarding the different disability types, and the impact they have on QoL for caregivers was unable to be conducted. This limitation indicates caution should be taken when generalising these results to the population of intellectually disabled children. This caution is especially important due to previous research showing QoL to be lower for those caring for a child with ASD when compared to other childhood disabilities (Lewis et al., 2006; Mungo et al., 2007; Olsson & Hwang, 2001). These differences may be due to the higher level of behavioural support that is often required when a child has a diagnosis of ASD.

The difference in participant numbers between Group One and Group Two may also have had an influence on the different results. Time and financial restraints in the current study impeded the ability to source equal participant numbers. It is unknown whether equal numbers were affected by lack of clarity in the Information Sheet given to participants, or due to lack of social support for those caring for a child with a disability. Those who responded in Group One may have felt they did not know someone who met the criteria for Group Two. If this is the case, then it highlights the lack of social support those caring for a child with a disability face. It may be that they tend to isolate themselves completely, or that their main interactions are with other families of children with a disability.

Future research. Future research into the differences in QoL for those caring for a child with a disability compared to those caring for a child without a disability is imperative. Future research would benefit from ensuring equal participant numbers in each group. It would also be beneficial to have equal numbers of disability type to investigate if previous international research in this area is applicable to New Zealand. Research of this type may identify at risk groups within New Zealand, which in turn may lead to better service provision to ensure the health, safety and wellbeing of those who identify as members of the group. Research where there are equal participant numbers will also enable greater generalisation to the population as a whole.

The social supports caregivers of children with a disability link into, and why those relationships occur is worth further investigation. Comments from participants indicate a lack of understanding and tolerance from the general population in terms of acceptance of the child with a disability. Research in this area could help identify the major areas of concern. It may also indicate if there is a difference within certain regions in New Zealand to allow for research in those areas. Regions where support is high could help develop and maintain supports in regions that report low levels of social support.

Relationship between behaviour and quality of life. The results indicated a relationship between behaviour and QoL. Positive behaviours had a moderate relationship with increased QoL, while problem behaviours showed a moderate relationship with reduced QoL scores. Group One scores for the Positive Behaviours section of the NCBRF were very low. Group One had high scores within the Problem Behaviour section. The negative relationship between QoL and NCBRF responses were strongest for the Conduct Problem, Insecure/Anxious, Hyperactive, and Self-Isolated/Ritualistic. The relationship between each of these and QoL was significant, and indicates that difficulties in these areas impact on caregivers QoL. These results replicate those found in previous studies that found a relationship between children's behaviours and caregivers QoL (Lecavalier et al., 2006; Maes et al., 2003; McIntyre et al., 2002; Richman et al., 2006).

The nature and direction of the relationship between behaviour and QoL is unable to be determined in the current study. Possible inferences can be drawn that negative behaviour takes more time, energy and strength to combat and attempt to correct. Negative behaviour that is consistent provides little time for caregivers to recuperate and becomes accumulative in terms of decreasing caregivers QoL. Negative behaviour also acts as a barrier to families maintaining natural respite in the form of schooling. Schools have a history of refusing to accept children with high behavioural needs, or of sending them home during the day when the behaviour occurs. This puts extra pressure on caregivers and prevents them from having time to complete other general activities. It also reduces caregivers abilities to seek and maintain paid employment, as flexibility is required to ensure they are able to attend to their child at various times during the work day.

The alternative suggestion is that behaviour is a product of low QoL. This suggestion poses the theory that low QoL is often accompanied by depression or stress which prevents caregivers from implementing and maintaining successful behaviour interventions. A lack of behavioural interventions causes negative behaviour to increase, which in turn further decreases caregivers QoL. This spiral downwards continues indefinitely, until intervention is sought. Either way children's behaviour clearly has a relationship to caregivers QoL and further research to clarify and determine the nature of that relationship may be of invaluable assistance to families.

Limitations. When considering these results caution should be applied before assuming they can be generalised to all children with an intellectual disability. The majority of participants were caring for a child with ASD. By nature, those with ASD tend to have high behavioural needs, and the assumption that all children with a disability have high behavioural needs is incorrect. Additionally respondents may have differing views and assumptions on what constitutes severe behaviours. Often when talking to families of children with high behavioural needs they under report the severity of the behaviour because it has become a normal part of life for them. This may mean that the behaviour reported in the current questionnaire is actually being reported at a lower rate of severity and frequency than is actually occurring.

The current research did not investigate what behaviour support had been, or was being provided to the families. Information of this type would have been beneficial when making inferences about the possible relationship between behaviour and QoL. This may also indicate if positive behaviour support interventions have resulted in increased QoL for caregivers.

Future research. Future research in this area may focus on specific behaviours between disabilities, and the impact these have on QoL for caregivers. Additional information regarding the types of behaviour interventions and the success of these in increasing QoL would also be beneficial. This type of information would help guide which supports provide the greatest benefit to families, and may help guide policy decisions regarding funded behaviour support. Negative behaviour appears to be the factor that has the greatest influence on acceptance into mainstream society. Future research into how best to address this issue may make accessing the community easier for those caring for a child with a disability.

Relationship between activities of daily living and quality of life. QoL was not found to be affected or influenced by the number of activities of daily living tasks requiring caregiver assistance. Mean QoL scores between low, medium and high support groups showed no statistical differences. There were no concerns with homogeneity between the groups, although responses were higher for those indicating medium support needs for their children. Previous research has shown high support needs of a child do have an impact on caregivers stress and depression scores (Epstein et al., 2008, Sales, 2003). The current study did not measure stress or depression in caregivers and can therefore not be compared to the results of previous studies. It is reasonable to assume that depression and stress have a relationship with a person's overall QoL, but this is not the focus of the current study and cannot be accepted as fact.

The method of reducing the raw activities of daily living scores into three categories; Low, Medium and High, may have impacted on the results. Individual areas of support may have a higher impact on QoL than overall support needs. In particular those needs that require more time to complete, or that result in socially inappropriate responses, may have a greater impact on QoL than other support needs. This theory ties in with the impact behaviour was found to have on QoL. Activities of daily living tasks that are difficult, and result in negative behaviours, may very well have an impact on caregivers QoL. Therefore it may not be the task itself which reduces QoL, but the behavioural response the task ignites in the child may have a large impact on QoL.

Limitations. Levels of assistance required with activities of daily living was not captured in the current research. Children requiring high levels of assistance, rather than oversight, to complete activities of daily living may have had an impact on caregivers QoL. Participants did not have the ability to record what types of difficulties occurred when completing activities of daily living. Participants also did not have the option of adding additional tasks of daily living that were impacted upon by caring for a child with a disability. These types of tasks could include, but are not limited to, increased difficulties with household cleaning, completing shopping, and household safety. Including these additional factors may have changed the results and shown a relationship between activities of daily living and caregivers QoL. The relationship between QoL and activities of daily living was not looked at in regard to the child's age.

Older children requiring high levels of support may have more of an influence on caregivers QoL than younger children requiring high levels of support. These possible differences may be due to an accumulative effect on QoL, or due to age related developmental expectations in place prior to the child's diagnosis.

Future research. Studies conducting in the future may wish to address some, or all, of the limitations in the current study. Addressing these limitations may provide valuable knowledge in identifying which activities of daily living, if any, have the biggest influence on QoL. This information would be invaluable in terms of assessing the needs of families caring for a child with a disability, and identifying supports that may be of assistance. This may also highlight any relationship the child's age may have to caregivers QoL.

Relationship between socio-economic and marital status and quality of life. Socio-economic status and marital status combined was not found to have a relationship with caregivers QoL. The majority of caregivers of a child with a disability were found to earn in excess of $40, 000. This is contrary to previous research that has shown caregivers of a child with a disability to be economically disadvantaged (Emerson, 2003). Caution should be given when considering this result as there are often additional costs to raising a child with a disability, compared to those raising a child without a disability. These costs can include, but are not limited to, non-funded disability supports, travel to medical appointments, loss of income and earning opportunities and educational support. Marital status had a higher influence on socio-economic status than on QoL scores, with non-partnered participants reporting lower overall socio-economic status. This may be due to single parents having to rely on government financial assistance, whereas those in a relationship may have the benefit of one person being in paid employment.

The lack of evidence to suggest that socio-economic status and marital status impacts on QoL may be due to a number of reasons. It may be that those who have a higher income and are partnered are more likely to participate in research. As disability support groups were the primary method of advertising the research there may be a relationship between those who choose to access support groups and marital or socio-economic status. In addition marital status may not impact on QoL for caregivers due to the primary day-to-day caregiver role traditionally resting with the child's mother.

Limitations. The current research did not allow for more in depth analysis of the relationship between socio-economic and marital status and QoL. Future research into what drives respondents to participate, or access support groups, may provide information on what encourages participation in research questionnaires. Participants did not have the ability to indicate if their current financial resources were lower due to caring for a child with a disability or what was their main source of income. Numerous participants in the current study indicated a wish to undertake paid employment, but faced difficulties sourcing an understanding employer who appreciated the need for flexible hours. Research in this area may help benefit caregivers wishing to seek employment.

In regards to marital status, information regarding the participants acceptance and satisfaction with their relationship was not captured. Sole parent participants also were not able to indicate if this status was at all related to raising a child with a disability. The nature of who in a relationship provided the majority of care for the child was not captured in the current research and may have had implications on the results.

Future research. In-depth investigation into the impact caring for a child with a disability has on caregivers socio-economic status and marital status is important. This type of research would help to identify areas of concern for caregivers, and to ensure that caregivers socio-economic needs are being met. Future research may also be beneficial in identifying what additional costs arise when caring for a child with a disability, and how these additional costs are funded. Research into the impact of raising a child with a disability in New Zealand, and the impact that has on forming long-lasting partnerships would allow for identification into any difficulties, and how these may be addressed.

Relationship between perceived satisfaction with support services and quality of life. Satisfaction with support services was found to have a weak positive relationship with caregivers overall QoL, providing support to the original research question. This result supports previous research that has found those who report higher levels of social support, also report higher levels of QoL (Helgeson, 2003; Schilling & Schinke, 1984; Tehee et al., 2009). In general terms higher satisfaction was reported with disability support groups when compared to government funded supports such as NASC and Environmental Support Services.

The differences in satisfaction levels between support groups may be due to the individual function of each service. Government funded disability supports often have strict eligibility criteria that excludes certain disabilities from accessing supports. The high number of participants caring for a child with ASD is an example of this criteria.

A diagnosis of ASD on its own does not ensure eligibility to disability support services in New Zealand. ASD must be accompanied with an intellectual disability, as diagnosed by a suitable professional, to ensure access to disability support services. This limits a large number of families in New Zealand from accessing any type of funded support services. Participants indicated the need to fight for funded support services, and that even after fighting support services did not always address the needs of the child or the family.

Differences in support agencies, and a lack of cohesiveness between these agencies was listed as a concern by some participants. This issue is already well known to the New Zealand Government, and as such new changes are currently being implemented. These changes will see the arrival of Whanau Ora and Local Area Coordinators. Whanau Ora is focused on supporting the family as a whole and ensuring they are linked into the most appropriate support agencies within their region. Local Area Coordinators provide a similar service but are focused more on the individual with a disability, rather than the family as a whole. Families and individuals will have the ability to choose between which of the two options they wish to access.

Limitations. The current research did not delve into which individual support services had the most impact on QoL, and it may be that certain supports provide a higher mitigation factor to QoL scores. Additional limitations to the current study included the lack of second level analysis regarding the level of supports provided by each support group to the individual respondent.

This information may have impacted on the relationship between QoL and support services with those receiving a high level of support, reporting higher satisfaction levels, and therefore having a higher QoL score. A further limitation was the necessary removal of respondents who reported low levels of satisfaction due to being unable to access services.

Future research. Future research in this area may benefit from addressing the limitations described above. In particular future research may also look at whether differences are apparent between regional areas in New Zealand due to some discrepancies in service provision throughout the country. It is also important to be able to identify which supports have the highest positive influence on QoL, and why these supports work for the families. On the other side of this, is identifying which supports do not work and why they do not work for families. This information would enable policy makers to determine where to invest money in ensuring the needs of families and individuals with a disability are met. Investigating what causes dissatisfaction with support services is also important. Participants qualitative responses indicated dissatisfaction was due to limited support services, and the repetition required when interacting with numerous agencies. This type of information could be quantified to enable a clearer picture in regards to what families want and need to best address their QoL. With the emergence of Whanau Ora and Local Area Coordinators research into the success of these ventures in addressing caregivers concerns is paramount.

Conclusion

The current research has provided some support to previous research that shows QoL is impacted on when caring for a child with a disability. This impact is further heightened when the child displays problem behaviours, or caregivers perceive low levels of satisfaction with supports. It did not support the theory that support with activities of daily living, or socio-economic status, or marital status impacted on QoL.

Further research is required to address the limitations of the study. In particular further research that has equal numbers of participants in Group One and Group Two would be beneficial. Investigating the differences in QoL between the two groups may provide invaluable information that could lead to addressing areas of concern for those caring for a child with a disability. Research into the cause of the differences in QoL between groups would provide the government with the tools to clearly identify which areas of social policy need to be addressed. Future research could also utilise other methods of measurement, to ensure the validity and reliability of the current research methods. The current research, and previous research clearly indicates that QoL for caregivers is dependent on the needs of those they are supporting. Further New Zealand based research is required to ensure that QoL discrepancies are clarified and addressed. Improving QoL for caregivers can only have a positive flow on affect to the care they are able to provide to their children, and the input they are able to provide to society as a whole.

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APPENDIX A

Objectives of the New Zealand Disability Strategy (Ministry of Health, 2001, p.2)

1. encourage and educate for a non-disabling society
2. ensure rights for disabled people
3. provide the best education for disabled people
4. provide opportunities in employment and economic development for disabled people
5. foster leadership by disabled people
6. foster an aware and responsive public service
7. create long-term support systems centred on the individual
8. support quality living in the community for disabled people
9. support lifestyle choices, recreation and culture for disabled people
10. collect and use relevant information about disabled people and disability issues
11. promote participation of disabled Māori
12. promote participation of disabled Pacific peoples
13. enable disabled children and youth to lead full and active lives
14. promote participation of disabled women in order to improve their quality of life
15. value families, whānau and people providing ongoing support.

APPENDIX B

Actions points relating to Objective 13 and 15 of the New Zealand Disability Strategy (Ministry of Health, 2001, p 27 & 29).

Actions for objective 13:

13.1 Ensure all agencies that support children, youth and families work collaboratively to ensure that their services are accessible, appropriate and welcoming to disabled children, youth and their families.

13.2 Ensure that the Youth Development Strategy recognises the needs of disabled children and youth.

13.3 Conduct anti-discrimination and education campaigns that are age appropriate and effective.

13.4 Establish a process for including advice from disabled people on disability issues for children and youth within relevant government agencies and Commissioners' offices.

13.5 Provide access for disabled children, youth and their families to child, youth and family-focused support, education, health care services, rehabilitation services, recreation opportunities and training.

13.6 Improve support for disabled children and youth during transition between early childhood education, primary school, secondary school, tertiary education and employment.

13.7 Introduce ways of involving disabled children and youth in decision-making and giving them greater control over their lives.

13.8 Develop a range of accommodation options so that disabled young people can live independently.

13.9 Provide and evaluate educational initiatives about sexuality, safety and relationships for disabled children and youth.

13.10 Ensure Ministry of Youth Affairs and Ministry of Social Policy undertake a leadership role in promoting the participation of disabled children and youth.

Actions from objective 15:

15.1 Ensure needs assessment processes are holistic and take account of the needs of families/whānau as well as the disabled person.

15.2 Improve the support and choices for those who support disabled people.

15.3 Provide education and information for families with disabled family members.

15.4 Ensure that, where appropriate, the family, whānau and those who support disabled people are given an opportunity to have input into decisions affecting their disabled family members.

15.5 Develop a resource kit for professional on when and how to interact with families/whānau of disabled people.

15.6 Work actively to ensure that families, whānau and those who support disabled people can be involved in policy and service development and delivery, and in monitoring and evaluation processes were appropriate.

15.7 Encourage debate around responsibility for caring, payment for caring and how to further recognise and value the caring role.

15.8 Provide families and those who support disabled people with information that is accurate, accessible and easily found.

APPENDIX C

Consent Form

Quality of Life for Caregivers of a child aged 6-16 years with Autistic Spectrum Disorder and/or an Intellectual Disability: A comparative study

I have read the Information Sheet provided and agree to participate in the study under the conditions set out in the Information Sheet. I understand that completion of the questionnaire implies my consent to participate in this study.

The code name I have agreed upon with the person I am completing this study in conjunction with (my 'pair') is: ________________

I am in Group: One (child with a disability) ____________
Two (child without a disability) ____________

Questionnaire

Quality of Life for Caregivers of a child aged 6-16 years with Autistic Spectrum Disorder and/or an Intellectual Disability: A comparative study

Your Age: ______________

Age of Child: ______________

Your Gender: Male ☐
Female ☐

Child's Gender: Male ☐
Female ☐

Your Ethnicity: _____________________

Child's Ethnicity: _____________________

Region You Reside In: _____________________

Socio Economic Level of Family Unit:	Under $20,000	☐
	$20,000 - $30,000	☐
	$30,000 - $40,000	☐
	$40,000 - $50,000	☐
	Over $50,000	☐
Marital Status:	Single	☐
	Defacto	☐
	Married	☐
	Divorced	☐
	Widowed	☐

Child's Disability:_________________________________

Age of any other children in household:_______________________________

Do they have a disability:	Yes	☐
	No	☐
Do you have any medical conditions:	Yes	☐
	No	☐

If yes, what are they:

____

____

____

Have you ever been diagnosed with depression or any other mental health condition:	Yes	☐
	No	☐
If yes, is this diagnosis current:	Yes	☐
	No	☐

Activities of daily living that the child with a disability needs assistance with:

☐ Getting in and out of bed

☐ Showering

☐ Dressing/undressing

☐ Grooming – including dental and nail care

☐ Toileting

☐ Continence

☐ Menstruation

☐ Medication

☐ Eating

☐ Drinking

☐ Health Management

What support services do you currently access for this child:

☐ Local NASC

☐ Disability Support Group (e.g. Parent to Parent)

☐ Enable New Zealand (Equipment)

☐ Regional Children's Health Unit (e.g. Paediatrician)

☐ Other

If Other, please list:

____

____

____

____

____

____

How satisfied are you with the support services you receive from:

Local NASC

Very Dissatisfied ☐
Moderately Dissatisfied ☐
Satisfied ☐
Moderately Satisfied ☐
Very Satisfied ☐

Disability Support Group

(e.g. Parent to Parent)

Very Dissatisfied ☐
Moderately Dissatisfied ☐
Satisfied ☐
Moderately Satisfied ☐
Very Satisfied ☐

Enable New Zealand

(Equipment)

Very Dissatisfied ☐
Moderately Dissatisfied ☐
Satisfied ☐
Moderately Satisfied ☐
Very Satisfied ☐

Regional Children’s Health Unit

(e.g. Paediatrician)

Very Dissatisfied ☐
Moderately Dissatisfied ☐
Satisfied ☐
Moderately Satisfied ☐
Very Satisfied ☐

Other	Very Dissatisfied ☐
	Moderately Dissatisfied ☐
	Satisfied ☐
	Moderately Satisfied ☐
	Very Satisfied ☐

Please comment on two or three things which you believe would further enhance your quality of life:

____

____

____

____

____

____

____

____

____

____

Quality of Life Index

Part 1: For each of the following, please choose the answer that best describes how ***satisfied*** you are with that area of your life. Please mark your answer by ticking the relevant box. There are no right or wrong answers.

How satisfied are you with:	**Very Dissatisfied**	**Moderately Dissatisfied**	**Slightly Dissatisfied**	**Slightly Satisfied**	**Moderately Satisfied**	**Very Satisfied**
Your health?	☐	☐	☐	☐	☐	☐
Your health care?	☐	☐	☐	☐	☐	☐
The amount of pain you have?	☐	☐	☐	☐	☐	☐
The amount of energy you have?	☐	☐	☐	☐	☐	☐
Your ability to take care of yourself without help?	☐	☐	☐	☐	☐	☐
The amount of control you have over your life?	☐	☐	☐	☐	☐	☐
Your chances of living as long as you would like?	☐	☐	☐	☐	☐	☐
Your family's health?	☐	☐	☐	☐	☐	☐
Your children?	☐	☐	☐	☐	☐	☐
Your family's happiness?	☐	☐	☐	☐	☐	☐
Your sex life?	☐	☐	☐	☐	☐	☐
Your spouse, lover or partner?	☐	☐	☐	☐	☐	☐
Your friends?	☐	☐	☐	☐	☐	☐
The emotional support you get from your family?	☐	☐	☐	☐	☐	☐
The emotional support you get from people other than your family?	☐	☐	☐	☐	☐	☐
Your ability to take care of family responsibilities?	☐	☐	☐	☐	☐	☐

How satisfied are you with:	**Very Dissatisfied**	**Moderately Dissatisfied**	**Slightly Dissatisfied**	**Slightly Satisfied**	**Moderately Satisfied**	**Very Satisfied**
How useful you are to others?	☐	☐	☐	☐	☐	☐
The amount of worries in your life?	☐	☐	☐	☐	☐	☐
Your neighbourhood?	☐	☐	☐	☐	☐	☐
Your home, flat, or place where you live?	☐	☐	☐	☐	☐	☐
Your job (if employed)?	☐	☐	☐	☐	☐	☐
Not having a job (if unemployed, retired, or disabled)?	☐	☐	☐	☐	☐	☐
Your education?	☐	☐	☐	☐	☐	☐
How well you can take care of your financial needs?	☐	☐	☐	☐	☐	☐
The things you do for fun?	☐	☐	☐	☐	☐	☐
Your chances for a happy future?	☐	☐	☐	☐	☐	☐
Your peace of mind?	☐	☐	☐	☐	☐	☐
Your spiritual/cultural wellbeing?	☐	☐	☐	☐	☐	☐
Your achievement of personal goals?	☐	☐	☐	☐	☐	☐
Your happiness in general?	☐	☐	☐	☐	☐	☐
Your life in general?	☐	☐	☐	☐	☐	☐
Your personal appearance?	☐	☐	☐	☐	☐	☐
Yourself in general?	☐	☐	☐	☐	☐	☐
Your ability to care for your child?	☐	☐	☐	☐	☐	☐

Part Two: For each of the following, please choose the answer that best describes how ***important*** that area of your life is to you. Please choose your answer by ticking the relevant box. There are no right or wrong answers.

How important to you is:	**Very Unimportant**	**Moderately Unimportant**	**Slightly Unimportant**	**Slightly Important**	**Moderately Important**	**Very Important**
Your health?	☐	☐	☐	☐	☐	☐
Your health care?	☐	☐	☐	☐	☐	☐
Having no pain?	☐	☐	☐	☐	☐	☐
Having enough energy for everyday activities?	☐	☐	☐	☐	☐	☐
Taking care of yourself without help?	☐	☐	☐	☐	☐	☐
Having control over your life?	☐	☐	☐	☐	☐	☐
Living as long as you would like?	☐	☐	☐	☐	☐	☐
Your family's health?	☐	☐	☐	☐	☐	☐
Your children?	☐	☐	☐	☐	☐	☐
Your family's happiness?	☐	☐	☐	☐	☐	☐
Your sex life?	☐	☐	☐	☐	☐	☐
Your spouse, lover or partner?	☐	☐	☐	☐	☐	☐
Your friends?	☐	☐	☐	☐	☐	☐
The emotional support you get from your family?	☐	☐	☐	☐	☐	☐
The emotional support you get from people other than your family?	☐	☐	☐	☐	☐	☐
Taking care of family responsibilities?	☐	☐	☐	☐	☐	☐
Being useful to others?	☐	☐	☐	☐	☐	☐
Having no worries?	☐	☐	☐	☐	☐	☐

How important to you is:	**Very Unimportant**	**Moderately Unimportant**	**Slightly Unimportant**	**Slightly Important**	**Moderately Important**	**Very Important**
Your neighbourhood?	☐	☐	☐	☐	☐	☐
Your home, flat, or place where you live?	☐	☐	☐	☐	☐	☐
Your job (if employed)?	☐	☐	☐	☐	☐	☐
Having a job (if unemployed, retired, or disabled)?	☐	☐	☐	☐	☐	☐
Your education?	☐	☐	☐	☐	☐	☐
Being able to take care of your financial needs?	☐	☐	☐	☐	☐	☐
Doing things for fun?	☐	☐	☐	☐	☐	☐
Having a happy future?	☐	☐	☐	☐	☐	☐
Peace of mind?	☐	☐	☐	☐	☐	☐
Your spiritual/cultural wellbeing?	☐	☐	☐	☐	☐	☐
Achieving your personal goals?	☐	☐	☐	☐	☐	☐
Your happiness in general?	☐	☐	☐	☐	☐	☐
Being satisfied with life?	☐	☐	☐	☐	☐	☐
Your personal appearance?	☐	☐	☐	☐	☐	☐
Are you to yourself?	☐	☐	☐	☐	☐	☐
Taking care of your child?	☐	☐	☐	☐	☐	☐

Nisonger Child Behaviour Rating Form

Please describe any special circumstances or mediating factors that may have affected the child's behaviour in the recent past (the last month or two) or prevented you from making complete ratings:

Please describe the child's behaviour as it was at home over the last month by choosing one option from each of the following, there are no right or wrong answers:

In the last month, this child has:	Not True	Somewhat or Sometimes True	Very True or Often True	Completely or Always True
Accepted redirection	☐	☐	☐	☐
Expressed ideas clearly	☐	☐	☐	☐
Followed rules	☐	☐	☐	☐
Initiated positive interactions	☐	☐	☐	☐
Participated in group activities	☐	☐	☐	☐
Resisted provocation, was tolerant	☐	☐	☐	☐
Shared with or helped others	☐	☐	☐	☐
Stayed on task	☐	☐	☐	☐
Was cheerful or happy	☐	☐	☐	☐
Was patient, able to delay	☐	☐	☐	☐

For each problem that occurred, please choose the correct response box by ticking it. Please do not skip any questions. If you do not know the answer or have not had a chance to observe the child for a given time, tick the 'behaviour did not occur or was not a problem' option.

Behaviour	**Did not occur or was not a problem**	**Occurred occasionally or was a mild problem**	**Occurred quite often or was a moderate problem**	**Occurred a lot or was a severe problem**
Apathetic or unmotivated	☐	☐	☐	☐
Argues with parents, teachers, or other adults	☐	☐	☐	☐
Clings to adults, too dependent	☐	☐	☐	☐
Cruelty or meanness to others	☐	☐	☐	☐
Crying, tearful episodes	☐	☐	☐	☐
Hits or slaps own head, neck, hands or other body parts	☐	☐	☐	☐
Defiant, challenges adult authority	☐	☐	☐	☐
Knowingly destroys property	☐	☐	☐	☐
Difficulty concentrating	☐	☐	☐	☐
Disobedient	☐	☐	☐	☐
Rocks body or head back and forth repetitively	☐	☐	☐	☐
Doesn't feel guilt after misbehaving	☐	☐	☐	☐
Easily distracted	☐	☐	☐	☐
Easily frustrated	☐	☐	☐	☐
Overly sensitive; feelings easily hurt	☐	☐	☐	☐
Exaggerates abilities or achievements	☐	☐	☐	☐
Explosive, easily angered	☐	☐	☐	☐
Has rituals such as head rolling or floor pacing	☐	☐	☐	☐
Fails to finish things he/she starts	☐	☐	☐	☐
Feelings easily hurt	☐	☐	☐	☐
Feels others are against him/her	☐	☐	☐	☐

Behaviour	**<u>Did not</u> occur or <u>was not a problem</u>**	**Occurred <u>occasionally</u> or was a <u>mild problem</u>**	**Occurred <u>quite often</u> or was a <u>moderate problem</u>**	**Occurred <u>a lot</u> or was a <u>severe problem</u>**
Harms self by scratching skin or pulling hair	☐	☐	☐	☐
Feels worthless or inferior	☐	☐	☐	☐
Fidgets, wiggles, or squirms	☐	☐	☐	☐
Shy around others; bashful	☐	☐	☐	☐
Gets in physical fights	☐	☐	☐	☐
Irritable	☐	☐	☐	☐
Repeatedly flaps or waves hands, fingers, or objects (such as pieces of string)	☐	☐	☐	☐
Isolates self from others	☐	☐	☐	☐
Lying or cheating	☐	☐	☐	☐
Nervous or tense	☐	☐	☐	☐
Gouges self, puts things in ears, nose, etc., or eats inedible things	☐	☐	☐	☐
Overactive, doesn't sit still	☐	☐	☐	☐
Overly anxious to please others	☐	☐	☐	☐
Overly excited, exuberant	☐	☐	☐	☐
Physically attacks people	☐	☐	☐	☐
Refuses to talk	☐	☐	☐	☐
Repeats the same sound, word or phrase over and over	☐	☐	☐	☐
Restless, high energy level	☐	☐	☐	☐
Runs away from adults, teachers or other authority figures	☐	☐	☐	☐
Says no one likes him/her	☐	☐	☐	☐
Secretive, keeps things to self	☐	☐	☐	☐
Repeatedly bites self hard enough to leave tooth marks or break skin	☐	☐	☐	☐
Self-conscious or easily embarrassed	☐	☐	☐	☐
Shifts rapidly from topic to topic when talking	☐	☐	☐	☐
Short attention span	☐	☐	☐	☐

Behaviour	**<u>Did not</u> occur or <u>was not a problem</u>**	**Occurred <u>occasionally</u> or was a <u>mild problem</u>**	**Occurred <u>quite often</u> or was a <u>moderate problem</u>**	**Occurred <u>a lot</u> or was a <u>severe problem</u>**
Shy or timid behaviour	☐	☐	☐	☐
Steals	☐	☐	☐	☐
Odd repetitive behaviours (e.g. stares, grimaces, rigid postures)	☐	☐	☐	☐
Stubborn, has to do things own way	☐	☐	☐	☐
Sudden changes in mood	☐	☐	☐	☐
Sulks, is silent and moody	☐	☐	☐	☐
Physically harms or hurts self on purpose	☐	☐	☐	☐
Talks back to teacher, parents or other adults	☐	☐	☐	☐
Talks too much or too loud	☐	☐	☐	☐
Temper tantrums	☐	☐	☐	☐
Threatens people	☐	☐	☐	☐
Threatens to harm self	☐	☐	☐	☐
Engages in meaningless, repetitive body movements	☐	☐	☐	☐
Too fearful or anxious	☐	☐	☐	☐
Underactive, slow	☐	☐	☐	☐
Unhappy or sad	☐	☐	☐	☐
Violates rules	☐	☐	☐	☐
Withdrawn, uninvolved with others	☐	☐	☐	☐
Worrying	☐	☐	☐	☐
Argues with other children or peers	☐	☐	☐	☐

Developed by M.G. Aman, M.J. Tassé, J. Rojahn, and D. Hammer, 1995.

Thank you for taking the time to complete this questionnaire. Your assistance is appreciated.

APPENDIX D

Letter to Disability Support Groups

To whom it may concern:

My name is Natasha Browne and I am currently completing my Master's Thesis in Psychology. My thesis project is aimed at identifying the difference in quality of life for caregivers of children with Autistic Spectrum Disorder and/or an Intellectual Disability when compared to caregivers of children without these conditions. This study hopes to highlight not only areas that need addressing, but also to highlight the positive aspects of the caregiving role. My supervisor on this project is Ian Evans, Professor, Massey University.

I am writing to your organisation as I would greatly appreciate your assistance in posting a small message, in either your newsletter and/or on your webpage, informing people of the study. The message would provide a webpage and cellphone number for people to contact who would like to take part in the study. The study will be done via a questionnaire, which would take no more than 15 minutes to complete. Participation is completely voluntary.

I have included in this letter a copy of the information sheet for participants for you to consider. This information sheet will give you an outline of the questionnaire and information on how it is to be distributed to participants.

Please contact me if you are able to assist with this and I will work with you to determine the message that you may be able to include in your newsletter and/or website.

My contact details are:

Email:	natasha.browne.1@uni.massey.ac.nz
Phone/Text:	022 621 0563

Thank you for taking the time to consider this request. I look forward to hearing from you in the near future.

Many thanks,

Natasha Browne

APPENDIX E

Information Sheet

Quality of Life for Caregivers of a child aged 6-16 years with Autistic Spectrum Disorder and/or an Intellectual Disability: A comparative study

Information Sheet for Participants

Do you have a child with a disability who lives with you? If so, I would like to invite you to take part in a study investigating differences in quality of life.

My name is Natasha Browne and I am currently completing my Master's Thesis in Psychology. My supervisor on this project is Ian Evans, Professor, Massey University.

My thesis project is aimed at identifying the difference in quality of life for caregivers of children with Autistic Spectrum Disorder and/or an Intellectual Disability when compared to caregivers of children without these conditions. This study hopes to highlight not only areas that need addressing, but also to highlight the positive aspects of the caregiving role. We are not assuming that quality of life is in any way lessened by having a child with a disability to care for—in fact many families report a whole host of positive outcomes. However we are especially interested in your feelings about the kinds of supports and service you receive. Finding out more about how support services might be improved is one of the goals of this research project.

Participation in this study is entirely voluntary.

A brief outline of the study:

Quality of life is an area of research that has spanned many years and continues to remain in focus worldwide. Research using New Zealand participants however is limited, and there are no studies that mirror the current project in New Zealand. The research and data will be collected via a questionnaire, either online or paper-based depending on your preference. This questionnaire will take around 30 minutes of your time.

How do I become a participant?

You are invited to complete the enclosed questionnaire and return it using the enclosed pre paid envelope. Alternatively you are invited to access the online questionnaire via the following web link: **http://psych-research.massey.ac.nz/browne/index.htm**.

This study is made up of two different groups:

Group One – is a caregiver of a child aged between 6 – 16 years old with an intellectual disability and/or Autistic Spectrum Disorder

Group Two – is a friend of the person in Group One who is the caregiver of a child aged between 6 - 16 years old without a disability

As the study is a comparative study I would appreciate your assistance in having a friend participate in the study too. For example: if you are in Group One, are you able to find a friend who can be in Group Two, and vice versa? The reason for this is that a good friend or even an acquaintance is likely to experience some of the general sources of stress as well as enjoyment as you do yourself. Thus we will be able to see how you are affected by the one thing that is very different—having a child with a disability in your home to care for. Unfortunately only pairs can be accepted when compiling the results to ensure that the research questions can be answered.

How will the researcher know who makes up a ‘pair’?

At the start of the questionnaire you will need to decide on a code word for you and your friend to use. This could be the name of a pet, your favorite cartoon character, or any other word you would prefer to use. Both you and your friend will enter the same code word on your individual questionnaires so they can be matched up in the study.

What happens after I finish the questionnaire?

A summary of the study's findings will be made available online for you to access if you wish. The link to these results will be published in various support group websites and newsletters. If you have any questions relating to the study you can contact me on 022 621 0563 or Natasha.Browne.1@uni.massey.ac.nz .

Confidentiality

Any information received will remain in a secure location at Massey University. This information will only be able to be accessed by myself or my supervisor. Data will remain stored for up to 5 years and then be disposed of in a safe manner. The only data that will be published is statistical information gathered in the questionnaire. No names or contact details of participants will be released. Participation will remain anonymous and your name will never be included on the questionnaire.

Please be aware that whilst I am employed at the local Needs Assessment Service Coordination agency your questionnaires will remain anonymous and your service will be in no way affected by this study.

Ethical Approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 09/49. If you have any concerns about the conduct of this research, please contact Professor Julie Boddy, Chair, Massey University Human Ethics Committee: Southern A telephone 06 350 5799 x 2541, email humanethicsoutha@massey.ac.nz

Your Rights

Completion and return of the questionnaire implies consent. You have the right to decline to answer any particular question

Thank you…

I would greatly appreciate your participation in this study. Thank you for considering this request.

Yours sincerely,

Natasha Browne

Student – Massey University

Natasha.Browne.1@uni.massey.ac.nz

022 621 0563

Ian Evans

Professor, Massey University

I.M.Evans@masey.ac.nz

06 3569-099, Ext 2070

APPENDIX F

Letter to Radio Stations and Newspapers

To Whom It May Concern:

My name is Natasha Browne and I am currently completing my Master’s Thesis in Psychology. My thesis project is aimed at identifying the difference in quality of life for caregivers of children with Autistic Spectrum Disorder and/or an Intellectual Disability when compared to caregivers of children without these conditions. This study hopes to highlight not only areas that need addressing, but also to highlight the positive aspects of the caregiving role. My supervisor on this project is Ian Evans, Professor, Massey University.

I have made contact with your organization as I would greatly appreciate your assistance in promoting the research I am currently undertaking. This research is the first of its kind within New Zealand due to the inclusion of a comparison group. People within the disability industry are well aware of the difficulties facing caregivers, however the gap between quality of life for caregivers of children with a disability compared to those caring for children without a disability has never been quantified.

Currently the research is being advertised within national support groups, however participation has been slow. I believe this may be due to the small number of people who access support groups on a regular, continuous basis.

I would greatly appreciate any assistance you can offer in terms of promoting this research. This may be in the way of a radio interview/newspaper article to ensure people have the opportunity to learn of the research, and participate if they wish.

If you are able to assist me in this matter, my contact details are:

Email: natasha.browne.1@uni.massey.ac.nz

Phone/Text: 022 621 0563

Thank you for taking the time to consider this request.

Many thanks,

Natasha Browne

Student
School of Psychology
Massey University

Please note: This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 09/49. If you have any concerns about the conduct of this research, please contact Professor Julie Boddy, Chair, Massey University Human Ethics Committee: Southern A telephone 06 350 5799 x 2541, email humanethicsoutha@massey.ac.nz

APPENDIX G

Letter to Schools

To whom it may concern,

My name is Natasha Browne and I am currently completing my Master's Thesis in Psychology. My thesis project is aimed at identifying the difference in quality of life for caregivers of children with Autistic Spectrum Disorder and/or an Intellectual Disability when compared to caregivers of children without these conditions. This study hopes to highlight not only areas that need addressing, but also to highlight the positive aspects of the caregiving role. My supervisor on this project is Ian Evans, Professor, Massey University.

I have contacted your school as I would greatly appreciate your assistance in regards to informing people of the study. I propose to send to the school a number of questionnaire packs which would include all the information potential participants would require. The packs will contain an information sheet, a copy of the questionnaire, and a reply paid envelope for those who choose to participate. As this is a comparative study, a second set of the information sheet, questionnaire and reply paid envelope will be included for the participant to pass on to the person they would like to act as their 'pair' in the study. These packs could be distributed to children with ASD and/or an intellectual disability, between the ages of 6 – 16 years, for them to take home to their caregivers. Participation is completely voluntary and potential participants are under no obligation to complete the questionnaires.

I have included with this email an attachment with the information sheet and questionnaire for the schools information.

If your school is able to assist me in informing potential participants about this research please do not hesitate to contact me so information can be sent out. It would be appreciated if questionnaires could be sent out before the end of the current term. However, due to limited time frames I understand this may not be possible and therefore early in the next term would be appreciated.

My contact details are:

Email: natasha.browne.1@uni.massey.ac.nz

Phone/Text: 022 621 0563

Thank you for taking the time to assist me in this matter.

Many thanks,

Natasha Browne

Student
School of Psychology
Massey University

Please note: This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 09/49. If you have any concerns about the conduct of this research, please contact Professor Julie Boddy, Chair, Massey University Human Ethics Committee: Southern A telephone 06 350 5799 x 2541, email humanethicsoutha@massey.ac.nz