# THE EFFECTS OF THE CHRISTCHURCH EARTHQUAKES OF 2010 AND 2011 ON THE QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS WITH DISABILITIES

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# List of Abbreviations

| | |
|---|---|
| ADD/ADHD | Attention deficit disorder/ Attention deficit hyperactivity disorder |
| ASD | Autism Spectrum Disorder |
| CBD | Central Business District |
| CCC | Christchurch City Council |
| CDHB | Canterbury District Health Board |
| CERA | Canterbury Earthquake Recovery Authority |
| CHP | Centre for Health Promotion, University of Toronto |
| CP | Cerebral Palsy |
| EQ(s) | Earthquake(s) |
| EQC | Earthquake Commission |
| IEP | Individual education plan |
| MCDEM | Ministry of Civil Defence and Emergency Management |
| MOE | Ministry of Education (New Zealand) |
| MOH | Ministry of Health |
| NLD | Non-verbal learning disorder |
| NZ | New Zealand |
| NZCCP | New Zealand College of Clinical Psychologists |
| ORS | Ongoing Resourcing Scheme |
| PedsQL | Paediatric Quality of Life instrument |
| PTSD | Post-traumatic stress disorder |
| QOL | Quality of life |
| QOL-PDD-SV | The Quality of Life Instrument for People with Developmental Disabilities – Short Version |
| RTLB | Resource Teachers: Learning and Behaviour |
| SES | Socioeconomic Status |
| SPSS | Statistical Package for the Social Sciences |
| USAR | Urban Search and Rescue |
| WHO | World Health Organisation |
| WHOQOL - BREF | World Health Organisation Quality of Life instrument |

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# Abstract

This study explored the effects of the Canterbury earthquakes of 2010 and 2011 on different areas of quality of life (QOL) for children and adolescents with disabilities. Using a survey developed from the *Quality of Life Instrument for People with Developmental Disabilities – Short Version* (QOL-PDD-SV) (Brown, Raphael & Renwick, 1997) and *The World Health Organisation Quality of Life - (WHOQOL)-BREF*, parents or caregivers were asked to identify what level of importance and satisfaction their child or adolescent placed on areas of QOL including physical health, psychological health - stress levels and coping ability, attachment to their neighbourhood, friends, family, leisure activities, community access and schooling. They were also asked to determine what level of impact the earthquakes had had on each area of their child or adolescent's life and overall quality of life in the aftermath of the earthquakes. A total of 31 parents of 22 males and 9 females between the ages of 2.5 years to 19 years of age (mean age: 12.6 years) responded. The results were collated and analysis was run to measure for the effect of age, gender and geographical location. The results found that the earthquakes affected nearly every area of QOL for the children and adolescents. The biggest impact on the children's psychological health and their ability to cope It was observed that younger children (<13) were more likely to record improved or lessened effects from the earthquakes in psychological health areas. However, the areas of social belonging and friendships were the least affected by the earthquakes. Female children were more likely to indicate higher scores for social belonging after the earthquakes. Many parents observed that their children developed improved coping skills over the earthquake period. The findings in this study offer a better understanding of how earthquakes can affect the quality of life children and adolescents with disabilities.

# Chapter 1 Introduction

Natural disasters occur as a result of naturally occurring physical events or hazards including earthquakes, floods, landslides, wildfires or tsunamis that negatively impact on a population within the event's path or location (Shaw, Espinel & Schultz, 2012). Exposure to these adverse events may cause significant stress in people's lives. The purpose of the present study was to explore the impact of a natural disaster, the Christchurch Earthquakes (EQs) of 2010 and 2011, on the quality of life (QOL) of children and adolescents with a disability. The study examined concepts of disability, QOL, and the characteristics of the Christchurch earthquake, and then explored the results of a specially designed survey. In this chapter, the first section will discuss the study of disability in New Zealand and then look at services provided for children with disabilities in NZ. The next section will look at the concept of QOL and how it can be used to evaluate outcomes for children and adolescents with disabilities before examining natural disasters and the Christchurch EQ and how QOL can be used to investigate the effects of the EQ on children and adolescents with disabilities.

Disability is a complex topic that comes with many preconceived ideas and a long legacy of controversy and debate. For a long time, different fields of research including education, social science and rehabilitation viewed the "disadvantage associated with disability as an individual problem caused by impairment" (Priestley & Hemingway, 2007, p.1). However, in more recent times there has been a realisation that an individual does not have the disability rather it is the environment that they interact with that disables them. Therefore the idea and definition of disability must be viewed in light of interactions of individuals with their environment.

The World Health Organisation (WHO) views disability as referring to the interactions between individuals with health conditions and their personal and surrounding environments. Disability is referred to as,

> an ‘umbrella’ term for impairments, activity limitations and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.   (WHO, 2014).

However, disability is often more than just a health limitation. The individual may have an impairment or health condition which can affect one’s physical, sensory, neurological, intellectual, or psychological aspects. A disability may be a consequence of the negative or restrictive interactions of the individual with an impairment with their surrounding environment. Therefore, the disability resides in the society not in the individual.

The New Zealand Disability Strategy Disability (2000) goes on from this, believing disability to be “a process …. where 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”(p.3). Therefore disability can be defined in the form of barriers or difficulties that may limit or even prevent the individual from participating in chosen everyday life activities. Therefore, when someone is said to have a physical disability, they may have difficulty in physically accessing their environment without using a mobility device such as a wheelchair. A person who is said to have a neurological disability may have to rely on public transport because the risk of seizures occurring prevent them from driving. Someone with a sensory disability from a hearing impairment may require access to a sign-language interpreter to access educational opportunities.

Barriers are also present in the attitudes and lack of understanding in workplaces for those with impairments which may limit access to employment. This could come in the form of lack of flexibility in hours to reduce tiredness or even an inability to see beyond what someone cannot do and not developing pathways for an employee with a disability to advance in their position or workplace. This in turn can limit financial outcomes creating further difficulties and barriers including access to better housing, treatments and an overall sense of wellbeing and purpose in their lives. It is therefore vital that barriers for all people with impairments are removed or significantly reduced to enable them to participate in activities which help them to fulfil their lives.

### Impairments Associated with Disabilities.

There are many types of conditions or situations that can cause or create an impairment or disability. Because of this, similar impairments or disabilities are grouped together defined by the area or type of impairment such as a physical or sensory impairment or a psychological condition. The New Zealand Disability Survey (2006) adopted five broad areas or activities of the body that may be affected by disability1; physical, sensory, psychiatric/psychological, intellectual and other (see Table 1). As shown in Table 1, each of these areas has different effects on the individual and may be a consequence of one or more impairments or conditions.

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1 In most published studies, and in the present study, when the term ‘disability’ is used, it will follow the New Zealand Disability approach, however, for ease of description, study participants may be referred to as having ‘a physical disability’, from that can be inferred they have an impairment that in their engagement with their environment restricts them physically.

Table 1
Disability Type and Impairment as defined by Statistics New Zealand 2013[2].

| Area | Impairment | Examples |
|---|---|---|
| Sensory | *Hearing*: individual with hearing impairments cannot hear or have difficulty hearing, even when using assistive hearing devices such as a hearing aid, grommets, or a cochlear implant. | Deafness or hearing loss as a result of birth condition or illness or accident. |
| | *Vision*: individual with vision impairment cannot see, or have difficulty seeing, even when wearing glasses or contact lenses | Blindnes or loss of vision as a result of birth condition or illness or accident |
| Physical | *Mobility*: individual with mobility impairment have difficulty with or cannot do one or more of the following:<br>• stand without assistive devices such as braces or crutches<br>• walk on a flat footpath<br>• move from room to room within the home<br>• bend down without support<br>*Agility*: individual with an agility impairment have difficulty with or cannot do one or more of the following:<br>• use hands to grasp an object such as a spoon or a pencil/crayon<br>• raise arms to take off a t-shirt. | Cerebral Palsy,<br>Spina Bifida<br>Paralysis as a result of an accident or illness<br>Loss of limb (s) as a result of accident or illness<br>Arthritis<br>Congenital malformations<br>Dyspraxia<br>Juvenile Arthritis |
| Psychological | In Children: having one or more of the following:<br>• occasional emotional, nervous, or behavioural problems that limit the type or amount of activity a child can do<br>• a long-term psychological or mental health condition that causes difficulty with everyday activities. | Autism Spectrum Disorder (ASD)<br>Post-traumatic stress disorder (PTSD)<br>Fetal-Alcohol Disorders<br>Depression |
| Intellectual | A recognised “intellectual disability”<br>May receive special education services | Down Syndrome<br>Williams |

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[2] http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013/Definitions.aspx

| Area | Impairment | Examples |
|---|---|---|
| | because of an intellectual impairment. May have difficulties in understanding instructions or ideas and have problems in verbal or written communication. | Syndrome<br>Global developmental delay (GDD)<br>Brain Injury as a result of injury or illness |
| Other | May have long-term conditions or health problems that cause ongoing difficulty with their ability to learn or remember, or cause difficulty with or stop them participating in everyday activities that other people their age can normally do, including difficulty speaking or being understood (where the disability is not classified as physical, sensory, intellectual or psychiatric/psychological).<br>In Children: includes difficulties with speaking and learning, as well as developmental delay.<br>*Learning impairment*: a long-term condition or health problem that makes it hard in general for someone to learn. | Attention Deficit Hyperactivity Disorders (ADHD/ADD)<br>Non-specific learning disorder (NLD)<br>Cystic Fibrosis<br>Epilepsy<br>Learning Disability |

Individuals may also live with the effects of multiple impairments or disabilities. The *New Zealand Disability Survey 2013* found that over half of all people surveyed reported multiple impairments (Statistics New Zealand, 2013). For example, someone with cerebral palsy may have mobility difficulties (physical disability) and limited or low vision (sensory disability), difficulty with speaking and learning (other disability) as well as living with the ongoing effects of a chronic health condition. A child may be diagnosed with both Down syndrome (an intellectual disability) and Autism Spectrum Disorder (ASD) (a psychological disorder).

It is also important to note that the effects of the disability for an individual with an impairment may be very different than for another person with the same impairment. This can be for a variety of reasons including personal factors, environmental factors and societal factors. For example, someone with a hearing impairment may experience difficulty in adjusting to their non-hearing situation if they have become hearing impaired later in life compared with someone who was born with a hearing impairment.

## Prevalence of disability in New Zealand

In the *Disability Survey 2013* it was estimated the nearly a quarter (24 percent) of the population live with the effects of a disability or impairment (Statistics New Zealand, 2014). This is an increase on previous statistical analysis of people with disabilities in New Zealand (NZ) and is believed to be indicative of an aging population. The estimated number of children with disabilities is considerably lower with around 11 percent (13 percent male; 8 percent female) of children living in NZ aged between 0 to 14 years old reported to have some form of disability (Statistics New Zealand, 2014). The discrepancy between the prevalence of disability in children and those in the 15 years plus category is often explained by the increased in disability or level of need as seen in an individual's later years[3].

The most common recorded disability among the 0 - 14 years age group was "other" disability including "other" impairment which comprises of difficulties with speaking and learning, as well as developmental delay. Over 52 percent of children with disabilities or 6 percent of all children in NZ had difficulties with learning listed as an impairment type (Statistics New Zealand, 2014). Intellectual, physical and sensory disabilities were experienced by just one or two percent of the overall 0 - 14 years age group population of NZ. Four percent of the children had long term chronic conditions or health problems including diabetes, asthma or cerebral palsy. Two percent of children were found to have psychiatric or psychological disabilities (Statistics New Zealand, 2014). Over half of the children had had their disability or condition since

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[3] The Disability Survey conducted by Statistics New Zealand has the age categories of 0-14 years, 15 to 64 years and 65 plus years.

birth. A similar number were recorded as having multiple impairments (Statistics New Zealand, 2014).

### Children with disabilities in NZ

Children who live with the effects of a long-term disability and their families are often over-represented in the more negative statistics in terms of health, housing, access to education, job opportunities and income when compared to the main population (Office of Children’s Commissioner, 2012; Human Rights Commission, 2014). There is an association between lower socio-economic status and poverty and the families of children with disabilities (Stanley, 2007). In 2012, more than 17,500 children lived in households receiving the main income from a government benefit who also received a child disability allowance or additional funds to support a child in the household who had a disability. The reasons for this are numerous and may include the child or adolescent coming from single parent family homes, having a parent with a disability or a parent being unable to work as they have to spend a considerable amount of time caring for their child with a disability (Office of Children’s Commissioner, 2012). Additional costs may also be incurred in routine activities when there is a child with a disability including significant transport costs such as specially adapted vans to carry motorised wheelchairs or wheelchair taxi services. Similarly, having affordable housing that is adaptable to the child’s needs may also be prohibitive. Other items including special recreation and leisure activities and respite care that caters for the child’s special requirements may also be costly for a family (Office of Children’s Commissioner, 2012). Often the needs and requirements of children with disabilities and their families are very complex and no one system can work for all. These complex needs frequently continue into adulthood.

A disability may be diagnosed or recognised during the developmental period while other disabilities may be acquired through an accident or as a result of serious illness and therefore will not be recognised until after the particular causal event(s). Some examples of conditions that result in various forms of disability include attention deficit/hyperactivity disorder (ADHD), autism Spectrum Disorder (ASD), hearing and vision loss, cerebral palsy (CP), and Down syndrome.

The diagnosis of an impairment or disability can be exceptionally stressful for the individual and their family or support people and it is critical that the correct information is gathered to ensure the most accurate diagnosis for the individual and their family. In most cases, medical professionals rely upon a certain set of symptoms or test results that have been internationally recognised and approved as indicators of particular conditions or impairments (e.g. Diagnostic and Statistical Manual of Mental Disorders: DSM 5, (American Psychiatric Association, 2013). Some conditions may have a series of guidelines that have indicators based on a child’s developmental milestones such as the New Zealand Guidelines for the Assessment and Treatment of Attention-Deficit/ Hyperactivity Disorder (Ministry of Health (MOH) (2001) and the New Zealand Autism Spectrum Disorder Guideline (Ministries of Health and Education (2008). These may be used in conjunction with a range of clinical tests to check for or eliminate other potential conditions or causes of the impairments for differential diagnosis. These tests and guidelines are then used by medical specialists in conjunction with a detailed medical history of the child or individual which allows them to develop a better understanding of the condition or impairment for diagnostic accuracy.

It is not uncommon for children diagnosed with a disability to have simultaneous or comorbid conditions. These comorbidities may be related when one condition or disability causes another or there may be an underlying cause that makes the child vulnerable to both conditions, however, sometimes there is no relationship between the conditions. Chronic health conditions such as cystic fibrosis, spina bifida or CP are commonly associated with other comorbid impairments or disabilities. A child diagnosed with CP may have also have visual, hearing or cognitive impairments in addition to the physical disability which limits their mobility. The comorbid impairments may have resulted from the same process that caused the physical disability but they must still be separately recognised (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007). Other common childhood disabilities such as ASD are associated with comorbid conditions including epilepsy and bowel conditions as well as psychiatric conditions such as schizophrenia (Bauman 2010; Kohane et al., 2012). ASD is also a noted comorbidity with other conditions including Fragile X syndrome, Down syndrome and Muscular Dystrophy (Kohane et al., 2012).

## Services for Children with Disabilities in New Zealand

As previously noted, children with disabilities are often considered at higher risk of health complications, and therefore have a higher demand for medical and hospital treatment and other associated medical interventions. The provision of health and disability services for children with disabilities are guided by the objectives of the NZ Disability Strategy (2001). Medical treatment, therapy and other child development assistance are provided through specialist paediatric services available throughout NZ. Additional services may include group therapy, physiotherapy, occupational therapy and child psychologists. As a result, a child with a disability and their family can interact with a number of health professionals and services. The NZ MOH provides a Needs Assessment and Service Co-ordination (NASC) service which undertake a needs assessment for children with long-term disabilities. The NASC reviews the child’s strengths, support needs and goals and can help co-ordinate the wide-range of health and disability services that are available and able to provide support to the child (MOH, 2014).

The provision of educational services for children with disabilities in New Zealand is provided through the Ministry of Education (MOE). The Special Education group of the MOE provides information, services and funding to schools, students and their families to enable the student to attend school with their peers. Special education is defined as providing “extra assistance, adapted learning environments or programmes, or specialised equipment and materials to assist young children and school children to access the curriculum in a range of settings” (MOE, 2014). Special education in NZ is guided by a combination of government legislation including the Treaty of Waitangi; *Education Act* 1989 and *Human Rights Act* 1993 and national policies and guidelines including the National Education Guidelines, New Zealand Curriculum and Te Whaariki: Guidelines for Developmentally Appropriate Programmes in Early Childhood Services (MOE, 2014). These contributed to *Special Education 2000* which a) aimed to increase the educational opportunities and improve outcomes for children with special educational needs, b) ensure a clear and consistent resourcing framework, c) provide for equitable funding based on need rather than location or setting and d) to assist schools to take the leading role in the provision of services that best meets their student’s needs (MOE, 1996). It is envisioned that the child will receive a seamless uninterrupted education from the time that their needs are identified utilising the resources that they and their family think best suit the child’s needs in a manner that recognises the cultural background of each child (MOE, 16 Sept 2014). Special educational services in NZ are intended to ensure that every child with a disability is able to access education in a manner that best supports their needs.

One of the core policies of special education resourcing in New Zealand is that children and young people receive educational support according to their needs and not their medical diagnosis. Children are classified by the level of support needed to access the NZ curriculum with their peers. The provision and type of assistance depends on the level of need that the child requires in order to participate in education. There are three levels of support provided; students with very high needs, students with high needs and students with moderate needs. There are also early intervention services for children at preschool level. Services for children with very high and high needs include:

- "the Ongoing Resource Scheme (ORS) which provides support for additional teachers, teachers' aides, specialists and items a child might need in the classroom";
- "the Communication Service which provides support for children who have difficulties with talking, listening and understanding language",
- "the Severe Behaviour Service which provides support for children experiencing severe behaviour difficulties; and"
- "the High Health Needs Fund which provides a teacher aide for a child with a medical condition that requires special care in order for them to be able to attend school safely (MOE, 2014)".

Children with moderate needs can have access to:

- "the Special Education Grant to fund resources and materials, training for teachers or additional specialist services";
- "Resource Teachers: Learning and Behaviour (RTLBs) who work in school clusters to provide assistance to students who learning or behavioural difficulties";
- "Vision or Hearing Support for children who are blind or have low vision or deaf or hearing impaired where schools can call on specialist teachers; and"
- "the Physical Disability Service where schools can call on Physiotherapists and Occupational therapists to assist students (MOE, 2014)".

The majority of children are deemed to have low (41 percent) or medium (45 percent) level support requirements. According to the MOE, in July 2014, there were 8,252 students receiving ORS funding representing represented 1.1% of the total schooling population. Of these were 6,086 students (74%) funded at High Need, 1,909 students (23%) funded at Very High need, and 257 students (3%) funded under the extension category of ORS (Education Counts, 2014). In the 2006 *Disability Survey,* it was found that 46 percent (estimated 5 percent of the total number of children in education) of the children in the survey required some form of educational assistance with their schooling[4]. This included those children who attend special educational settings because of long-term conditions, those who had Individual Education Plans (IEP) because of learning or developmental difficulties and those with learning difficulties dyslexia, ADD or ADHD. (Statistics New Zealand 2006).

Irrespective on the level of support needed, children with disabilities are entitled to receive education in the setting they and their family choose (Education Act 1989). However, reviews undertaken found that only half of schools in NZ could be considered mostly inclusive of all students and their learning needs (Education Review Office, 2010). Under the Success for All – Every School, Every Child programme (2010), the NZ government envisioned inclusive practices to be incorporated in all schools by 2014 (MOE, 2010). To ensure the attainment of this goal, the MOE developed and enlarged existing programmes to assist children who had special educational needs including enabling more children to receive funding for very high and high educational needs, the establishment of outreach services with specialist teachers who travel to regular schools to work with students with special educational needs and provide knowledge and assistance to the classroom teachers and the distribution of best practice guidelines for

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[4] These results from the 2013 *Disability Survey* have not yet been released. In 2006 the percentage of children aged 0-14 years with a disability was 10 percent of the total disability population.

assistance with transition from school to post-school life. These practices and processes are assessed by the Educational Review Office (ERO) who report on the progress that each school is making in achieving the government's vision of an inclusive educational system.

## Effects of disability

The effects of disability are as varied as the individuals who live with disabilities. Every person experiences their disability in a different manner, therefore no exact effects of disability can be drawn. The different experiences of disability varies according to the specific nature and severity of the disability along with the person's physical characteristics and their ability to cope. These can impact on and are in turn impacted by the individual's physical, social and economic environment within which they are living. One situation where individuals with disabilities are believed to be negatively affected is a significant disaster event.

Research studies of the effects of disabilities on individuals is especially important. In the field of disability research, QOL has become a foundation in the study of the outcomes for people with disabilities (Halpern, 1993). This has, in part, been driven by the recognition by policy makers of the importance of using QOL frameworks in the development and assessment of the success of different programmes and policies designed to improve the outcomes for those living with disabilities (Zekovic & Renwick 2003). It is vital that QOL research with children and adolescents with disabilities gives direction and positive outcomes for future developments and policies.

## Quality of Life (QOL)

The World Health Organisation has defined QOL,

> …an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept

> affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHOQOL Group, 1997, p.1.)

This definition is interconnected with the WHO’s founding concept of health as being ‘a state of complete physical, mental, and social well-being not merely the absence of disease” (WHO, 1946, p.1[5]). However, it is widely accepted that QOL is a complex topic to define and research. Schalock (1996) identified several key characteristics to the concept of QOL;

> To understand an individual’s perspective on their QOL requires an in-depth knowledge of them. The concept embodies general feelings of well-being, opportunities to fulfil one’s hopes and dreams and positive social interactions. It cannot be separated from an individual’s developmental stage, their support network and relevant life domains. Thus, it gives the researcher a sense of reference and guidance in approaching QOL issues (Schalock 1996, p.126).

Among the social science field of QOL research, there is a general understanding that QOL refers to the idea of holistic well-being, that is encompassing the individual’s state-of mind within the context or environment that they exist in. Albrecht and Devlieger (1999) note that the domain of disability goes far “beyond health related concerns to encompass the person’s wellbeing, definition of self and social position” thus it is essential not to restrict the study of QOL in disability to health issues. Many factors can influence the QOL and wellbeing of those with disabilities. These might include levels of education, employment and

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[5] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

independence from others.  The support of family, friends and community involvement also has a significant impact on individuals’ with a disability QOL. However, the experience of pain and isolation often attributed to those with disabilities (Albrecht & Devlieger, 1999) would in all probability have a negative influence on their QOL.

Many different dimensions or domains of QOL have been identified and measured. These domains may include biological, material, social, behavioural or psychological factors that can be studied both objectively and subjectively (Felce & Perry 1995).  Schalock (1996) reported eight dimensions that should be included in the measurement of QOL (See Table 2). These consist of areas that cover “emotional well-being, social relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights” (1996, p. 127). In 2002, an international group of researchers (Schalock, et al.) expanded Schalock’s (1996) eight dimensions and added specified sub-domains (See Table 2).

Table 2
Quality of Life Domains (Schalock et al., 2002, pp. 463-4)

| Domains | Sub-Domains |
|---|---|
| Emotional well-being | “Having a safe, stable and predictable environments, positive feedback” |
| Interpersonal relations | “Affiliations, affections, intimacy, friendships and interactions.” |
| Material well-being | “Ownership, possessions and employment” |
| Personal development | “Education and habilitation, purposive activities and assistive technology” |
| Physical well-being | “Healthcare, mobility, nutrition and wellness.” |
| Self-determination | “Choices, personal control, decisions and personal goals” |
| Social inclusion | “Natural supports, integrated environments and participation” |
| Rights | “Privacy, ownership, due process, barrier-free environments” |

One model that addresses QOL for people with disabilities which focuses on overall health and wellbeing rather than the impact of illness or impairment was developed by the Centre for Health Promotion, University of Toronto (CHP). The researchers Raphael, Renwick, Brown and Rootman (1996) realised that conceptually QOL must apply to all people and not only people with disabilities as a distinct group. Second, there was a recognition of the need of a holistic approach to the concept of QOL which addressed as many interrelated aspects of a person’s life as possible. Next, they incorporated the level of personal control that one has over their life as an indicator of QOL. Finally, they acknowledged that the perspective of the individual must be paramount and emphasised whenever possible (Renwick et al., 2003).

The CHP approach conceptualises QOL as the degree to which a person *enjoys* the important *possibilities* of his/her life (Raphael et al., 1996). The concept of enjoyment encompasses two meanings: the experience of satisfaction or the possession or achievement of some characteristic as demonstrated in the expression "She enjoys good health".

Table 3
Centre for Health Promotion Quality of Life Domains (adapted from Raphael et al., 2001, p.181)

| Domain | Subdomain | Description |
|---|---|---|
| Being<br>“the basic aspects of who one is” | Physical Being | Physical health. Personal hygiene. Nutrition. Exercise. Grooming. Clothing. General physical appearance. |
| | Psychological Being | Psychological health and adjustment, Cognitions. Feelings. Evaluations concerning the self and self-control. |
| | Spiritual Being | Personal values, personal standards or conduct and spiritual beliefs. |
| Belonging<br>“the fit with one’s environment” | Physical belonging | Where one lives. Personal space and privacy. Importance of the neighbourhood. |
| | Social belonging | Having a special person.Family. Friends. |
| | Community belonging | Access to education or training or meaningful employment. Access to places in the community. |
| Becoming<br>“the purposeful activities carried out to achieve personal goals, hopes and wishes” | Practical becoming | Daily activities: Work or attending school or a program, Household activities. Caring for someone or a pet. |
| | Leisure becoming | Things done for enjoyment. Being able to visit or socialize with others. Having hobbies or options for spare time. |
| | Growth becoming | Things done to improve. Learning new things, solving problems with others and the capacity to cope with change. |

Possibilities are described as the outcomes from the different opportunities and limitations each person has in their life and reflects the interaction of personal and environmental factors (Raphael et al, 1996). The individual’s opportunity for enjoyment and possibilities are measured against the CHP QOL model’s three life domains: (1) Being, (2) Belonging and (3) Becoming, each of which have three further sub-domains. *Being* reflects “who one is” and has three subdomains that look at the physical aspect of one's life, the psychological aspect and the concept of spiritual being. *Belonging* concerns how the person's fits with their environment and has the subdomains of physical the place where they live and social and community belonging. *Becoming* relates to "the purposeful activities carried out to achieve personal goals, hopes and wishes" and has the subdomains of practical, leisure and growth becoming (Raphael, Renwick, Brown & Rootman, 1996 pp. 80-81). Each of the subdomains have further defined areas of relevance to an individual's QOL (see Table 3).

QOL in the CHP Model consists of the relative importance or meaning attached to each particular dimension or area of QOL and the extent of the person's enjoyment with respect to each dimension. The extent of a person's QOL in the areas of Being, Belonging, and Becoming and the sub-domains is determined by two factors: importance and satisfaction. Each subdomain is assessed by two inter-related themes; how important is this area of their life for the person and how satisfied is the person with it. If the person places significant importance on an area of their lives and they are very satisfied with it, then it could be concluded that that area of their lives is good for them, indicating a high QOL. If they placed little importance on an area and were very happy with it, then a similar conclusion could be drawn. If, however, they deemed something to be of significant importance and yet were not happy with it then it could be concluded that this is an indicator of a low QOL. Thus, in this way quality of life is adapted to the lives of all people, at any time, and from their individual perspectives (Quality of Life Research Unit, n.d)

In a 2003 study, Renwick, Schormans and Zekovic reported on the development of a conceptual framework for children with developmental disabilities. The participants included parents of 30 children (N=23 boys) aged between 3 and 12 years old diagnosed with various developmental disabilities including Autism, Asperger syndrome, Down syndrome, Fetal Alcohol syndrome, Fragile X, and Pervasive Developmental Disorder. This qualitative study identified three broad fundamental themes related to QOL for children including the child, their familial environment, and the broader environment, including where they live, their local community, school they attend and institutional bodies such as government agencies whose policies can impact on the lives of their families. All of these elements are involved in “an ongoing multidimensional, interactive and dynamic relationship” (p. 110). Therefore this model assumes that the better fit or interaction between the elements, the better the QOL of the child will be and conversely, a poorer fit equals a poorer QOL. Essentially, the child’s QOL is determined by the where the dimensions overlap or as one parent described it, "…quality of life means to me giving them the best that you can give them, whether that's financially, mentally, emotionally, physically, spiritually, in any form of life, just giving to them, the maximum that you can give them" (p. 111).

Renwick, Schormans and Zekovic (2003) reviewed the broad elements defined with the three domains from the CHP model of QOL, being or who the child is perceived to be, belonging or the child’s connections with people and places and becoming or the child’s nurtured growth and development (p.111, refer to Table 3). Parents were asked to review the different domains and how they saw these as relevant to their child. With the being domain, parents expressed hope that that their child would be seen and treated by others as a child first rather than defined by having a disability. They saw the belonging domain as good because it acknowledged the importance of positive interaction with people important to the child and their community. The becoming domain was good where the child’s major needs had been met and that other people’s expectations where recognised and matched with the child’s abilities. One of the important features recognised about this framework was that it looked at the child’s whole life rather than focusing on any limitation. It also recognises the interconnections between the child, their family and other important people such as friends and their "overall fit with their environment" (p. 112). This study revealed that QOL models for children need to acknowledge what is most important to the child within its immediate and wider environment.

### QOL Measurements for Children

There are two common forms of instruments used in determining the QOL of children and adolescents with disabilities, 'generic' and those that are 'condition specific'. The latter are more commonly found in instruments that focus on health related QOL (HRQOL) but it is still necessary to identify the differences (Zekovic & Renwick, 2003). A generic instrument will measure a wider range of domains of QOL and also has the advantage that results can be compared across different 'clinical populations' (Waters, Davis, Ronan et al., 2009). However, the comprehensive nature of the generic instrument may mean they miss clinically important information (Zekovic & Renwick, 2003). Condition-specific instruments are designed to investigate the specific needs and issues that arise from a particular condition or disorder and thus may be able to determine more subtle concerns and changes that arise for children with that condition than a generic instrument. The condition-specific instrument may ask condition-specific questions and focus on domains that are believed relevant to that particular condition group, however, this then can create difficulties if making comparisons between different groups (Waters, Davis, Ronan et al., 2009). Because both forms of instrumentation are beneficial, many researchers use them together to gather more complete data.

There are numerous instruments that have been developed to measure both children's and adolescent's QOL. Some of the instruments that have been regularly used to measure the QOL of children with disabilities include the generic Child Health Questionnaire (CHQ) (Landgraf, 1996) and the Paediatric Quality of Life (PedsQL)

(Varni et al., 1999). These instruments have been tested in various settings and with numerous groups of children including those with developmental disabilities and long-term chronic conditions.

The CHQ (1996) was designed as a generic instrument to measure functional health status, wellbeing and health outcomes of children aged 0-18. The parent (or proxy) are asked a series of questions (N=50) on the domains of "behaviour, bodily pain, general health, mental health, parent impact-emotional, physical functioning, parent impact-time, role-emotional⁄behavioural, role-physical, and self-esteem along with physical and psychosocial summary scores (Waters, Davis, Ronan et al., 2009, p.663)." Each of the domains and questions were determined by researchers who reviewed multiple surveys and questionnaires to compile the most relevant questions. It does allow for a self-report option for adolescents.

The PedsQL (1999) was designed as a comprehensive measure of HRQOL of children and adolescents aged between 2 – 18 years. It was developed for both healthy children and adolescents as well as those with a disability or chronic condition and focuses on QOL as determined in four areas, physical, emotional, social and school functioning (Zekovic & Renwick, 2003). A relatively short instrument, the PedsQL allows the child to self-report with focus on functioning and what the child is capable of doing as well as what they have difficulty with (Waters, Davis, Ronan et al., 2009). The instrument has both generic scales and condition specific modules which allow for comprehensive data to be collected.

Although the CHQ and PedsQL are used to measure QOL, additional considerations are important. Turnball, Turnball, Wehmeyer and Park (2003) note that QOL measures "have multiple domains with multiple items in each domain" (p. 71). Thus, measurement can be a lengthy and extended process, which can be difficult for people with disabilities to complete. This requires researchers and interviewers to evaluate and consider the delivery mode and the questions that they ask in a QOL measurement to ensure that the process is not too lengthy.

A second complexity is that all QOL measurement tools have elements of subjectivity and objectivity, which also affects how the results can be conceptualised. Some researchers therefore favour measuring “objective satisfaction” such as the definable quality of the residence where the respondent lives or the level of care they receive over “subjective satisfaction” where they might assess how happy a respondent is with the quality of their residence or the care they receive because the latter is ‘merely a response to objective conditions’ (Turnball et al., 2003, p. 71). Schalock (2000) suggested that some domains are more suited to subjective measurement while others such as material goods may suit an objective assessment.

A third complexity is that many items used to measure QOL are in fact frequently designed to measure HRQOL (Zekovic & Renwick, 2003). A study by Rosenbaum, Livingston, Palisano, Galuppi and Russell (2007) set out to assess the relationship between the QOL and HRQOL of 203 adolescents with CP. The study used the CHP QOL model instrument; Quality of Life Instrument for People with Developmental Disabilities (QOL-PDD) and the Health Utilities Index, Mark 3 (HUI3) to measure HRQOL. The results found that there was a very weak relationship between the two concepts and that the HUI3 only explained a small variation (14%) in QOL scores. This would suggest that it is important to focus on QOL and HRQOL as separate dimensions of people with disabilities.

A fourth complexity is the format of measurement. Different formats are used to assess QOL for those with disabilities including surveys, questionnaires, interviews (Turnball et al., 2003). In cases of severe disability where the individual is unable to independently respond or answer questions, often the individual's family or caregivers are asked to assess the individual's QOL. This is called proxy assessment. Since the subjective appraisal of the objective conditions, and its importance, are key features of QOL, proxy assessment may not give an accurate measure of QOL. A review of the literature by Murrell (1999) shows that when QOL assessments by the individual are compared with assessments by family or caregivers, often the family or caregivers will rate the QOL of the individual with a disability differently. Although other studies have indicated that the reliability and validity between proxy assessment and child assessment is still be applicable in many settings (Varni, Limbers & Burwinkle, 2007). Similar arguments from Wallender, Schmitt and Koot (2001) support the argument that proxy assessment cannot be discounted for a number of reasons including, the level of child development, comprehension of the concepts and the frequent use of time frames. All of these considerations point to the need for proxy assessment although there may be a stronger weighting placed on objective rather subjective scores.

Finally, Waters, Davis, Ronan and colleagues (2009) have suggested that documentation of the Quality of Life of children and adolescents with disabilities must not only consider all aspects of their life that they deem are important but also be very aware of the ongoing changes in their lives.

### Impact of Natural disasters on QOL

Unexpected or sudden stressful events can have significant impact on an individual's quality of life such as the experience of a disastrous event. A disaster is defined by WHO as a severe ecological and psychological disruption that greatly exceeds the coping capacity of the community (1992). The International Federation of the Red Cross and Red Crescent Societies (IFRC) expands on this seeing it as, "a sudden, calamitous event that seriously disrupts the functioning of a community or society and causes human, material, and economic or environmental losses that exceed the community's or society's ability to cope using its own resources" (IFRC, 2014). The IFRC believe that certain groups are more vulnerable or have a higher probability of diminished capacity to adapt to the effects of disaster. These include families with young children and unaccompanied children, older adults without family support and those with disabilities (IFRC, 2014). However, the impact of such events on the lives and livelihoods of many people caught up by them can often have far reaching consequences, including dramatically impacting their quality of life. The devastating force of a natural disaster can be seen in the experiences of the Christchurch EQ series of 2010 and 2011.

## Christchurch Earthquake Series of 2010-2011

Between September 4, 2010 and January 2012, the city of Christchurch, New Zealand was struck by a series of destructive earthquakes that resulted in the loss of 185 lives, widespread damage to a substantial number of the region's residential and business properties and community facilities along with significant disruptions to infrastructure. The area, including Christchurch and the neighbouring territorial authorities of Selwyn and Waimakariri[6], with an estimated pre-earthquake population of 463,900[7] experienced 56 earthquakes of magnitude 5.0 or over during that period.

The initial earthquake on September 4, struck the region at 4.36 am with a recorded magnitude 7.1 at a depth of 10 kilometres (GNS Science, 2014). The

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[6] From here on the area will be referred to as Christchurch unless mentioning the specific territories or townships. If referring to Christchurch City, then this will indicate the areas of Christchurch city and Banks Peninsula that are under the governance of the Christchurch City Council. Waimakariri district is referring to the area under the governance of the Waimakariri District Council and includes the townships of Rangiora and Kaiapoi. Selwyn refers to the area that is under the governance of the Selwyn District Council and includes the townships of Darfield, Lincoln and Rolleston.

[7] Statistics New Zealand, (2010). *Subnational Population Estimates: At 30 June 2010.*

earthquake was centred 30 kilometres west of Christchurch near the township of Darfield along a previously unknown faultline (GNS Science, 2014). The event itself was felt extensively throughout the South Island and the lower North Island of New Zealand and while locally there was extensive material damage to buildings and infrastructure, there was no directly attributable fatalities and surprisingly few serious injuries (N=2; McLean, Oughton, Ellis, Wakelin & Rubin, 2012)[8]. This was believed due to the early hour that it occurred when most people were home and in bed asleep and because of New Zealand's strict building codes put in place because of the country's proximity above two major tectonic plates (The Pacific and The Australian) which sees a number of earthquakes every year (GNS Science, 2014). Essential lifeline services including water supply and wastewater systems, electricity, telephone communications, were knocked out in the region although the majority of homes (in the main centres) had most services restored to workable conditions within two days (Ministry of Civil Defence and Emergency Management (MCDEM), 2011).

Some areas of greater Christchurch were much more significantly affected by the damage than others. Significant building and ground damage occurred around Darfield near the epicentre of the original quake. Other areas including the township of Kaiapoi and the eastern suburbs of Christchurch city were hit by the liquefaction process that made thousands of homes uninhabitable. Liquefaction is a silt-like substance that is ejected from the ground due to pressure from the forces beneath the surface. These movements liquefy the sediments below and force them up through widening cracks on the surface under house foundations, throughout properties, roads and footpaths. Some soils around Christchurch and the surrounding districts were prone

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[8] Review of the Civil Defence Emergency Management Response to the 22 February Christchurch Earthquake. One death from a heart attack was believed to have likely occurred as a result of the Sept 4, 2010 earthquake but cannot be directly attributed.

to liquefaction by virtue of being loose sandy or silty soils below the water table (Environment Canterbury Regional Council, 2014). The silt mixed in with the overflow from broken water and sewage pipes made liquefaction a dangerous combination for the residents affected and slowly solidified once exposed to the open air. Those homes and areas which were most affected by liquefaction found water and sewage facilities were significantly damaged and forced many to leave for temporary shelters set up around the city in recreation facilities and halls or to organise temporary toileting (such as port-a-loos or chemical toilets) and to have clean drinking water bought in by truck.

Another significant EQ occurred at 12.51 pm on February 22, 2011 at magnitude 6.3, 5 kilometres deep with its epicentre in the Port Hills which run along the southern edge of the city. While technically an aftershock of the Darfield EQ, this event was particularly devastating because of its proximity to the city and the central business district (CBD) (10 kilometres southeast) and its shallow depth. This combined with unique geological forces that created higher ground movement than previously ever recorded for any earthquake (GNS science, 2014). Of the 185 lives lost, 169 were known to have occurred within the CBD as a result of catastrophic building failure and collapse or falling debris from unreinforced masonry.

Following the devastating aftershock, a national emergency was declared on the morning of 23 February, remaining in force until April 30, 2011. Within hours of the EQ, both national and international urban search and rescue (USAR) teams were called in to search the many damaged buildings in the CBD and in other affected areas around the city. Local and visiting defence force personnel were mobilised to provide assistance to struggling local emergency services in the hours after the main earthquake.

The entire CBD was placed under a police-cordon with only personnel directly connected to the search and rescue efforts allowed through.

Emergency medical services were stretched to provide assistance to the people severely injured by the earthquake. The local central hospital, a main medical centre for the South Island was stretched by the extent of severely injured patients in the aftermath of the event. Following Civil Defence emergency plans, patients with complex or fragile conditions were removed to hospitals in other main centres which had been placed on standby (MCDEM, 2011). Other vulnerable persons including older people residents of severely damaged rest homes were also evacuated to other centres around New Zealand.

The suburbs of Christchurch that had been significantly affected during September were damaged once again but on a much larger scale. While nearly all areas of the city had some damage as a result of the February aftershock, as Figure 1 shows, the most significant damage extended over much of the centre, and eastern areas of the city. As a result of September 4 earthquake, over 31, 000 tonnes of silt, ejected through liquefaction, was removed. The February 22 event resulted in 397,000 tonnes of silt removed to landfill (Villemure, Wilson, Bristow, Gallagher, Giovinazzi &Brown, 2012). The effects of the ground movement also raised the levels of the water table the region was situated on contributing to extensive flooding in low lying areas along the rivers and streams which criss-crossed the city and further contributed to the damage.

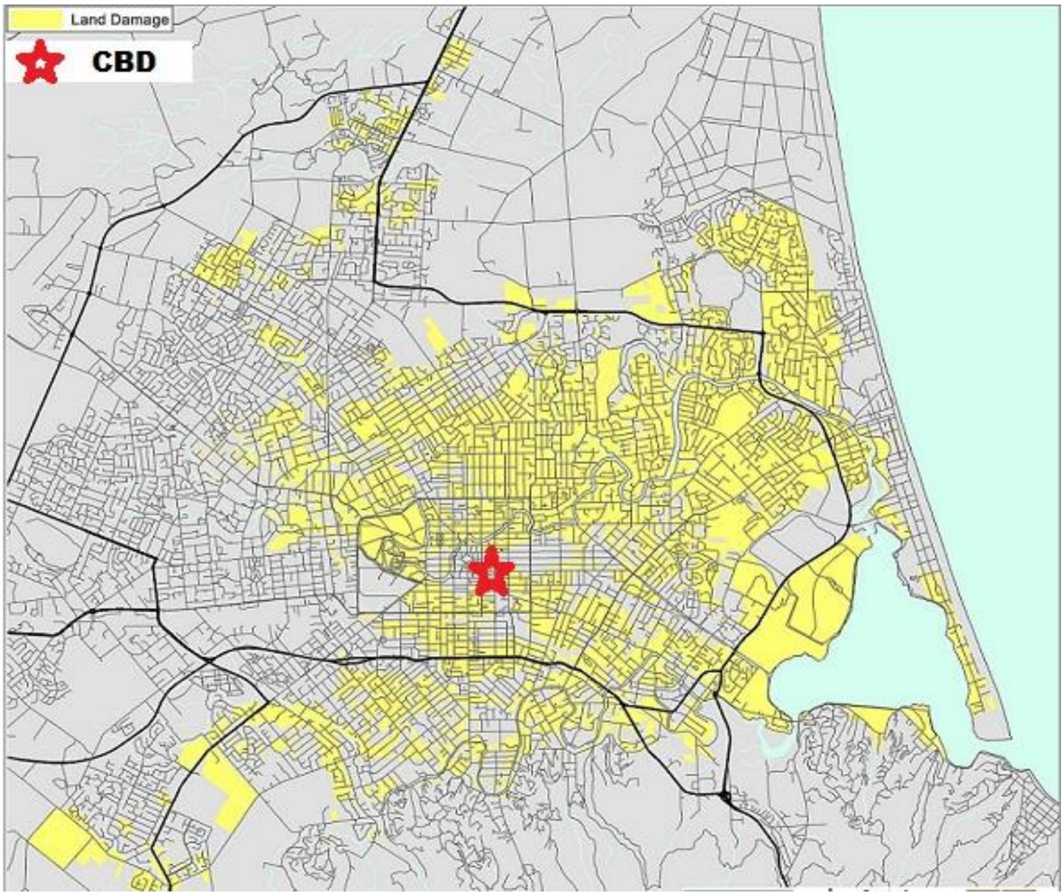

*Figure 1* Map of extent of land damage from liquefaction observed after 22 February, 2011 Earthquake. (Tonkin & Taylor, 2011, used with permission.)

The Feb EQ also had a considerable impact on the hillside suburbs where roads into the stricken areas became practically impassable through a combination of damaged roads caused by liquefaction along the coastal areas and falling boulders from the surrounding hillsides. Outlying hillside suburbs of the city were cut off and some residents were forced to evacuate because of extensive rock falls and the risk of more from continuing aftershocks.

In eastern Christchurch which included some of the most damaged areas from liquefaction (see Figure 1), difficulties were enhanced by lack of resources. Areas including, Aranui, Bexley, Central New Brighton and Wainoni were some of the lowest socio-economic areas of the region, with many of the residents lacking the resources to get through the immediate aftermath of the earthquake (Christchurch City Council, 2014[9]). Significant issues in the immediate aftermath included access to clean drinking water, damaged waste water infrastructure and food supply which was limited as local supermarkets were closed (Television New Zealand. (23 February, 2011). Many residents were unable to stock up on emergency food supplies and also lacked private transport to access the distant supermarkets.  The roads and bridges in the area were severely damaged. Any available public transport had also ceased for the time being (Holton-Jeffreys, (2011). To combat this, water was trucked into the area and a desalination plant was set up in the eastern beach suburb of New Brighton. Local volunteer groups formed to organise 'kitchens' and assist struggling and vulnerable residents. A volunteer group supplied hot meals by helicopter into the area to be distributed amongst the residents.

The disruption to the city continued for much longer as significant areas were cordoned off in 'red (no-go) zones', people had to leave uninhabitable homes and businesses were forced to move or ceased to operate. As a direct result of the February EQ, overall employment in Canterbury fell by over 28,000 people (8.3%) (Statistics NZ, 2011). The remaining infrastructure was struggling to keep working and essential services were significantly disrupted. All schools in the region were closed for a minimum of two weeks with some remaining shut indefinitely as concerns over damage to buildings and the grounds required substantial remediation.

Further large earthquakes occurred on June 13 with a magnitude 5.8 followed by a magnitude 6.0 a couple of hours later, bringing more liquefaction to already heavily damaged areas in the eastern suburbs. A similar sequence of aftershocks on December

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[9] CCC, (2014). *Community profile: Aranui/Wainoni/Bexley*. Accesssed from: http://resources.ccc.govt.nz/files/cityleisure/statsfacts/statistics/communityprofiles/2014/burwoodpegasus/communityprofile-burwoodpegasus-aranuiwaionibexley.pdf

23, 2011 which saw the city's attempts to recover heavily affected as residents struggled to come to terms with the uncertainty surrounding the earthquakes.

Stressors other than aftershocks developed for the people of Christchurch in the post-EQ phase. Thousands of people were left with the uncertainty over the future of their homes as the Earthquake commission (EQC), established by the New Zealand government in 1945 to primarily provide cover for residential properties in the event of an earthquake and other natural disasters[10], started to make preliminary assessments of damaged properties within days of the main event. However, the ongoing nature of the EQ series meant that there had to be new and additional assessments carried out and the workload increased as more properties were included after each major event.

The extensive damage caused by liquefaction and lateral spread to the land in primarily the river suburbs around the eastern suburbs, saw the implementation of a "redzone" and a "greenzone". Properties in the redzone were deemed too difficult or too costly to repair as a result of the damage to the land. Owners of homes in the red zone areas were bought out by the NZ government at an amount based on four year-old valuations levels and required to leave the property that for many, had been their family home. The houses were then to be removed and the land returned to grassland. More than 7,300 residential homes in the flat area of Christchurch and Kaiapoi were red zoned or deemed unrepairable by Christchurch Earthquake Recovery Authority with another 475 red-zoned in the Port Hills region (CERA 2014).The impact of significant areas of the city being red-zoned or deemed unrepairable resulted in entire communities having to leave and find new homes. This resulted in large areas becoming deserted,

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[10] It was originally the Earthquake and War Damage commission but this was later dropped to just Earthquake Commission.

while other areas of the city have had to deal with an influx of new people and a shortage of suitable accommodation.

By 2014, geologists had recorded over 12,000 earthquakes since September 2010. While the majority of these were no more than magnitude 3.0, the relatively regular occurrence of larger EQs (4.5 to 5 + magnitude) acted as a constant reminder for people living in the city (GNS Science, 2014). The ongoing nature of the events saw the population experience considerable stress and anxiety beyond that period as they were never certain if the EQs had “finished” (Christchurch Earthquake Recovery Authority, 2012). Because of this the Canterbury earthquakes could accurately be described as a multiple event as opposed to just one event (Shirlaw, 2014). The original EQ in September 2010 was a significant event that generated traumatic stress in itself by virtue of its unexpected nature and the amount of damage caused, and while people were still recovering, the event in February 2011 and in in effect, returned many people right back to the beginning of the traumatic recovery stage again (Gluckman, 2011). The ongoing effects of the EQs were experienced every day by residents in the city through visual reminders from road works, buildings waiting to be demolished, empty space where damaged buildings have been removed as well living and working in temporary buildings while they wait for home repairs or rebuilds to take place.

Maybe the biggest an ongoing areas of stress that has arisen for people in post-EQ Christchurch is the difficult decisions around repairs or rebuilds to their damaged but habitable properties. For those who were not redzoned, the delay in getting a decision made on the fate of their homes has led to, in some cases, families forced to stay in houses despite considerable damage or shift numerous times because of ongoing delays (Greenhill, 7 August 2014). Ongoing and complicated discussions between EQC and insurance companies have seen many home owners caught “in the middle” as a suitable outcome is determined (Stylianou, 4 September, 2014). The financial and emotional strain from the sometime protracted decision making process has taken its toll on a number of people across the city.

## Children in the Christchurch Earthquake disaster

The effects of the EQs in Christchurch, have equally disrupted and caused significant difficulties for the children and adolescents of the city. In Christchurch, the February 22 event occurred at a particularly critical time with many children at school, people at work and families potentially separated across various sites around the city. Shaw, Espinel and Schultz (2012) cites that in the immediate aftermath of a disaster, children may experience significant loss of family or friends and belongings or be exposed to varying scenes of devastation.

In Christchurch, children and adolescents were particularly vulnerable to traumatic exposure especially during the February 22 earthquake. There were four primary and two secondary schools that were situated within the Christchurch CBD at the time. In addition to this, at least two other primary schools had school groups that were on field trips in central city locations (P. Drayton, personal communication, May 20, 2011).

Furthermore, the Post-Primary Teachers Association had organised for its members (most secondary school teaching staff) to attend paid union meetings either in the morning or afternoon. This had the majority of the city’s state secondary schools operating half-days to allow teachers to travel for the meeting in the Christchurch Town Hall in the CBD. Schools either closed at 12 pm thus releasing many students to walk or bus home early (Radio New Zealand, Tuesday 22 Feb, 2011) or they opened at 1 pm to allow teachers to attend the morning sessions (Connelly, 2013). Since a number of students bus to and from school, a higher than average number of school students were potentially within the CBD going into the central bus exchange to change buses or to meet up with friends or caregivers. If they were exposed to the devastation and loss of life that occurred within the CBD of Christchurch as a result of February 22, the effects of the EQ may be heightened for many of these children and adolescents regardless of the whether their own homes and suburbs were particularly effected by EQ damage..

P Drayton (personal communication, May 20, 2011) reported that a bus chartered to take a class group from a nearby primary school class group to the Art Centre in the CBD happened to have stopped at lights next to a historic church building at the exact time the EQ struck. Bricks from the falling building fell onto the roof of the bus, crushing it while the driver attempted to control the vehicle during the EQ. The driver continued to drive and returned the students to their school uninjured albeit quite traumatised by what they had experienced. When the bus returned to the school, they found a number of bricks and roof tiles from the building still on the roof.

Other children were forced to wait at their schools for family or transport to collect them. The extensive damage to the roading infrastructure from the earthquakes and the amount of liquefaction along with loss of power to traffic lights controlling intersections, meant that traffic was chaotic especially for people trying to reach family and homes in the eastern suburbs. This saw many instances of children waiting at schools well into the evening. One intermediate school group was on a camp on Banks Peninsula, when the EQ occurred. The teachers and parent helpers decided to return to the school not arriving back to their school site in the eastern suburbs until very late in the evening. As a result, some children were forced to remain at the school overnight because caregivers could not be reached (M. Coulter, personal communication, March 23, 2011).

Educational services were severely disrupted for many children in the weeks after the EQ. All schools were closed from February 22, 2011 until further notice for emergency inspections to be carried out and the buildings deemed safe to re-enter (Radio New Zealand, Tuesday 22 Feb, 2011). In the weeks and months immediately following the EQ over 12,000 school children were enrolled in other schools around New Zealand including re-enrolments in other schools in Christchurch city and Selwyn and Waimakariri districts (Statistics NZ, 2011). The Ministry of Education allowed children who had left the affected areas to enrol in the local school wherever they were staying. Many small area-schools in more rural regions of the South Island were ill-prepared for the number of students arriving from Christchurch often traumatised from their experiences and unfamiliar with their surroundings. Many of these enrolments were temporary and by September 2011, over half of these children had returned to their original school (Statistics NZ, 2011).

In Christchurch, the majority of schools were able to reopen within three weeks. A further 24 schools remained closed for longer and nine schools (two primary, one intermediate and six secondary) were found to be unable to reopen on their existing sites and “co-located or site-shared” with other local schools for periods ranging from one month to more than a year. For the affected school this resulted in the majority of the schools having reduced teaching time with the host school starting earlier in the morning and in the afternoon then “handed over” the site to the visiting school for the remainder of the day. For a number of parents and students it created additional stress with earlier travel times for the morning classes and late night finishes for some in the afternoon classes (Ham, Cathro, Winter & Winter, 2012). It also added additional financial burdens to some families. While not an ideal situation in many areas it was the only workable option at the time

Children and adolescents were also described to experience considerable stress and anxiety as a result of the EQs. Shirlaw (2014) noted that in the months following the EQs parents, schools and medical professionals reported an increase in behaviour changes, and other problems relating to stress and anxiety as well as an increase in depression. Children were even reported to experience stress-induced alopecia or hair-loss (McKenzie-McLean, 24 August, 2011). The Canterbury District Health Board also recorded an increase in the number of adolescents who were referred to specialist mental health services when acute admissions levels in the first four months of 2013 were already at 70% of total admissions from 2012 (Mathewson, 18 May 2013). As this shows the effects of the Christchurch EQs on children continued even after the number of earthquakes experienced had decreased.

### Children with disabilities in the Christchurch Earthquakes

Little, however, is known about the impact of the Christchurch earthquakes on children or adolescents with disabilities. Most, if not all will have experienced similar issues that other children and adolescents in the affected region have dealt with, including the stress, fear and anxiety generated from the experience of the EQs, and the uncertainty that they bring, potential exposure to significant hazards and trauma, potential separation from a main caregiver even if only temporarily, loss of homes, communities and friends, uncertainty over schooling futures, changes to the school day and even changes of school, along with the constant reminders of the damaging effects that the EQs can have.

Children with disabilities are noted to be particularly more vulnerable to injury or death in the aftermath of a disaster (Chou, Huang, Lee, Tsai, Chen, & Chang, 2004) and long-term physical, psychological and educational issues (Peek & Stough, 2010). However, there is very little research done that looks at the effects of disasters with children with disabilities. Murray (2011), concluded after a thorough review of the literature on the requirements of children with disabilities in a disaster, that there were just five articles that addressed the needs of the child population. From a purely physiological position, children in general are more vulnerable to the physical effects of a disaster through having smaller body frames and immature skeletal systems which put them at greater risk of severe internal injury in a disaster (Murray, 2011). They are also more at risk from respiratory conditions through a faster breathing rate which makes them more vulnerable to dust from collapsed structures (Murray, 201) However, often the physical risks are greater for children with disabilities in the event of an acute or sudden onset disaster such as earthquakes (Peek &Stough 2010). In the event of an earthquake, a child in a wheelchair will need assistance to take cover and in many cases it may be physically impossible to get under a desk or into the classic 'turtle position' that school children are taught to use in emergency drills[11]. A child who has a visual impairment would not be make their way safely and quickly without significant assistance to a shelter and may even miss the visual warnings that so often accompany evacuations and emergencies. A child with an intellectual disability may become confused or panic if they don't understand what is happening and may not seek shelter or safety without an adult intervention.

Poverty or lower socioeconomic status of families of children with disabilities may limit their ability to access critical information such as emergency warnings,

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[11] Ministry of Civil Defence Management (2007) http://www.whatstheplanstan.govt.nz/

preparation plans for the possibility of a disaster or where to seek help or assistance in the event of a disaster (Morrow, 1999). There may also be a higher chance of limited financial resources to cover disaster related costs. In the aftermath of a disaster, those with fewer financial resources may be more heavily reliant on outside assistance for basic needs, including shelter and food (Morrow, 1999). This may reduce opportunities to recover quickly from the impact of the disaster. It is also possible that there will be less resources to access essential medication which may have been lost or left behind in an emergency evacuation. Many of these families may have had utilised various social support systems that are severely disrupted and unavailable for some considerable time after the event. All of these factors combine to ensure that children with disabilities are more vulnerable especially those from lower-socioeconomic families.

Even when there are significant warnings or alerts, children with disabilities and their families are also less likely to leave an area that is under threat. Research has found that up to 25 percent of families or households with a member reported as having a disability are less willing to evacuate when urged to do so owing in part to issues with suitable transportation and a lack of accessible shelters (Van Willigen, Edwards, Edwards and Hesse, 2002). The lack of suitable transport may be linked to effects of poverty for families of children with disabilities as they may lack the financial resources to have appropriate transport and are therefore reliant on suitable public transport. However, there are other complicating factors around transport including children with severe disabilities that require the use of special seats or restraints and therefore they cannot be moved safely without them. Those who are reliant on wheelchairs will require the use of specially adapted vehicles or vans. In the event of an evacuation, transport for people with disabilities such as wheelchair taxis may be overburdened and therefore people may be exposed to greater effects of the disaster if they are not able to leave in time. If families are concerned about how their child will react while being transported or whether the transport is suitable they may be less willing to go even under significant threat from an impending disaster such as a hurricane or flood.

Accessibility issues, such as difficulty in accessing buildings are also a significant issue and risk factor for children with disabilities and their families in the event of a disaster. If children with disabilities are evacuated to a shelter, there is evidence to suggest that their vulnerability is heightened by interaction with inexperienced staff who do not understand the special needs of a child who may have particularly sensitive health needs and requirements (Peek and Stough 2010). A welfare shelter may not be able to provide the dietary requirements of a child with significant feeding difficulties and therefore that child could be at risk of being underfed or risk severe food allergy reactions. There can be issues around shelter buildings having suitable bathroom and toileting facilities for children with significant physical disabilities which may cause significant distress to the child and their family. Even if there is no need to evacuate, previously accessible buildings may become inaccessible because of damage or a lack of electricity may render electric lifts and ramps out of action and therefore, the child and their family is severely restricted in where they can go. All of these concerns can make it very difficult for families of children with disabilities to access help in the event of a disaster as the child’s needs may be very specific and they would rather risk staying or returning home before it is considered safe especially in seismically active environments which may expose them to further risk to their physical safety and health.

Children with disabilities are also believed to be more at risk from a negative psychological health impact, such as post-traumatic stress disorder (PTSD). However, very little research has been carried out looking at the impact of disasters on the psychological health of children with disabilities (Peek & Stough 2010, Murray, 2011). In the event of a disaster, the stresses of the event may see the child become disorientated or distressed especially if they do not understand what is happening. This will, in all probability, impact on their psychological wellbeing at least in the immediate aftermath of the event. It is therefore dependent on the parent or caregiver to assist and support the child to understand what has happened. If the parent or caregiver is separated from the child, then this may negatively affect the child as they will also have associated anxiety because of unfamiliar people and situations. There is evidence that separation from a parent or caregiver during a disaster can result in a higher level of psychological problems and PTSD (Osofsky, Osofsky & Harris, 2007).

The impact of stresses resulting from a disaster and its aftermath may depend on the child’s pre-disaster psychological health It is possible that some children with disabilities will experience psychological reactions during and after a disaster, including anxiety, regression, depression, somatic complaints, sleep disorders and acting out behaviours (Murray, 2011).  While, these are also observed post-disaster in many children without disabilities, there is evidence that with pre-existing mental health issues, there is a perceived higher likelihood of a child developing post-disaster psychological health issues such as depression or PTSD (Christ & Christ, 2006, Shaw et al., 2012).

Wider issues in community emergency planning and management can contribute to children with disabilities and their families being at a disadvantage in a disaster situation. Peek and Stough (2010) suggest that this may in fact occur at all government levels. Many of the issues with accessibility, transport and threat of physical harm could be alleviated with involvement in community disaster management planning. However, often it takes a significant event to reveal the limitations to existing emergency plans for children and others with disabilities. Emergency plans often fail to incorporate the potential for special requirements of children with disabilities including vital medical and mobility equipment which can result in them being left behind or evacuated without these often essential tools. Lack of arrangement of accessible evacuation shelters with suitable facilities for children with disabilities will see them being avoided and families preferring to risk staying at home or having to be removed to shelters or facilities further away from their social supports.

One study that looked at the effects of the Christchurch EQs on people with disabilities was carried out by Phibbs, Woodbury, Williamson and Good (2012). They investigated what were the issues experienced by adults with disabilities following the 2010/2011 EQs. Using a mixed methodology design, the study included 23 qualitative interviews and 35 survey respondents comprised of 25 people with disabilities and 10 family members. The study found a number of key areas that affected the personal lives of the participants. None of the respondents believed they were prepared for the events of 2010/2011 and the lack of accessible information and equipment made emergency preparedness difficult. Some of the people interviewed had on-going health concerns or were at higher risk of complications and were reliant on medications that they were not always able to access. The EQs broke down the key support networks for many of the respondents which left them feeling vulnerable. Other respondents noted that it was a challenge to get to welfare centres and when they were there, the environments were not very disability-friendly and some felt particularly vulnerable. Phibbs and colleagues reported that nearly two-thirds of the respondents indicated that they or their family member had been evacuated with one reporting being evacuated five times. Often they had limited alternative accommodation because of accessibility issues. The damage to houses from the EQs forced some to stay in motels or other similar types of accommodation which often came at a significant financial cost.

Accessibility and mobility was also prominent in the study by Phibbs and colleagues. This was especially the case in mobility and transport options, which were of particular concern for those with visual impairments and mobility issues. The damage to the physical environment and the barriers put in place for protection actually created new risks. The disruption and changes to the public transport system also limited the access and independence of many with disabilities. Other factors including damage to lifts in buildings limited access for people with mobility issues. Access to important information was also discussed and a number felt that the information they needed was reasonably accessible but there were still numerous issues and barriers for all but two of the respondents. Most agreed that the information did not consider the needs of those with disabilities. Phibbs and colleagues (2012) noted that the respondents felt that there needed to be further engagement with the Civil Defence groups and other welfare agencies to develop disability awareness principles.

Phibbs and colleagues (2012) also discussed how some of the respondents had found various ways to cope in the aftermath of the EQs through helping others. Other factors included continued interaction with family and friends, along with support workers and colleagues all contributed to their resilience. The study found that the resilience of the individual was often highly dependent on their personal circumstances, socio-economic status and access to supports and social networks. The study by Phibbs and colleagues revealed that there was a considerable effect by the EQs on many areas of lives of people with disabilities.

## Quality of Life after Disasters

The effects of a disaster often have varying levels of impact on an individual and at the community level (Norris, Friedman, Watson, Byrne, Diaz & Kaniasty, 2002). These will also often vary by disaster type and location. To best understand and assist victims of disasters, a detailed picture needs to be drawn from a wide range of individuals who experience these events in order to determine not only what impact it may have had on their lives and where the need is most significant but also to provide ideas and information for future situations (Morrow, 1999). One way of measuring this is through QOL surveys. In the first instance, someone who has recently experienced a disaster or serious trauma has a higher likelihood of having a significantly decreased QOL. However, not everyone experiences a disaster in the same manner. Someone who was in the direct path of a tornado or a flood and lost their home or was injured is going to experience different effects on their QOL than someone who lived in the same area but wasn't directly affected (i.e. experienced the loss of electricity only). Other personal factors play a part in how people's lives are affected by disaster such as health and disability status and so people's QOL may be affected beyond the immediate effects of a disaster. Research on how QOL is affected by disaster can provide an in-depth picture of what happens in the lives of children and adolescents with disabilities post-disaster. It is of particular importance to evaluate the experiences of other populations that have also experienced significant earthquakes in order to determine their post-EQ QOL and potential areas of need for those children and adolescents with disabilities who have experienced the Christchurch EQs.

# Chapter 2 Literature Review

To understand the importance of measuring the quality of life (QOL) of children with disabilities in the post-earthquake (EQ) environment, it is essential to review and examine the existing literature. To identify relevant studies, a search was conducted of multiple databases including Medline Plus, PubMed, Ebsco, Psych Info, ERIC and Sociological Abstracts using search terms determined from initial reading on the subject. The dates were limited to those published from 01/01/ 1994 through to 30/06/2014. The initial subject search terms used were disaster* and quality of life. These were further refined using terms related to natural disasters (e.g. earthquake*, recovery, post disaster), children (i.e. child*, adolescent*, youth) and disability (e.g., intellectual disability, autism spectrum disorder).

The search revealed was that there was a limited number of studies on QOL of any population in a post-disaster context. While no studies appeared to have been published prior to 2000, many studies since then focused on adults. Two studies of adults with disabilities or long-term health issues were identified. Van den Berg and colleagues (2006) reported on the health related QOL of chronically ill adult survivors following a factory explosion. Stanley and colleagues (2011) studied the QOL of patients at a hypertensive clinic in the aftermath of Hurricane Katrina. No other studies were identified that specifically measured the QOL of any population with a disability in the aftermath of a disaster.

## The effects of EQs on the QOL of Adults

One of the earliest studies of the effects of an EQ on the QOL of an affected population was undertaken by Wang, Gao, Zhang, Zhao, Shen and Shinfuku (2000) who investigated the post-disaster effects on adult individuals (aged between 18-60 years) affected by a 6.2 magnitude EQ in rural China. The purpose of the study was to first, observe the longitudinal changes of QOL and psychological well-being on the individuals in the aftermath of the EQ using the WHOQOL-BREF for QOL assessment which measures four domains; physical health, psychological, social relationships and environment, and the Symptoms Checklist (SCL) for psychological distress symptoms. The second purpose was to study the relationship between QOL and the degree of disaster exposure, levels of post-disaster support for the affected population and other related variables. The researchers interviewed residents from two affected villages, A (N= 136) and B (N=199), 10 kilometres apart, three months after the earthquake with a follow-up interview six months later (Village A, N=100; Village B, N= 162). In addition, a control group (N=172) of similarly-aged adults who had not directly experienced the EQ were also interviewed. The results showed that nine months after the EQ both village groups A and B had significantly lower QOL scores in the psychological and environmental areas along with lower physical health scores when compared to the control group as well as significantly higher levels in measures for depression, anxiety and somatization. However, there was little change in any group on the socialisation domain of WHOQOL.

Wang and colleagues  (2000) undertook further QOL analysis on the two groups that were affected by the EQ. They found that group A (village determined not as severely destroyed compared to group B) reported poorer physical health in the WHOQOL-BREF compared to group B along with more negative psychological effects. When the results where compared over time, group B showed overall improvement in QOL measures as well as psychological wellbeing when compared to group A where there was little noted change across the affected domains and was in fact continuing to deteriorate. What the researchers observed was that while both groups A and B had been affected by the earthquake, one group (B) was considered to be ‘worse off’. However, group B had received greater post-disaster social support than those in group A. Those in group A, had moved back into their damaged homes sooner than those in group B and  were likely to have endured longer lasting effects of stress and anxiety due to continuing aftershocks while group B remained in emergency shelter and had assistance to rebuild their homes. The researchers believed that their results highlighted that the experience of an EQ had a multidimensional effect on QOL and it was essential that the entire population affected by the event received immediate and appropriate assistance to mitigate the potential long-term effects.

A series of studies by Chou and colleagues (Chou, F., Chou, P., Lin et al., (2004), Chou, F. Chou, P. Su, et al., (2004), Wu et al., 2006, and Tsai et al., 2007), reported on the QOL of adult survivors (age range: 16-99 years) of the Chi-Chi, Taiwan EQ that occurred in 1999 (magnitude 7.3). The unique aspect of this series of studies was that it allowed for longitudinal evaluation of the effects of the EQ on the QOL of the residents and the relationship with psychiatric disorders including PTSD and major depressive episodes (MDE). The original study Chou, F. Chou, P., Lin, et al., (2004), reported on interviews with over 4,000 residents living near the epicentre of the EQ using an adapted version of the Disaster-related psychological screening test to assess psychological symptoms and the Survey Short Form-36 item (SF-36) to examine QOL. The SF-36 assessed any health change in the past year and two dimensions of QOL including ‘physical component summary’ (PCS) and ‘mental component summary’ (MCS).  These two dimensions estimate health-related functions for eight subscales: “'physical functioning'; 'role limitations due to physical problems'; 'bodily pain'; 'general health'; 'role limitations due to emotional problems'; 'vitality'; 'social functioning'; and 'mental health"' (p.1091). The study carried out within 4 to 6 months of the EQ categorised the respondents into four groups defined by their level of psychiatric impairment; healthy (no psychiatric impairment observed), mild, moderate and severe level of psychiatric impairment. The researchers found that those who were diagnosed as psychiatrically impaired were more often older females who had experienced significant financial loss. This had a strong correlation with significantly lower overall QOL scores in both the physical and mental categories measured.

A related study carried out 21 months after the EQ by Chou, Chou, Su et al., (2004) investigated the QOL and associated risk factors of 461 adult residents in a Taiwanese village near the EQ's epicentre. This study used the Taiwanese version of the QOL instrument, SF-36 and participating psychiatrists administered the Mini-International Neuropsychiatric Interview to determine psychiatric risk factors of the respondents. The respondents were later divided into different groups depending on the psychiatric diagnosis; PTSD and MDE, other psychiatric diseases and healthy. The results showed that nearly a third of the respondents had some form of psychiatric illness which had a positive correlation with QOL scores in all areas measured except bodily pain and social functioning. However, the mean scores on the PCS for respondents in the PTSD, Others and Healthy groups and the MCS scores for the Others and Healthy groups were similar to the scores of the healthy United States population (Chou, Chou, Su et al., 2004). The mean PCS and MCS scores for those in the PTSD and MDE groups were significantly lower than those in the Healthy group which suggests that people who experience or develop these psychiatric conditions in the aftermath of a disaster are more likely to have a lower QOL than those who do not have or develop them. The researchers also identified a series of risk factors that corresponded with earlier findings (Chou, Chou, Lin et al., 2004) including being an older female or one who had experienced significant financial loss or a change to previous social networks as a result of the EQ. Any of these factors when combined with mental health issues indicated a stronger probability for a significant decrease in QOL.

Two later studies carried out by Wu et al., (2006) and Tsai et al, (2007) reviewed the QOL and the relationship with psychiatric conditions of the same adult population three years after the initial EQ. These studies using the same instrument, the MOS SF-36, allowed for greater understanding of the long-term effects of EQs on the QOL of survivors. The study by Wu and colleagues (2006) interviewed 405 residents of a small village to evaluate the long-term effects of identified risk factors from Chou, Chou, Su et al., (2004) on an individual’s QOL after the EQ. The study found that there was a noted improvement over time in the overall QOL of respondents diagnosed with PTSD or MDE which the authors suggested was strongly associated with the long-term medical and psychiatric intervention they had received for their conditions. Tsai and colleagues (2007) also noted a similar relationship between the decrease in the levels of post-traumatic stress symptoms (PTSS) and an improvement in QOL over time. However, the study found that those with persistent PTSS and or who had delayed-onset PTSS had significantly lower QOL than people who had no diagnosed psychiatric condition. The researchers found that respondents who presented with delayed-onset PTSS recorded notably lower QOL scores when PTSS occurred compared to their earlier QOL scores. The researchers concluded that the survivors’ QOL was dependent on the progression of PTSS

Ke, Liu and Li (2010) explored the relationship between the HRQOL and the importance of social support for survivors of the 2008 magnitude 8.0 EQ in Wenchuan, South West China. The cross-sectional study of 1617 adult (16 years plus) residing in shelters from across the affected area included 665 full-time students. The MOS SF-36 was used to evaluate HRQOL and the Social Support Rating Scale (SSRS) to evaluate three dimensions of social support. These include subjective support or the perceived personal connections someone feels they can call on in a time of need, objective support or the actual support they have received, and support-seeking behaviour or the ways a person will actively seek support. The results found that the survivors had considerably lower scores across all the domains of HRQOL measured when compared to the general population of the region. However, there were greater differences in the mental health domains than the physical health domains. Older people and women were at greater risk of lower HRQOL while people with a higher level education functioned better in day-to-day roles. Interestingly, the unemployed or full time students reported better general health than the employed. The extent of EQ damage in the area they lived also affected HRQOL scores with residents in the zones with only moderate or minimal damage more often reporting better general health and mental health than those in the most affected areas but experienced greater limitations in performance of day-to-day activities. Ke, and colleagues (2010) also found a positive correlation between strong objective and subjective social support in nearly all the domains of HRQOL measured by the MOS SF-36. However, there was a discrepancy between actual social support received and perceived social support for those with poorer mental health which the authors suggest contributed to poorer overall HRQOL.

Valenti and colleagues (2013) focused on estimating the changes in QOL of a general adult population over an 18 month period after the 2009 L’Aquila magnitude 6.3 EQ. The study included 397 adults (18 years and older) who had experienced the EQ and did not have any comorbidities including physical, degenerative or psychiatric conditions at the beginning of the study. Using the WHO-QOL BREF to evaluate QOL, the sample was assessed at four different intervals over the 18 month period and the results were then analysed by age, gender and education level. The results indicated that overall QOL scores in all domains, physical health, psychological, social relationships and environment were higher 18 months after the EQ. However, the participants had lower QOL scores at nearly all intervals when compared to with the QOL of other European populations, where the mean scores of a healthy population is >70% on a scale from 0-100. This trend was reversed when the social relationships domain was measured which was >70% at the beginning of the period and fluctuated across the sequence but still remained high. Men tended to show a slight improvement in physical health (Mean men = 68.18/100; Mean women 67.26/100) than women over the time period but showed less improvement over the same interval than women in the psychological domain (Mean men = 66.66/100; Mean women 68.48/100). Older adults were more likely to show a greater variation in psychological wellbeing than the younger respondents. However, lower education levels contributed to a lower overall QOL score regardless of age or gender.

### QOL of Older Adults after Earthquakes

Two articles have examined the effects of an EQ on the QOL of older adults (>65 years). Comparable to people living with disabilities, older residents are noted to be particularly at risk from the negative effects of an EQ (Chou, Y-J., 2004). Ardalan and colleagues (2011) reviewed the long term effects of a magnitude 6.6 EQ in Bam, Iran on the QOL of older survivors. The study interviewed 210 participants (65-95 years) five years after the initial event using the WHOQOL-BREF. The results were then compared with that of a general adult population who were not exposed to the EQ. The study found that nearly half of the respondents rated their overall QOL as “neither good nor poor” with over 60 percent scoring the same for overall health. Mean scores in all physical health, psychological and environment were lower than the scores for the general adult populations. Although social relationships were in fact scored higher in the study group although these were potentially at risk for those who had poorer psychological and physical health scores. This study identified that younger (65-70 years) male respondents had higher overall QOL scores. However, the authors noted that the long-term effects of the EQ continued to have a significant impact on the majority of older participants and well-designed interventions are needed to lessen the long-term impacts on older populations.

Giuliani and colleagues (2014) investigated the perceived QOL and wellbeing of older residents who were displaced following the EQ in L'Aquila, Italy. This study asked the respondents to compare their QOL from before the EQ to their perceived QOL at the present time. The study included 571 residents aged 65 and over who were recruited during the anti-influenza immunisation period. Post-graduate physicians administered a standardised 36-item questionnaire with closed, multiple choice answers that measured "demographics, everyday activities, health, perceived well-being [using two visual analogue scales: happiness/well-being and physical well-being], and the quality of life in the city (p.532)". In nearly all areas measured, the respondents reported they were happier or more positive prior to the EQ happening. These results were even more pronounced in individuals who were living in temporary housing compared to those who were living in their own home or in rented accommodation. This study also identified social isolation as a risk to the older population's QOL in the aftermath of the EQ. The respondents did not report spending much time on social activities. This was attributed in part by the authors to be a repercussion of the effects of relocation on previously established social networks. This was especially noticeable in women respondents. Where new housing and infrastructure was built, there was a failure to implement the facilities that had previously encouraged social interaction and engagement especially for this group. The authors noted that it is important the needs of different populations are considered in the post-disaster setting to ensure continued socialisation opportunities to enable older people to be an integral part of the community.

### QOL of adults with a chronic illness after a disaster

Like older adults, adults living with a chronic illness are also vulnerable in the event of an EQ or other disaster event (Chou et al. 2004). Two studies explored the effects of a disaster on this population. Van Den Berg, Van Der Velden, Yzermans, Stellato and  Grievink (2006) explored effects of a factory explosion in Enschede in the Netherlands on the HRQOL of survivors who had chronic illnesses prior to the event. The longitudinal study of 1216 adults (18 years and older) included 487 (58% female) respondents with at least one chronic illness, including high blood pressure, allergies and arthritis. Using the Dutch version of the RAND -36, five subscales including social functioning, general health perceptions, bodily pain, physical and emotional role limitations were measured on three different occasions; 2.5-3.5 weeks after the event, 18 months after the event and 4 years after the event. Depression and anxiety levels were measured using the Dutch version of the Symptom Checklist (SCL-90). The results showed that survivors with chronic illnesses appeared to have some problems with social functioning and bodily pain at 18 months post –disaster but fewer emotional role limitations. However, there was no significant interaction effects for general health, physical role limitations. (Van den Berg et al. 2006). Similarly, scores for feelings of depression, anxiety and PTSD symptoms did not reveal any significant difference between the chronic illness group and those without. The researchers concluded that having a chronic illness did not predict a decrease in overall HRQOL in the aftermath of a disaster.

Stanley, Muntner, Re, Frohlich, Holt, and  Krousel-Wood (2011) assessed QOL of patients with hypertension in the aftermath of Hurricane Katrina in New Orleans, United States. The researchers interviewed 211 adults (mean age 63.5 years) using the MOS SF-36 to assess QOL and a questionnaire that asked about the patient's experience of Hurricane Katrina and a Hurricane Coping Self-efficacy Scale which measured the patient's ability to do day-to-day activities and cope with psychological stresses in the post-hurricane environment. Additional supplementary questions were also asked which looked at distance to travel in order to visit with family and friends, the extent of damage to their property and what caused most stress in the aftermath. The results revealed that nearly all areas of QOL were affected after the hurricane with the exception of social functioning. QOL was noted to be particularly affected by lower levels of coping ability and in patients who reported higher levels of post-disaster stress brought about by personal and financial losses or health concerns. However, the effects of distance and lack of visits from family and friends and significant damage to homes and properties also contributed to a reduced QOL in the post-disaster environment.

### The effects of Earthquakes on the QOL of Children, Adolescents and Youth

Four articles have looked at the specific effects of EQs on the QOL of children and adolescents. Ceyhan and Ceyhan (2007) compared the QOL and academic achievement of university students who had experienced the 1999 Marmara EQs six years beforehand with students who had not been exposed to the EQs. A total of 407 students aged between 17- 27 years with a mean age of 21 years. Approximately half were aged between 11-21 years at the time of the EQs. The WHOQOL-BREF was used to measure QOL scores. Exposure information was gathered in interviews, including any loss of family or significant others in the EQs, the extent of EQ damage to the students' homes, the type of shelter used after the EQs and whether psychological help was received. Achievement was determined as their grade point average (GPA) at their study institution. The researchers found that the QOL psychological and environmental domain scores and academic achievement were significantly lower for the group exposed to the EQs. The study identified that the younger survivors scored lower in the psychological domain and had lower GPA scores. Financial difficulties after the EQs were associated with lower scores for the additional QOL domains of physical health and environment. The study identified that it is important to ensure the availability of long-term post-disaster psychological assistance for survivors.

Goenjian, Roussos, Steinberg, Sotiropoulou, Walling, Kakaki, and Karagianni (2011) investigated the relationship between QOL and levels of PTSD and depression amongst adolescent (age 13 – 18 years) survivors of the 1999 Parintha, Greece magnitude 5.9 EQ. The study involved a 32 month follow-up of 511 (female: 297; male: 214) students attending high school in a city near the epicentre of the EQ who had been assessed for EQ exposure and PTSD along with depressive symptoms three months after the event. The present study incorporated the Quality of Life Questionnaire (QOLQ), a 24 item questionnaire designed to measure five areas of QOL for adolescents; family relations, social interactions, anxiety/somatic complaints, alcohol/drug and related academic problems and risk taking behaviour. The study also asked the participants to measure the frequency of objective and subjective experiences of the EQ such as whether during the EQ they had been trapped (objective) or whether they had feared being trapped during the EQ (subjective). Goenjian and colleagues (2011) also included questions regarding trauma reminders over the previous month including sounds, places, signs of destruction, faces or feelings. The researchers reported that the overall QOL score was 77.4 for the whole group (77.3 for females and 77.4 for boys). It was also noted that there was a significant correlation between the total QOLQ score and the five domains with the PTSD and depressive symptoms scores very significant relationships found for all domains except social relations and risk taking. Although it was found that depressive symptoms were correlated higher with the QOLQ scores with anxiety/somatic symptoms the highest correlation rather than PTSD scores. The study found that the depression severity levels at three months after the EQ was the best predictor for QOL scores at 32 months after the EQ.

Two studies looked at the effects of EQs on the HRQOL of children and adolescents after the 2008 magnitude 8 EQ in Sichuan province, China. Jia, Tian, He, Liu, Jin and Ding (2010) characterized the QOL and mental health status of 596 child survivors aged between 8 and 16 years from villages within the most severely affected areas. The study carried out 15 months after the EQ utilised the PedsQL for HRQOL which includes 23 items and four subscales which included measurements for physical functioning, emotional functioning, social functioning, and school performance. The scores from these give the total physical, and psychosocial summary scores. The children were also assessed for PTSD and symptoms of depression. The study found that the mean HRQOL score for all participants was 82.2 (out of 100) however, significant decreases were noted in children with PTSD (70.0) compared to those without PTSD (83.9) and those with and without depression (71.7 and 83.9). Given that one in five children and adolescents were identified with having PTSD or depression the EQ had a considerable impact on the HRQOL of many of the respondents.

Tian, Jia, Duan, Liu, Pan, Guo, Chen and Zhang (2013) carried out a longitudinal follow-up of HRQOL to the study conducted by Jia and colleagues (2010) at 36 months after the EQ. Utilising the PedsQL, the study re-interviewed 430 children and adolescents aged between 8-16 years from the original study (Jia et al., 2010). It was observed that females and older children aged between 13-16 years were more likely to experience a significant decrease in HRQOL the longer time passed. This decrease was also noted in children who had witnessed deaths or serious injuries or had extreme anxiety about their own safety. However, the majority of children without significant EQ-related experience also showed decreased HRQOL. This might suggest that there is a delayed response amongst adolescents who do not necessarily directly experience EQ trauma. The authors suggested that it could be in response to a lack of psychological assistance or social support for children and adolescents who are deemed to not require it in the aftermath of an EQ. The study also observed that both scores of HRQOL in the measured population were lower than the population average indicating that the EQs did affect the long-term HRQOL of children and adolescents.

There are some significant limitations in the literature. One noted limitation with the literature on children and adolescents is the frequent use of HRQOL instruments to assess for overall QOL. While the HRQOL studies are multidimensional and invaluable to the assessment of clinical outcomes, the optimal focus is on physical and psychological health and the HRQOL does not incorporate a wider holistic approach to overall QOL. The PedsQL used by Jia et al. (2010) and Tian et al., (2013) is considered a comprehensive HRQOL instrument but its primary focus is still on clinical physical health outcomes. However, EQs can and do impact on all areas of an individual’s life including personal, psychological, family, social, and environmental and therefore the measurement of QOL should take a more holistic approach to measuring the effects of such disasters on children. Finally, the most important limitation of these studies is the failure to investigate the effects of EQs on the QOL of children and adolescents with pre-disaster disabilities and health issues. The studies that have focused on the effects of EQs on the QOL of children and adolescents have all concentrated on children and/or adolescents without noting any existing disabilities or health issues. All of the studies have reported the participants as having a lower QOL and experiencing psychological issues including PTSD or depression as a result of the trauma and loss resulting from the EQ but this is a post-disaster diagnosis and therefore does not contribute to the much needed literature on children with disabilities which pre-date disaster.

The lack of literature on the QOL of children with disabilities in disaster situations makes it more difficult to determine what effect the Christchurch EQs might have on the QOL of children with disabilities. However, evaluating the existing literature about the non-disaster QOL for children with disabilities alongside studies about children with disabilities during disasters may provide a foundation for hypothesizing the potential effects of a disastrous EQ on the QOL of Christchurch children with disabilities. The following section will look at the different domains of QOL for children with disabilities as set out in the Centre for Health Promotion model, including physical health, psychological health, social belonging, and community belonging.

## Quality of Life of for Children and Adolescents with Disabilities.

**QOL: physical health.** The domain of physical being is primarily concerned with physical health and how important this is considered for a child with a disability and how satisfied they are with their overall physical health. The general health of children with disabilities is frequently thought to be poorer than children without disabilities. One review by Allerton, Welch and Emmerson (2011) reviewed the health inequalities experienced by children (<18 years) with intellectual disabilities in the United Kingdom. The researchers reviewed 18 articles to identify relevant findings. The review found that children with intellectual disabilities were more likely to be obese with its associated health risks than their peers without disabilities. The review also noted that there was a higher prevalence and risk from epilepsy and a greater increase in comorbid conditions including ADHD and ASD. There were also increased probability of mental health disorders including depression when compared to their typically developing peers. Allerton and colleagues (2011) found also observed that parents and caregivers were more inclined to describe their child's general health as fair or poor compared to parents of children without disabilities.

There have been several studies with children that have indicated that poorer physical health can affect QOL. Dey, Landolt and Mohler-Kuo (2012) conducted a literature review and analysed 16 studies that compared the Health Related Quality of Life (HRQOL) of healthy children with children with confirmed diagnoses of a mental disorder including ADHD, Specific Learning Disabilities and ASD. In the reviewed studies, HRQOL was measured by both or either child reports and parent reports. The researchers noted that there were inconsistent results in terms of the relationship between the physical health scores and overall HRQOL across the disability types. While some of the studies had clinically meaningful effect sizes for physical (sub) scales the authors could not provide any further information on why this was. However, they observed that while the domain of physical health was lower as compared to a control group without disabilities, the impact of this difference was very small especially when compared to the impact of other measured domains such as emotional and family domains.

Waters, Davies, Nicholas, Wake and Lo (2008) collected parent reports on mental and physical health of more than 5,400 primary and secondary school students in Australia. About 48.5% had at least one physical health concern ("including asthma, chronic-respiratory-related problems, chronic allergies, chronic orthopaedic, chronic rheumatic disease, epilepsy, hearing and visual impairment and speech problems"), and 19.6% had a mental health concern (including anxiety, attention problem, behaviour problems, depression, developmental delay or intellectual disability and learning problem), and 26.9% had both a physical and a mental problem (p.420). The QOL scores of the children were not significantly related to any demographic variables such as age or gender, SES or parent level of education but were significantly related to their health. General health was negatively affected in children with physical and sensory disabilities and those with chronic conditions. However, children with developmental delay or intellectual disabilities did not appear to have a negative impact on their general health score. In fact all children with mental health concerns had slightly better general health scores than the majority of children with physical health concerns. The researchers did observe that the more health problems, the greater the impact. Children with one physical health problem had lower scores in five domains on average, including general health, mental health, emotional and bodily pain. While children who had multiple problems had significantly poorer health and scored lower across all domains measured.

As the literature has shown us the physical health-related QOL of children with disabilities can be lower than that of their peers. Likewise, the physical health is particularly vulnerable in a post-disaster environment (Peek & Stough, 2010). In some instances, a disaster may require evacuation, and the first-responders involved may not have the experience or knowledge of working with children who have disabilities, such as ASD or cerebral palsy. This situation could result in vital medical equipment upon which the child's health relies being left behind. In addition, evacuation might involve attending health care services that are unfamiliar with the medical history of the individual thus there is a greater risk of not receiving the right care or treatment as and when it is needed (Murray, 2011). Similarly, children might be separated from parents or caregivers and are at greater risk of further health consequences as those around them may not understand their special health needs such as special diets, medications or assistance with toileting. Physical health can also be diminished as there may be limited or no access to required medical equipment. Thus, the physical health of children with disabilities can become worse post-disaster (Peek & Stough, 2010), which can reduce QoL.

Children with disabilities' post-disaster physical health issues related to Hurricane Katrina were studied by Abramson and Garfield (2006). They found that access to medical care and specialist treatment for children with disabilities was greatly reduced while their needs remained the same. They found that the loss of health information records limited or delayed access to medicine for 27% of households. Children did not receive their prescribed medication in 19% of cases in the post-Katrina environment. Children in temporary housing required additional specialist medical equipment with over two-thirds of respondents reporting that accessing the equipment was a significant issue (Abramson & Garfield, 2006). After the disaster, parents of children with disabilities were three times more likely to report that their children had poor or fair health (Abramson & Garfield, 2006).

**QOL: Psychological health.** Psychological being is primarily concerned with how children with disabilities feel about their mental health and how satisfied they are with their ability to control and regulate stress in their lives. The study of factors which impact on the psychological quality of life includes many areas including the prevalence of mental health condition(s), levels of self-esteem, stress and emotional wellbeing. Studies have found that children with disabilities have a higher prevalence of psychological health issues than their peers without disabilities. One study by Emerson & Hatton (2007) found that for children and adolescents with an intellectual disability the prevalence of a psychiatric disorder was 36 percent compared with 8 percent among children without. Other studies have reported that poor mental health can greatly impact on psychological QOL. Waters,  Davies, Nicholas, Wake and Lo (2008) found in their study on mental and physical health of more than 5,400 Australian primary and secondary school students, that children and adolescents with depression had significantly lower scores in the QOL domains related to psychological quality of life, including: mental health, self-esteem, and behaviour. Similar effects were reported for children and adolescents with other mental health problems (Waters, Davis, Nicholas, Wake & Lo, 2008).   Children and adolescents with physical disabilities who did not have mental health problems, had better overall psychological health. The researchers found that comorbid physical and mental health conditions had particular impact on the QOL scores for social, emotional, behaviour, self-esteem as well as family activity.

Psychological wellbeing has also been observed to be affected by an individual's level of stress and how they respond to stressful events. Lee, Harrington, Louie and Newschaeffer (2008), evaluated the difference in QOL as reported by parents of children with disabilities including those with ASD and ADD/ADHD with reports by parents of children without disabilities from a control group. In the areas related to psychological health, the parents of children with ASD were nearly three times more likely to be concerned about the child's ability to cope with stress compared to the parents of the control group. Concerns for their child's self-esteem was more than double for the parents of children with ASD when compared to the control group. Parents of children with ADHD did not report as high a level of concern in regard to their child's stress-coping and self-esteem. However, a number of parents of children with ASD and ADHD also reported concerns for their child being bullied which is known to initiate psychological health problems including stress and anxiety.

A study by Cramm and Neiboer (2012) found that there is a close link between the psychological or emotional health of children with disabilities and that of their parents. They conducted a longitudinal study in the Netherlands that investigated the relationship between the QOL of 108 parents and their children with an intellectual disability (ID). The research evaluated the impact of five QOL domains on the overall QOL of children with ID; including the social and emotional wellbeing of the children and their parents. The results found that the indicators of emotional well-being for the children, changes in their emotional well-being and changes in parental social and emotional well-being were the strongest predictors for QOL in children with an ID. The researchers observed that there is a close link between the emotional well-being of children with ID and their parents' emotional well-being. Parents who reported lower stress levels had a higher emotional well-being and simultaneously reported their children as having higher emotional well-being.

There is a strong indication that that the ongoing trauma will negatively impact on the psychological health of children and adolescents with disabilities. Unfortunately very few studies have investigated the potential outcomes. What is suggested that like all children, when they are exposed to ongoing and repetitive traumatic experiences they will respond in a number of ways and their reactions to the stressful events will be dependent on other personal and external factors including age, gender, personality, parent influences and exposure to events (Shaw et al., 2007, Peek & Stough, 2010, Murray, 2006, 2011, Shaw et al., 2012). Responses to these events can include any number of regressive behaviours, sleep and appetite disturbances, heightened anxiety symptoms, behavioural issues including increased violence, school refusal and learning issues, withdrawal from family and friends, sadness and pre-occupation with the events of the disaster (Murray, 2006, Shaw et al., 2007). Any of these can have long-term negative effects on the psychological health of the child. If a child is constantly exposed to reminders of the event(s) such as repeated aftershocks after large EQ or sounds or sights that act as triggers or "traumatic reminders" (Shaw et al., 2007) their psychological health recovery may take much longer and impact negatively on their QOL.

According to Shaw and colleagues (2007) two types of psychological reactions are seen in children after disasters, acute stress responses and chronic stress responses. The majority will experience acute stress responses especially during the impact of the actual event and the days and weeks after the event. In children, these responses could include, changes in bodily function such as somatic complaints and disturbance of sleep; changes in behaviour including regressive behaviours; changes in mood including fears and anger responses; changes in thinking such as loss of trust and changes in interpersonal relationships including withdrawal and poor school performance (Shaw et al., 2007). For the majority, these symptoms will dissipate over time as the stressors reduce, however in natural disasters, post-disaster stressors may continue to affect the child and their families which can lead to chronic stress responses that continue for lengthy periods of time. These include anxiety and mood disorders, dissociation, disruptive behaviours, loss and grief reactions, personality changes, psychiatric comorbidity, somatic complaints and central nervous system changes. Sometimes, there may even be delayed psychological responses which is especially a risk children as they get older and start to fully understand the implication of what happened. If there is a lack of medical intervention, these can lead to longer term issues including acute stress disorders and PTSD. Other mood disorders including depression also have a high prevalence (up to 40 percent in some cases) in (Shaw et al. 2007). It is therefore, essential that the psychological responses of children and adolescents monitored in the aftermath of disasters to ensure that it does not impact significantly on their QOL.

One area of concern for the post-disaster psychological health of children and adolescents is that studies addressing post-disaster adult populations have found that there is a link between pre-disaster psychopathology and a heightened risk factor for post-traumatic stress disorder (PTSD) (Norris et al., 2002). One study that examined this link in children and adolescents was undertaken by Asarnow et al., (1999). This study investigated symptoms of PTSD, depression, general anxiety, and social impairment in 63 children ranging in age from 8 to 18 years who had experienced the 1994 Northridge, Los Angeles earthquake. These children had been selected from a pre-earthquake study that was investigating childhood-onset depression at the time of the EQ. In the initial study prior to the EQ over thirty percent of the children were self-reported as having either major depression (parent reported: 48%), a major anxiety disorder (parent reported: 41%) a disruptive behaviour disorder (parent reported: 57%) such as ADHD or having no diagnosis at all (parent reported: 17%). A number of children were also reported to experience comorbidities of the above mentioned conditions.

Asarnow et al. (1999) post-EQ study, approximately one year after the EQ, used the Children's Posttraumatic Stress Disorder Reaction Index (CPTSD-RI) (Pynoos et al., 1987) to assess PTSD reactions in the children where scores of 12 to 24 equal mild PTSD; 25 to 39, moderate PTSD; 40 to 59, severe PTSD; 60 or greater, very severe PTSD. The Earthquake Exposure Questionnaire, Child Form (EEQC) was used to assess objective aspects of the EQ including injuries or damage to their home, subjective assessments of risk and vulnerability, and post-EQ hardships (Asarnow et al. 1999). The results indicated that the majority of children (43/63) scored low on the PTSD risk range, however 19 percent reported mild PTSD and 9.5 percent recorded moderate PTSD scores. There was a higher chance of symptoms of PTSD being reported for children who had a pre-EQ anxiety disorder (self-report mean: 14.29; child and parent report mean: 13.5 (mild PTSD) compared with those who had no pre-EQ anxiety disorders (self-report mean: 8.59; child and parent mean: 8.38). Subjective exposure measures including resource loss and perceived stress were also found to indicate a higher risk for PTSD symptoms. Significant associations also linked symptoms of PTSD to other impairments including depression symptoms and general anxiety. The researchers noted that their study highlighted the complex links between trauma exposure, depression and PTSD observing that while there was a correlation between PTSD and depression symptoms after the EQ, pre-existing depression did not seem to predict post-EQ PTSD.

Another noted area of concern for the psychological health and wellbeing of children with disabilities is the potential effect the disaster can have on their parents or caregivers. Peek and Stough (2010) suggest that children with disabilities have greater reliance on their parents for functional assistance and emotional support. In the aftermath of a disaster, children with sensory disabilities or intellectual disabilities may require their parents or other significant caregiver to communicate for them or explain the situation or event to them. If the parent is experiencing emotional or psychological distress due to the trauma, then this can affect how they respond and assist their child. As Cramm and Neiboer (2012) found there are close links between the emotional wellbeing of the parent and their child with a disability. Mental health experts acknowledge that there are strong links between parental distress or psychopathology and a likelihood of diagnosis of PTSD in the child (Shaw et al., 2012).

Peek and Stough (2008) suggested the possibility that parents of children with disabilities may already be under considerably more pressure in the pre-disaster situation compared to parents of typically developing children. There have been a number of studies that have identified that parents of children with disabilities often have higher recorded levels of stress than parents of children without disabilities (Dyson, 1996; Hassall, Rose & McDonald, 2005; Smith, Oliver & Innocenti, 2001). This can be for numerous factors, including health, educational or financial concerns associated with the care and outcomes for their child with a disability. However, it is conceivable that they and their children are at even more considerable risk of significant psychological distress or impairment in the post-disaster environment. The literature on the probability of a PTSD diagnosis strongly associates pre-existing stressors and psychopathology with an increased chance of PTSD in the aftermath of a disaster (Asarnow et al. 1999; Norris et al., 2002; Shaw et al., 2012). In children, the likelihood of PTSD is strongly associated with family outcomes, in particular parental psychopathology. If a parent is susceptible to psychological distress, then there are strong indicators that a child may develop similar symptoms. This would then support the probability that children with disabilities are at a greater risk of developing long-term psychological health concerns in the wake of a disaster.

Another factor that puts children with disabilities at greater risk of long-term psychological impairment is potential difficulty in accessing appropriate and knowledgeable treatment in the wake of a disaster (Peek & Stough, 2010). Damaged facilities may preclude ease of access for children with physical limitations which may require them to travel further to access the required treatment. Similarly, given that health facilities may be damaged, there may be increased pressure for room on undamaged facilities due to the disaster which could see previously available psychological treatment services reduced. This could also be affected by a lack of sufficient or skilled staff experienced in various mental health conditions who may have had to evacuate or leave the area or have been seconded to more urgent areas. As well as the lack of accessible psychiatric treatment facilities, children with disabilities may find conventional treatments for psychological conditions such as PTSD are not as beneficial to them. This is because effective treatment of such conditions often involves processing of emotions and feelings. Children with ASD or other ID who have pre-disaster information processing disorders may not respond to this type of treatment (Peek & Stough, 2008).

One important aspect of psychological QOL in a post-disaster context is coping ability. Coping is a skill used to respond to stress including disaster-related stress and is linked to psychological health. Therefore it is important to look at how children and adolescents cope with stressful situations. Compas, Connor-Smith, Saltzman, Thomsen and Wadsworth (2001) identified coping as one aspect of an individual’s reaction to stress and defined it as “the conscious volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances” (p.89).

Children, adolescents and adults may have or use different coping strategies. Children using problem-focused coping strategies might engage in information seeking activities while an emotional outburst would be seen as a form of emotion-focused coping. A child seeking to enhance personal control over their environment and emotional reactions would be using primary control strategies while a secondary control strategy sees the child use an adaptive response to the situation through reframing, acceptance or distraction (p.120). The engagement and disengagement response has its' basis in the fight (engage) or flight (disengage) response (p.89) and are either orientated towards the stressor (engagement) or away such as distraction (disengagement). What strategy is utilised by a child or adolescent depends on the situation and the level of control they have over that particular situation. Compas and colleagues (2001) noted that any study of coping in children and adolescents must recognise that coping is complex and multidimensional.

Compas and colleagues (2001) reported that research studies have clearly indicated that there is a distinct relationship between coping and child or adolescent psychological adjustment to stress. They reported that studies which examined coping and psychological constructs, broadly categorised as internalizing and externalizing behaviours, found that problem-focused and engagement coping were associated with better outcomes and psychological adjustment in both children and adolescents (Compas et al., 2001). The researchers highlighted the importance of taking the context of coping into account in that the outcomes are determined by the level of engagement with the stressor event and maybe ineffective in situations that are out of the child's or adolescent's control (p. 119). They also observed that none of the studies looked at the coping levels of children or adolescents with specific diagnoses.

Pfefferbaum, Noffsinger, Wind and Allen (2014) linked current ideas about stress and coping to documented evidence of the effects of disasters on children and their responses to them. They discovered that there needs further clarification on different concepts of coping as well as establishing means to measure coping methods.

A child’s stage in development plays a significant role in how they cope with disasters, however, there are other factors that determine the efficacy of what coping strategies the child uses and what strategies they will use. Children are affected by disasters according to basic demographic factors including their age, gender, race and ethnicity but also more complex characteristics including disposition, pre-disaster adjustment and psychological functioning as well as their level of exposure to disaster, family reactions and support and the overall level of community adjustment and recovery, which would be factors involved in considering psychological being  and the development of coping skills as a marker of growth becoming in overall QOL assessment.

For some children with disabilities developing the capability to adjust and adapt to changes maybe complex. This in part depends on the limitations associated with their disability. Activity and experiential limitations would affect the development of coping skills. Children with an intellectual disability may struggle to develop coping skills due to cognitive or memory limitation on understanding as disaster situation or considering alternative strategies (Peek & Stough, 2010; Murray, 2011. There is also the possibility that children with disabilities may have fewer opportunities for such experiences because of more limited social interactions with their peers who could model coping skills.

Asarnow et al. (1999) in their study of children one year after the Northridge EQ evaluated the different coping responses children used to cope with the EQs and their prevalence for PTSD symptoms. The study used the Coping Responses Inventory from the Health and Daily Living Form (Moos 1988), where children were asked to rate how frequently they used different coping strategies. The scores were then totalled and assessed against measures that determine whether they use one of three coping strategies. These included Active cognitive coping where the child would actively think about the stressor and try to see positives and better understand their situation; active behavioural coping where the child will engage in actions or behaviours to help them understand the situation; and avoidance coping, including cognitive and behavioural means to "avoid thinking about the stressor or avoiding the stressor" (Asarnow et al. 1999, p. 1018). The results indicated that there was a marginal association between avoidance coping and PTSD which was consistent with other studies. However, children who used high rates of active cognitive coping also had a high association with PTSD. In this scenario, the researchers believed that children with symptoms of PTSD relied on cognitive as well as avoidance coping strategies and as such "ruminated" on previous experiences including EQs (Asarnow et al. 1999, pg. 1022).

Valenti, Gabrielli and Tomassini (2011) studied how children and adolescents with ASD coped with and adapted to post-EQ events in the L'Aquila, Italy earthquake. This study included 18 participants (children = 9; adolescents =9) over the year subsequent to the earthquake and compared their results with 42 children (N=20) and adolescents (n = 22) diagnosed with ASD who had not experienced the earthquake. Using the Italian version of the Vineland Adpative Behaviour Scales, the researchers measured adaptive skills in communication, daily living, socialisation and motor skills at three separate occasions. The first administration was taken just days before the earthquake occurred, the second six months afterwards and the final administration was one year after the earthquake. The results showed that there were significant decreases in all four measured domains in the children and adolescents with ASD who were exposed to the earthquake after 6 months, with the most dramatic impact on the socialisation domain. However, psychological adjustment had improved by the 1 year anniversary although not to the baseline levels taken prior to the earthquake. This indicates that children with ASD may have coping strategies that produced this result. However, studies of changes in psychological QOL have not been reported, although this could also confirm the presence of coping skills. It was observed by Valenti and colleagues (2011) that the adaptability of the children with ASD depended highly on their inclusion in routine, intensive rehabilitation and the re-establishment of every-day routine as quickly as is possible.

**QOL: Social belonging.** Social belonging includes the quality of friendships, social interactions and social activities. One aspect that defines the QOL of people with disabilities is their social connectedness to family and friends who are important to them. For children, a strong indicator of QOL is the importance they place on friendship. The ability to develop and maintain friendships contributes greatly to the QOL of children with disabilities. Mokhtari (2008) conducted a phenomenological study with five adolescents with an ID, including Down syndrome and Fragile X Syndrome about their experiences of friendship. All of the adolescents reported having between 2 to 5 friends and all but one reported their best friend as also having a disability. The respondents saw their friends as important in their day-to-day events while at school but also noted that it was important to continue contact outside of school to maintain the friendship.  They associated being with their friends as, “making them happy, and feeling good about themselves” but also about being able to trust them when they felt angry or upset. However, nearly all the participants in the study expressed a desire to have and develop more friendships which suggests that they place great importance in friendships. This study supports the assertion that friendship has great benefit for the QOL of adolescents with disabilities.

However, it is often suggested that children and adolescents with disabilities are more likely to struggle to make friends and have fewer friends than their peers (Heyne, Schlein & McAvoy, 1994). One Canadian study by Solish, Perry and Minnes (2010) examined the nature of friendships of children with disabilities, focusing on those with ASD and those with an ID without ASD compared with children without a disability. They found that children with ASD and ID had significantly fewer friendships than other children. More than half of the children with ASD were reported as having no friends compared to 21 percent of children with ID and just 1 percent of children without a disability. While children with ID were found to have more friendships than those with ASD, there were indications that the extent of the friendships was limited as just 7 percent reported having more than 5 friends compared to over 67 percent of other children. Parents also reported that just 10 percent of children with ASD had a defined best friend compared to 27. 6 percent of children with ID and 72.8 percent of children without a disability. When the researchers compared the level of social interaction between the different groups, it found that just 50 percent of children with ID had the opportunity to play at a friend's home compared to 90 percent of children without a disability. Children with ASD were noted to have more friends come over and play (32%) but in comparison with 56 percent children with ID and 83 percent of children without disabilities.  This would suggest that developing and maintaining friendships is a constant struggle for some children with disabilities.

The impact of disasters on the friendships of children with disabilities and how this affects their QOL has not been researched, however, it is highly likely that the significant disruption that is often evident in the aftermath of any disaster will have an impact on friendships between children with disabilities and their peers. As Peek and Stough (2008) and Solish et al. (2010)  note, children with disabilities tend to have pre-existing difficulties in developing social relationships and may experience any loss of friends more acutely. Friends are lost because families may need to move to new homes or work, schools may close because of damage or post-disaster changes in infrastructure, or because the child may be struggling with psychological difficulties which may impact on a child’s ability to maintain contacts. (Shaw et al., 2012). Abramson and colleagues (2006; 2007) studied disaster-displaced children and noted that many children had to move schools or move homes or had more time off school for health concerns which in turn potentially affected their ability to maintain friendships established before the disaster.

Children with disabilities are also dependent on their caregivers for support and access to maintain and encourage new friendships (Matheson, Olsen & Weisner (2007). The impact of the disaster and its aftermath on their families will also play a critical aspect in maintaining pre-existing friendships. If a parent or main caregiver is struggling to cope with the changed circumstances or is experiencing psychological trauma, they may become more isolated from the community and so isolate their child as well. This in turn is a strong pre-cursor for a child developing PTSD symptoms (Shaw et al., 2012). Children who experience mental health conditions may experience difficulties in establishing and maintaining relationships with their peers. As some children with disabilities experience difficulties in expressing how they feel emotionally and thus may remain undiagnosed, they are more at risk of long-term mental health effects and thus further distance themselves from existing friendships and the opportunity to develop new ones (Peek and Stough 2008).

Social Belonging is also affected by access to and participation in social and leisure activities, being able to meet up with friends and family or participating in a recreation or organised activity such as sport is an important factor in contributing to their social wellbeing and overall QOL. Participation in recreational or leisure is a universally accepted factor in the contribution to a child's general health and wellbeing as it enables social interaction and learning opportunities (King, Law, King, Rosenbaum, Kertoy & Young, 2003). For children with disabilities, recreational or leisure activities often provide much needed opportunities for social interaction which is often noted as being less developed (Solish, Perry, & Minnes, 2010). There are, however, often limitations in the level of participation in recreational or leisure activities for some children with disabilities. These may come in the form of environmental barriers such as access to facilities or appropriate transport to a recreational activity. Community barriers may also exist through a lack of acceptance or support for the special needs of children with disabilities which enable them to participate. Research suggests that participation by children with disabilities in recreational and leisure activities is less than their peers (Solish, Perry, & Minnes, 2010).

King, Law, King, Rosenbaum, Kertoy and Young (2003) and King et al (2009) outlined a series of factors that influence the participation of children and youth with physical disabilities in recreational or leisure activities. Three factors, environmental, family and the child were identified to contribute to the level of participation by a child with a physical disability. Environmental factors included the need for supportive physical and institutional structures and access to supportive relationships for the child as well as the parents. The family influences included financial and time concerns, a supportive home environment and a family preference for recreation. At the child's level, important factors included the child's self-perception of their ability along with their physical and emotional functional capabilities and their preferred recreational activities. The researchers acknowledged that all factors had to be considered when addressing the leisure and participatory needs of children with disabilities and their families. Without these factors being addressed then children with disabilities could be limited in their access to meaningful recreational activities contributing to a decreased wellbeing.

The concept of enjoyment and "fun" is seen to be at the heart of childrens' choice and engagement with recreation and leisure activities. In a phenomenological study by Heah, Case, McGuire and Law (2007), children with disabilities, including CP, developmental delay and ASD and their parents were asked what successful participation in recreational or leisure activities entailed. The researchers asked a series of questions of families with children with disabilities, including what the child liked to do for fun, what they liked about what they did and their satisfaction with the activities. The children and their parents observed that "having fun" was a very strong criteria for them to enjoy participating in a recreational activity. One child commented, "When I'm having fun, I don't really like to stop" which the parent agreed in saying, "If he enjoys it and follows through with it, I would say [the activity] is successful". Another child stated that he was happy with the activities he participated in because "Because I enjoy doing them." The children and their parents all agreed that if the child found the activity boring then they would not participate in it. Successful or meaningful recreation or leisure activities were noted in many different areas, not just sport or organised activities as a parent observed that she was happy when her son enjoyed watching television since he struggled with other activities and that perhaps he felt watching television was an activity he could successfully engage with. The researchers noted that successful participation in recreation or leisure activities was often measured by the level of success or accomplishment the child felt within that activity which would contribute to their overall sense of wellbeing.

Another theme that emerged from the Heah, et al, (2007) study that considered what successful participation by children with disabilities was, was the opportunity to spend time with others. One parent viewed successful participation as “being with people. He just loves it. He is very people oriented. Loves having friends and people to do things with” (p.42). The researchers also noted that some families indicated that while participation in an activity itself had little meaning for the child, the ‘shared experience’ with others in the process was very important in the child’s development (p.44). The findings would suggest that social interaction is vital in promoting the social belonging aspect of QOL of children with disabilities and their families.

However, the literature indicates that the opportunities for social interaction are reported to be far fewer than for children without disabilities (Heyne, Schlein & McAvoy, 1994; Matheson, Olsen & Weisner, 2007). Solish, Perry and Minnes (2010) compared children with ASD and ID with their typically developing peers for their level of involvement in various types of activities, both informal and formal and with whom they participated with in the activity. They identified social activities (e.g. going to birthday parties, visiting friends, having sleepovers, talking on the phone or going to the movies) and recreational activities (e.g. playing team sports, swimming lessons, dancing lessons or music lessons) which would afford opportunities for social interaction. The researchers found that both groups of children with disabilities participated in significantly fewer social and recreational activities than their typically developing peers. Just 23 percent of children with ASD and 34 percent of children with ID participated in social activities with their peers compared to 61 percent of other children. Only 17% of children with ASD participated in recreational activities. The research confirms that children with disabilities may have fewer opportunities to participate in social activities with their peers.

However, disasters may impact on the social interactions and activities of children with disabilities and thus affect QOL. There is no literature that has looked at the impact of a disaster on the quality of social interaction and activities of children with disabilities. However, it is reasonable to envisage that there will be potential damage to facilities where social interaction may have previously occurred. Schools, recreation halls, shopping malls, cinemas, churches, sports centres and other places where people congregate or meet with friends and associates may be damaged or even destroyed in the aftermath of a disaster thus dispersing and isolating the people who may have used the facilities for social contact. Children or adults may have been in particular buildings at the time of the disaster such as an earthquake and may subsequently fear re-entering a similar style of building or being in an enclosed space. Since participation in social activities is already strained for some children with disabilities and their families (Solish, Perry & Minnes, 2010; Heah, Case, McGuire & Law, 2007), the removal of familiar resources may cause further strain and decrease the opportunities for social interaction.

It is also possible to speculate that quieter leisure activities such as watching television, listening to music or playing computer games along with various other activities may be effected by loss of power. While this loss may be only be temporary, it may cause distress or alarm to a child who may not necessarily comprehend what is happening around them. Similarly, common activities such as walking, biking, swimming, visiting friends and family may be severely restricted by lack of access to roads or dangerous environments in the aftermath of events such as earthquakes or floods. Organised activities including sports and lessons will be cancelled, support people may have been displaced or had to move away, records and contacts may be lost or the activities have needed to be relocated further away. With potential disruption to pre-disaster transport options for children with disabilities, this could further limit their ability to access social activities in the post-disaster setting. As the literature has identified that opportunities for recreation and leisure can be more limited for a child with a disability when compared to their peers without a disability, any loss or restriction on what activities they engage in for fun and enjoyment is likely to be felt more acutely. Since they may be less able to adapt or compromise on the activities participated in because of differing physical, cognitive or social aptitudes, their changed levels of social engagement and inability to participate in the same leisure activities may negatively impact on their social QOL.

**QOL: Community Belonging.** For children with disabilities the ability to access places of importance to them within their community does contribute to their sense of belonging and QOL. Access to community educational and recreational facilities allows a child with a disability along with their family to participate in everyday activities and potentially develop skills that can contribute to better adult outcomes. Quality community access for those with disabilities has been measured through ascertaining whether an individual with a disability has been able to access any community activity that they have wished to engage with. In a US study of young adults with ID, Kampert and Goreczny (2007) sought to ascertain which key areas of importance to individuals with disabilities, including consumer satisfaction, dignity, choice, community inclusion, and overall quality of life, would contribute most positively to an improvement in their lives. They researchers found that more participants sought or felt that an increase in their community participation, such as attending church services or going to a restaurant would contribute to an improvement in their lives. This desire was often linked with a desire to increase social interaction. While this study only considered young adults with disabilities, it does suggest that increasing community access for individuals with disabilities may contribute to greater wellbeing.

Solish, Perry and Minnes (2010) in their study that reviewed the participation levels of children with disabilities, in particular ASD and ID, also observed that children with disabilities participated in less activities within their local community compared to children without disabilities. This included going to local parks, the movies or going out for meals. It was, however, noted that children with disabilities were markedly more likely to go to the local mall than children without disabilities. This, the researchers thought, could be because of the higher number of activities carried out with adults by the ASD and ID groups when compared with their peers. When access to community recreational facilities for lessons was considered, the children with disabilities did not attend lessons for swimming at local pools, sport or other activities at the same levels as their peers without disabilities. Although potential reasons for this were not captured by the study, it was suggested that the need for and lack of additional supports for these classes may contribute. Solish and colleagues noted that a number of children with disabilities did attend community activities; however when compared with their peers without disabilities, there were sizeable differences. The findings found that just 17 % of children in the ASD group and 39 % of children with ID participated in recreational activities compared with 64 % of children without disabilities. While there was no clear analysis over the lack of engagement with community facilities, it was implied that some children with disabilities may encounter barriers in accessing community facilities which do not adequately meet their needs.

A study that did attempt to analyse the availability of community programmes for children with disabilities was carried out by Heah, et al. (2007). The researchers, asked the families of children with disabilities, including ASD, CP and developmental delay to outline barriers to their child's successful participation in recreational activities. The parents in the study gave various reasons. Some indicated it was very difficult to find appropriate community organisations that offered suitable programmes for their child with a disability while others found that their community programmes actively encouraged and promoted different activities for children with a range of disabilities. One parent pointed out the difficulty of finding the appropriate skill-level group, saying, "They said they would help me if I could find the kids. But I couldn't find anybody. Because you have a lot of wheelchair clubs, and you have other kids' clubs. But you don't have anything in between". Other parents identified the importance of working with other parents of children with disabilities to locate community programmes which were available and appropriate for their children. The researchers noted that there was a range of experiences with community organisations with some of the parents expressing frustration at feeling they were not being heard while others felt satisfied with the programming available. This would suggest that community belonging needs of some children with disabilities are not being fully met.

There is no research that has looked at the impact of a disaster on the quality of community belonging or access for children and adolescents with disabilities. Damage to existing community facilities such as schools, halls, libraries, pools and shopping malls could increase limitations for access to community activities. The community programmes that are designed for children with disabilities and their families may be discontinued or relocated because of lack of staffing or funding issues in the aftermath of the disaster. Similarly, transport infrastructure that previously existed for children with disabilities may have been severely disrupted which can isolate the child and their family from accessing their community. The isolation from their local community could create further social concerns for children with disabilities post-disaster and may force families to have to move to new areas in order to gain better community access. This in itself could generate further stresses as the child and their family will then need to develop new community links.  This combined with pre-existing or limited community belonging issues may only further delay or severely impact on a child with a disability's QOL.

Consistent and meaningful participation in purposeful activities has significant positive impacts on Community belonging and Social belonging of an individual with a disability. For a child with a disability, participation in education is an important aspect of their everyday lives. However, in order to gain meaningful benefit from education, children with disabilities may require additional supports to participate in the school environment alongside their peers. These might include teacher aides to assist them with managing their behaviour in class or the playground or a variety of assistive technologies to assist them to communicate and interact with their peers. These supports ensure that every child is able to fully participate and gather the most benefit from the educational service provided.

Eriksson, Welander and Granlund (2007) investigated the degree of participation in school activities of children with and without disabilities. They assessed participation in structured (such as lessons or sport) and unstructured (playtime) activities as well the degree of autonomy that each child had in their participation and the level of support needed to participate in activities. All the children with disabilities scored lower in relation to their peers in each measured area. Younger children were participated in more activities than older children (age range 7 to 12 years) and this was observed in both groups of children with disabilities. However, those who needed more support with activities were less likely to be involved or participate in activities. The researchers also made the critical observation that on most occasions, children with disabilities were not selected to play with other children which would indicate a potential isolation and may impact negatively on their social and community belonging domains of QOL

Schools are seen as a vital connection within a traumatised community to assist children and their families come to terms with what has happened and begin the process of rebuilding their lives. Schools can provide a constant for children in an otherwise unsettled environment. When children do not re-engage in schooling following a disaster, it can leave them at significant risk of negative outcomes and poorer QOL (Murray, 2011). Wider studies show the impact of disasters on schooling in general is significant through loss of schools caused by damage and the upheaval associated with evacuation and probability of having to attend new schools with different teachers and students in a changed environment (Petal, 2008).

This was evident in a series of reports which surveyed displaced families impacted by Hurricanes Katrina and Rita (2005). Abramson and Garfield (2006) noted that ten percent of the school aged children living in temporary accommodation at the time of the study around Louisiana were not attending school, with 13 percent of 12-17 year olds not engaged in any formal schooling. In addition to this, 22 percent of children had missed ten or more days of school in the previous months which suggested a serious disengagement with schooling. In 2007, Abramson, Garfield and Redlener reported on the impact of the hurricanes on displaced families in the hardest hit areas of Mississippi. They found similar issues with school disengagement, noting that 29 percent of children aged between 6-12 years had missed at least 10 days of school in the past month. This rose to 41 percent of secondary school aged students. It was also reported that nearly half of the children would be attending a new school their new post-Katrina community in the next school year. Abramson and colleagues (2007) suggested that the children were going through significant educational upheaval.

While both Abramson et al (2006, 2007) studies included a number of families with children who had significant chronic health conditions or disabilities, there was no differential examination in relation to the impact on their schooling. Peek and Stough (2010) noted that (at that time) little research had been carried out that looks at specific impacts of disasters on the education for children with disabilities. Most of the potential schooling outcomes have been extrapolated from literature that looks at the educational impacts on children in general in the aftermath of disaster. Children with disabilities are seen to be more vulnerable to significant educational risk as they often rely on stability and consistency in their daily routine which is frequently disrupted post disaster. This occurs because schools may close, even temporarily, which disrupts regular routine for children.  Families may be required to evacuate long-term or their teaching staff may also be required to move or evacuate.

McAdams-Ducy and Stough (2011) examined the post disaster environment of children with disabilities when they explored the role special education teachers played with the children and their families after Hurricane Ike, which made landfall at Galveston, Texas. Schools were closed for at least three weeks and for two of the four teachers interviewed, their classrooms were so damaged a complete relocation of students to another school was required. The study found that there was loss of resources including wheelchairs to make school attendance possible. Similarly teachers noted that the students lost academic, behavioural and social skills after missing instructional time.  The study noted that the enforced time-off school upset the children as they “think they need to be at school” (p.16.) One teacher encouraged the students to come and visit before the school reopened so they could get “some sort of normalcy”. Behavioural issues were also noted with some children being “more clingy” when they were dropped off at school (p.12). The loss of classrooms also affected the children’s behaviour as teachers were forced to change routines and share resources and the teachers observed unsettled behaviour amongst their students. Some of this unsettled behaviour was also attributed to the emotional impact that the children had experienced with personal losses in their home lives carrying over into the loss of familiar classrooms and environments. The study found that the schools were vital in helping the children and adolescents refocus after such a significant disaster.

Peek and Stough (2010) suggest that additional stress on the child with disabilities education is also more pronounced as they often have numerous educational specialists who interact with them and their families in the school and classroom environments to ensure they access the curriculum. In the aftermath of a disaster, displacement of families and separation from educationalists such as skilled teacher aides who know the child and their challenges can further isolate or deprive the child in an educational setting. New relationships with teaching staff and specialists may have to be formed as suggested in McAdams-Ducy and Stough (2011) which may contribute to a setback of the child’s educational development and QOL (Peek and Stough 2010).

### QOL in the aftermath of the Christchurch EQs of 2010 and 2011

While no studies have been done that have looked at the impact the 2010/2011 sequence of EQs on the QOL of children with disabilities in Christchurch, a survey was carried out by CERA in 2012 to evaluate the post-EQ wellbeing and perceptions of the region’s recovery. It included 2381 responses from residents (18 years and older), who resided in either Christchurch city (N=1156), Selwyn (N=618) or Waimakariri district

(N=607). Respondents were asked about their overall QOL, sense of social connectedness, health and wellbeing, and the effects on their everyday lives of a range of negative and positive impacts of the EQs. The data was weighted to ensure an accurate comparison could be made between respondents in the different districts measured. Nearly three-quarters of residents in the wider Christchurch region thought their life was good or very good with just 7% believing it to be poor. However, over half of the respondents believed their QOL had deteriorated since the EQs began. Four out five residents reported experiencing stress over the last year, with nearly a quarter indicating it was almost constant (CERA, 2012). The sense of social connectedness was stronger for many residents surveyed with over half of respondents indicating they felt a sense of community. Although this was not observed in younger respondents (18 to 24 years). People who had had to move since the September 4. 2010 EQ were also much less likely to experience the sense of community.

Respondents were also asked to indicate whether they had experienced any negative issues or concerns from a list of 26 and to rate the level of impact it had on their lives, the majority indicated that they had experienced at least 10 of the issues in the past year. Of these, the most significant issue experienced by respondents was the loss of recreational, cultural and leisure facilities (69%), Distress and anxiety from aftershocks (66%) and dealing with EQC/ Insurance issues in relation to personal property in the previous year (64%) (CERA 2012). All of these issues had a negative impact on at least 35% of the respondents. Other issues including making decisions about houses, living in a damaged home, uncertainty over the family’s future in Canterbury and extra financial burdens were also rated as prevalent issues for at least half of the residents. When people were asked to rate a list of 10 possible positive issues, 76 % of people also indicated that they believed they could take pride in their ability to cope under pressure. Nearly 70% indicated that their family had greater resilience, while a renewed sense of life (68%) and heightened sense of community also were seen as having positive everyday outcomes for at least 35 % of the respondents. Spending more time with family was another highly rated positive outcome for over half of the respondents that impacted on their overall wellbeing. The CERA wellbeing survey showed that the post-EQ QOL of people in Christchurch was generally good, but there had been a number of significant negative issues and concerns from the EQs that had affected a large proportion of the population. Despite this, there was strong evidence of overall resilience in people and their families.

While there have been a growing number of studies reviewing the QOL of adults and children and adolescents without disabilities, the literature on the effects of disasters on the QOL of children and adolescents with disabilities is non-existent. The literature addressed in this study, has identified this gap, however, it is important to summarise the findings and how these might be related to the QOL of children with disabilities. The studies which looked at the QOL of adults in the aftermath of severe EQs found that in all instances, individuals who had experienced the EQ had decreased QOL when compared with non-affected control groups (Wang et al 2000, Chou et al 2004, Ke et al. 2010 and Valenti et al. 2013). This was echoed in studies that looked at older adults and adults with chronic illnesses.

All studies identified a close relationship between levels of psychological QOL and overall QOL. When a low scores were recorded in the psychological health domain, it correlated that overall QOL scores would be affected. Studies that carried out longitudinal analysis of affected population, observed that this correlation was evident even three years after the event (Wu et al. 2006, Tsai et al. 2007). This effect was observed in some older adults up to five years after the EQ. It was not obvious though in individuals with a chronic illness who had experienced a traumatic event.

Social factors were seen to play a part in determining the levels of QOL in the aftermath of an EQ. With Chou et al. 2004 and Ke et al. 2010 noting that those who received social support or maintained pre-disaster social connections often showed improved QOL over time. This was also observed in Ardalan et al. (2011) and Guiliani et al. (2014) studies of older survivors.

The post-disaster literature on the QOL of children and adolescents without disabilities found similar occurrences as observed in the studies on adults. All studies observed a decreased level of QOL in the child survivors up to six years after the event (Ceyhan & Ceyhan, 2007). However, it was frequently mentioned that there were differing levels of effect depending on the level of exposure to the effects of the disaster (Ceyhan & Ceyhan, 2007; Goenjian et al., 2011; Jia et al. 2010 and Tian et al., 2013). Children and adolescents who were directly exposed to the traumatic effects of the EQs or had endured personal or family loss were found to experience long-term negative effects on the QOL than their peers.

Like the studies on adult population, the psychological health domain was a strong indicator for the overall post-disaster HRQOL (Jia et al. 2010 and Tian et al. 2013) and QOL of children and adolescents without disabilities. The studies also found links between effects of age (Ceyhan & Ceyhan, 2007; Tian et al. 2013) and gender (Goenjian et al., 2011; Tian et al., 2013) and long term negative effects on psychological health and overall QOL. Ceyhan & Ceyhan (2007) and Tian et al. (2013) observed that adolescents were at a higher risk of decreased QOL scores. This was also noted by Goenjian et al (2011) and Tian et al. (2013) to be more prominent in adolescent females. These negative effects in the adolescent population were also observed to develop over time after the EQ.

The information on the impact of EQs or other disasters on the QOL of children with disabilities must be inferred from the limited amount of literature that currently exists about the experiences of children and adolescents with disabilities in disasters. The literature on the domains of QOL, shows that children with disabilities may be disadvantaged or behind in development of necessary social, educational and emotional skills. Studies on the domain of physical health reveal that frequently general health scores for children with disabilities are lower than those of children without disabilities. This is more evident in children who have comorbidities including a mental health condition (Waters et al. 2008; Dey et al. 2007).  In a disaster, children with disabilities may be particularly vulnerable in terms of their healthcare needs as they may require additional equipment to ensure appropriate care or treatment. Studies analysed (Peek & Stough, 2010; Abramson & Garfield, 2006) found that children with disabilities may have issues accessing equipment or treatment in the aftermath of disasters.

Psychological health was another area were children with disabilities are more vulnerable to negative effects on their QOL post-disaster. Asarnow et al. (1999) found that children with pre-existing anxiety issues had a higher prevalence of PTSD symptoms. Other factors including parental distress and the inability to comprehend what is happening may also put children with disabilities at a greater risk to their psychological QOL. Similarly, coping ability for children with disabilities may be severely impeded as they may not have the capability, experience or the social connections to enable them to adjust to a changed environment. The studies by Asarnow and colleagues (1999) and Valenti and colleagues (2011) indicated that the coping skills and adaptability of children with pre-existing disabilities can be affected significantly by EQs. Asarnow et al. (1999) found that children with a tendency to avoid or overthink difficult events were more at risk of PTSD.  Valenti and colleagues suggest that coping skills are very dependent on appropriate assistance and the reestablishment of routines. Peek and Stough also suggested that the strong connection between the emotional wellbeing of parents and their children with disabilities was a potential risk area for negative effects on the QOL domain of psychological health.

There was also a strong connection between the effects of EQs or disasters on the QOL domain of social belonging including friends, socialising, recreation and leisure. While there are no studies that have looked at the impact of disasters on social belonging of children with disabilities, it is possible to evaluate literature on non-disaster social aspects of children with disabilities. The studies by Heah, et al. 2007 and Solish, et al. 2010 indicated that children with disabilities often have fewer friends, engage in fewer or different recreational activities and therefore often have fewer opportunities for socialising than their peers without disabilities. These findings are found to reflect what is suggested in Peek and Stough (2010) that children with disabilities are at greater risk of social isolation in the aftermath of disaster which will impact on their QOL.

Similar issues arose in community belonging with a lack of studies on the impact of disasters. There is a significant possibility potential damage to facilities in a child’s community will impact negatively on what they can do and therefore could contribute to a sense of community isolation. One of the key areas where social and community belonging come together is in school participation. For children with disabilities, developing and increasing participation in school activities is essential but as Eriksson et al. (2007) indicated, this may be dependent on having assistance to interact and engage and is often less than their peers. The impact on schooling in the aftermath of a disaster is also significant for children with disabilities. Abramson et al. (2006, 2007) noted that for some children going back to school was difficult as many had to change school. There were a number of days taken off owing to illness and some children simply had not returned. McAdams-Ducy and Stough (2011) also noted the difficulties that children with disabilities had in returning to changed schooling environments which not only sets back their academic achievement but also social skills and puts them at greater risk of social isolation.  This is not only likely to effect the QOL domain of social belonging but also puts the children at greater risk of psychological issues and thus affects the psychological health domain.

What the sections on the impact of EQs and other disasters on the different QOL domains of physical and psychological health and social and community belonging of children with disabilities reveals is there are large gaps in the QOL literature. When the QOL studies on the effects of disasters on adults and children and adolescents without disabilities were evaluated, they found that the EQs have negatively affected the population's QOL. These effects have long-lasting impacts on people's lives especially areas of psychological health and social wellbeing. This was confirmed in the CERA Wellbeing Survey, (2012) where over half of the adult respondents indicated that their QOL had decreased since the EQs began. Ongoing issues of stress and anxiety were also noted to have particularly negative effects on people's outcomes. However, the absence of literature on the effects of the EQs on the QOL of children and adolescents with disabilities in post-EQ Christchurch suggests that research is much needed to address this.

This study explored the questions; What was the impact of the Christchurch EQs of 2010 and 2011 on the QOL of school-aged children and adolescents with disabilities who are living in Christchurch and surrounding districts?  How did it affect different areas of QOL for the children and adolescents with disabilities including physical health and psychological health: stress and coping, the area lived in, friendships and socialising, community access, schooling and leisure activities?

# Chapter 3: Methodology

The aim of this study was to explore how school-aged children and adolescents with disabilities were affected by the Canterbury earthquakes period and their ongoing impact since September 2010 and review their ongoing QOL at the time of the study. A postal and email recruitment for a survey three months following the final > 5.0 magnitude earthquake of parents of children and adolescents between the ages of 3 – 21 years old who have a disability was undertaken.  All of the participants were expected to have been living in Christchurch City or the surrounding districts of Banks Peninsula, Selwyn or the Waimakariri at the time of any of the major earthquakes of 2010 and 2011. The design and procedures of the study were undertaken with the approval of the University of Canterbury's Human Ethics Committee.

## Instrumentation

The survey questions were drawn from three different sources; *Christchurch Earthquake: Taking Care of Yourself, The Quality of Life Instrument for People with Developmental Disabilities – Short Version* (QOL-PDD-SV) and *The World Health Organisation Quality of Life (WHOQOL)-BREF*. Underpinning the development of the survey was the *Christchurch Earthquake: Taking Care of Yourself* factsheet. This was developed by the NZ College of Clinical Psychologists (NZCCP) in response to the Christchurch earthquakes. Its primary role was to assist Christchurch residents to find ways to cope with the stress that resulted from the major earthquake itself and subsequent aftershocks as well as the damage resulting from the major February 22 aftershock. The factsheet identified five primary areas that people in the region should focus on including; maintaining their regular routines, staying connected with family and friends, conserving their energy, trying to maintain a healthy lifestyle and keeping themselves physically and emotionally safe (NZCCP, 2011). While not a questionnaire in the strict sense, the concepts were used to guide the selection of the questions used in the present study.

The survey consisted of 45 questions which were preceded by seven demographic questions. Excluding the demographic questions, a total of 30 questions were to be answered using a Likert scale, 13 questions were open ended and two questions had yes/no answer options. Demographic information was collected about the child or adolescent at the beginning of the survey (See Table 4). These questions helped to discover basic information about the child or adolescent which would assist with comparison and data analysis. These questions included their gender, age at the time of survey completion, the nature of the child or adolescent's disability and where they lived. Questions about schooling included the year or level of schooling and the educational assistance they received (if any). One question was also asked to determine if the parent or caregiver had completed the survey and if the child or teen had participated in its completion.

Table 4
Demographic Questions

| Question #<br>*(Question type)* | Questions |
|---|---|
| #1 – 4b | |
| *(Option)* | 1. Is your child/ adolescent male or female? |
| *(Open)* | 2. What is the nature of your child's/adolescent's disability? |
| *(Open)* | 3. What is your relationship to the child/adolescent (e.g. Parent/Main caregiver/ Grandparent)? |
| *(Option)* | 4. Because different areas of Christchurch and surrounds have been affected differently by the earthquakes, the following question is to identify in which general area the child/adolescent resides: |
| *(Open)* | 4b. If "Don't live in Canterbury at the moment" is selected: why did the child/adolescent leave? |
| #8.1 - 8.2 | 1. What level of schooling is your child / adolescent at? |
| *(Specific options)* | 2. Does your child / adolescent receive some form of assistance with their education? |
| *(Open)* | |
| #12.1<br>(*Open*) | 1. Please indicate how much of the survey your child / adolescent was able to help you with. |

Twelve of the questions for the present study were drawn from *The Quality of Life Instrument for People with Developmental Disabilities – Short Version* (QOL-PDD-SV) (See Table 5). This instrument was designed by the Quality of Life Centre at the University of Toronto and defines QOL as "the degree to which a person enjoys the important possibilities of his or her life" or simply, "how good is your life for you?" (Brown, Raphael & Renwick, 1997, p.3). Psychometric properties of the instrument were reported on in two studies (Raphael et al. 1996, Raphael, Brown & Renwick, 1999). These studies found that the short version was especially appropriate for evaluation purposes (Raphael et al., 1999). The instrument identifies nine different domains of a person's life and measures the individual's quality of life through consideration of the level of importance one places on a domain and the subsequent level of satisfaction within that same domain.

*Table 5*

Survey Questions adapted from Brown, Raphael & Renwick (1997)

| Question # (*Type* [a]) | QOL Domain | Question(s) |
|---|---|---|
| 1.1 | Physical Health | 1 .How important to your child/ adolescent is their physical health? |
| 1.2 | | 2. How happy is your child/ adolescent with their physical health? |
| 2.1 | Psychological Health: Coping | 1. How well does your child / adolescent cope with things that bother or upset them? |
| 3.1 | Psychological Health: Stress | 1. How often is your child/ adolescent stressed or nervous about things in their life? |
| 4.1 | Physical Belonging: Area living | 1. How important to your child / adolescent is where they live? |
| 4.2 | | 2. How happy is your child / adolescent with where they live? |
| 5.1 | Social Belonging: Friends | 1. Is your child / adolescent happy with their friends? |
| 6.1 | Social Belonging: socialising | 1. Does your child/adolescent like getting together with friends and family? |
| 6.2 | | 2. How important to your child / adolescent is visiting/socialising with friends? |
| 8.3 | Community Belonging/ Education Access | 3. How important is it for your child / adolescent to attend school? |
| 8.4 | | 4. How happy is your child / adolescent with attending school? |
| 9. 1 (*Open*) | Leisure Becoming: Recreation | 1. What sort of activities does your child or adolescent like to do for fun? (e.g. watching movies, playing games, music, horse riding)? |

[a] All questions are Likert Scale 1 – 5 unless otherwise indicated.

This instrument has been used in studies with individuals with developmental disabilities including cerebral palsy, autism spectrum disorder and Rhett syndrome and intellectual disabilities as well as individuals with physical and sensory disabilities (Rosenbaum, Livingston, Palisano, Galuppi, Russell 2007).

Different domains of QOL were chosen and at least one subdomain was selected to represent them (See Table 5). These were incorporated in the present study. These included physical health, psychological health, physical belonging: where they live, social belonging: relationship with their friends, socialising with friends and family, community belonging: access and schooling, leisure becoming: what they do for fun or recreation and growth becoming: coping with changes in their lives. The majority of the quality of life questions (N=11) used a 5 point Likert-type scale for importance and another for satisfaction or happiness. The other question was open ended and asked about the child or adolescent's preferred activities. The area of QOL: Psychological health was covered in two areas, stress and coping with difficult events. This was supported by Compass et al, (2001) indicating that there is a distinct relationship between coping and child or adolescent psychological adjustment to stress. However, answers to psychological health: coping could also be used to indicate how a child or adolescent might see their ability to cope with changes in their lives which could also determine answers to the QOL: growth becoming domain. Respondents were also asked to consider what their child's strengths were in regards to coping over the months since the EQs began (See Table 6, Q# 11.1). While not directly taken from the QOL_PDD_SV, responses to this question could be used as a guide to the domain of growth becoming.

However, some QOL domains covered in the QOL_PDD_SV were excluded for various reasons. This included ensuring that the questionnaire would not take too long to complete as it was felt that too many questions would potentially deter participants. Another reason for exclusion was because of the anonymity of the survey and with no access to additional explanations or clarification from the researcher other than the introduction there was also concern that many participants may have found some of the questions confusing or irrelevant or misinterpret the intention behind the question and decide not to complete the survey. An area where this was thought possible included the spiritual being domain although the importance of celebrating with others would be potentially covered in the socialising/visiting with others question. It was believed that including the opportunity for respondents to add additional information after each section might overcome the potential gaps that excluding some of the QOL areas.

Other domains also had some questions that were not included out of consideration that they may not be age appropriate such as having a significant other from the social belonging domain. While it may be more accepted that older adolescents will have a boyfriend or girlfriend, it was decided to allow parents or respondents to indicate this in the additional information section if they believed it was important or relevant to their child. Access to work or meaningful work was also not asked because the focus was on school-aged children and adolescents. For older students with a disability, transition from school to adult life and work is a very significant stage (Halpern, 1994, Winn & Hay, 2009). The effects of the EQs on planning and preparation for transition and the QOL of young people with disabilities at the time is an area of significant important but it was outside the scope of this study. Some areas were not included because of the need to keep the survey brief and it was felt that one question from the domain covered the information required. An example of this was the selection of the importance and satisfaction with physical health from the Physical wellbeing domain in lieu of questions concerning hygiene and nutrition. While not diminishing the importance of these areas in the lives of children and adolescents living with the effects of a disability, it was determined that physical health was the wider reaching topic. It was also believed that children (younger) would not have quite as much determination over what was eaten and that the parent or caregiver determines the meal choices. Similar reasoning was applied to the area of hygiene.

An additional 29 questions were also included that were related to the QOL-PDD_SV domains but focused on the impact of the earthquakes on these respective areas (See Table 6). Similar to the importance and satisfaction questions, these were measured with a Likert scale but focused on the impact of the earthquake on the respective life area;

> Q3.2. How was your child/ adolescent able to deal with stressful events in
> the immediate weeks following the earthquakes?

The subsequent question asked for a comparison on how much had changed (if anything) from prior to the earthquakes;

> Q3.3. How would you rate your child's/ adolescent's ability to deal with
> stressful events now compared to before the earthquakes?

Table 6
Survey Questions that Address Effects of the Earthquakes

| Question # (*Type* [a]) | QOL Domain | Question(s) |
|---|---|---|
| 1.3 (*Y/N*[b]) | Physical Health | 3. Have they had any extra doctor or hospital visits as a direct result of the earthquakes? |
| 1.4 | | 4. How much have the earthquakes affected their overall health? |
| 1.5 | | 5. How would you rate their health now compared to before the earthquakes began? |
| 1.6 (*Open*) | | 6. Please add any additional comments. |
| 2.2 | Psychological health: Coping | 2. How well has your child / adolescent been able to cope with the immediate effects of the earthquakes? |
| 2.3 | | 3. How would you rate your child's / adolescent's ability to cope with things that bother or upset them now compared to before the earthquakes? |
| 2.4 (*Open*) | | 4. Please add any additional comments |
| 3.2 | Psychological Health: Stress | 2. How was your child/ adolescent able to deal with stressful events in the immediate weeks following the earthquakes? |
| 3.3 | | 3. How would you rate your child's/ adolescent's ability to deal with stressful events now compared to before the earthquakes? |
| 3.4 (*Open*) | | 4. Please add any additional comments. |
| 4.3 | Social Belonging: Area living in | 3. Have the earthquakes affected your child's / adolescent's happiness with where they live? |
| 4.4 (*Y/N*) | | 4. If additions were made to the house your child/adolescent lives in such as a wheelchair ramp or a modified bathroom; have the use of these been affected by the earthquakes? |
| 4.5 (*Open*) | | 5. Please add any additional comments |
| 6.3 | Social Belonging: socialising | 3. Where does your child/adolescent like to get together with friends? |
| 6.4 | | 4. Have the earthquakes affected your child's/adolescent's willingness/happiness to visit other people outside of their home? |
| 6.5 | | 5. Have the earthquakes affected your child's/adolescent's willingness/happiness to have other people visit or come over to their home? |
| 6.6 (*Open*) | | 6. Please add any additional comments. |

| Question # (*Type* [a]) | QOL Domain | Question(s) |
|---|---|---|
| 7.3 | Community Belonging: Access | 3. Following the earthquakes, has there been reasonable access to the usual places in the community that they visit? |
| 7.4 | | 4. How would you rate your child's / adolescent's access to the usual community places that they visit now compared to before the earthquakes began? |
| 7.5 (*Open*) | | 5. Please add any additional comments. |
| 8.5 | Community Belonging: Schooling | 5. Was your child / adolescent happy to return to school after the earthquakes? |
| 8.6 | | 6. Was your child/ adolescent able to go back to the same school or was there a change of location of school? |
| 8.7 (*Open*) | | 7. Please add any additional comments. |
| 9.2 | Leisure Becoming: Recreation | 2. How much has the earthquakes affected what your child/ adolescent likes to do for fun? |
| 9.3 (*Open*) | | 3. Please add any additional comments. |
| 10.1 | Overall Quality of Life | 1. How would you rate your child's / adolescent's overall quality of life? (WHO-QOL- BREF, 1991) |
| 10.2 | | 2. How would you rate YOUR overall quality of life? (The parent, caregiver)? (WHO-QOL-BREF, 1991) |
| 11.1 (*Open*) | Child's coping Strengths | 1. Thinking back over the months since the earthquakes began, what are your child's/adolescent's strengths especially in regards to coping? |
| 12.2 (*Open*) | | 2. Please add any additional comments. |

[a] Assume all questions are Likert Scale 1 – 5 unless otherwise indicated.

[b] Y/N refers to Yes/ No answering style

Three of the questions were specifically earthquake and disability related questions (see Table 6), drawn from the literature and local conditions, including whether there had been additional medical visits, how the earthquake had affected any additions such as a ramp or hoist (if any) to the residence. One question asked if they had to change schools as a result of the earthquakes. This was a response to schooling in Christchurch post-earthquakes which saw a number of predominately secondary schools site-sharing for at least a month because of serious damage to the facilities, school and grounds.

Because this study was exploring the QOL of children and adolescents it was determined that a question that asked about overall QOL would be included. The *World Health Organisation Quality of Life (WHOQOL)-BREF* comes from a project begun in 1991 with the purpose of developing an "international cross-culturally comparable quality of life assessment instrument" (World Health Organisation, 2012). The instrument assesses an "individual's perceptions in the context of their culture and value systems, and their personal goals, standards and concerns" (WHO, 2012). The survey covers areas which are part of four broad domains, physical health, psychological health, social relationships and environment. The *WHOQOL- BREF* has been used in studies with adolescents (Izutsu et al, 2005) and early adolescents (Chen et al, 2006), rheumatoid arthritis (Taylor et al, 2004), comparisons between various health conditions (Yao & Wu, 2005; Skevington & Crate, 2012) as well as in the general population and caregivers of children and adolescents with intellectual disabilities (Lin et al, 2009). It has also been increasingly used in various adult and adolescent populations who have experienced EQs (Wang et al., 2000; Ceyhan & Ceyhan; Ardalan et al., 2011; Valenti et al., 2013).

Two questions were included that came from or were based on WHOQOL-BREF. These included, “How would you rate your child's / adolescents overall quality of life?” and “How would you rate YOUR overall quality of life? (The parent, caregiver)?”. It was decided to include a question about the QOL of the respondent as the literature suggested that there were close links between the health and wellbeing of the child with a disability and that of their parent or caregiver (Peek & Stough, 2010; Murray, 2011). These questions used a 5-point Likert scale asking the respondent to rate from 1 (*very poor*) to 5 (*very good*)

The survey was trialled by friends and colleagues of the researcher. In order to assure a better fit for the questions, the invitation was restricted to people who had school-aged children of their own. These people included undergraduate and post-graduate students, community workers and school teachers. Feedback was gathered from the trial on questionnaire length, content and ease of understanding the questions and was largely positive.

## Ethical Procedures

These procedures received approval from the University of Canterbury Human Ethics Committee after recommendations for amendments were followed and approved in January 2012. (See Appendix A). The participants received an email from the agency or provider with whom they were signed up as a member or receive services from (Appendix B). If they chose to proceed with the survey, they were able to click on the link and read the information on the first webpage of the survey and click their agreement before proceeding to take the survey. The information on the first webpage covered their rights as participants and informed them that they could withdraw from the survey at any time while they were completing it. However, it was noted that once the survey was completed and submitted, a participant could not withdraw their information due to the anonymous nature of the research. Their informed consent was implied through their voluntary participation after reading an explanation of the study as approved by the University of Canterbury Human Ethics Committee in clicking the 'yes' button and taking-part in the survey. The survey did not allow anyone to proceed until a decision had been entered. If a participant chose the 'No' button, they were taken to the final information page of the survey thanking them for their time and directing them to further information if they wished. If a participant requested to complete the survey as a paper-copy then the same information sheet was provided and consent assumed through the completion and return of the survey.  All participants were assumed to be adults, 18 years or older as part of the consent process.

### Recruitment Procedures

Recruitment of participants was undertaken via a number of different avenues. Given the uncertain nature of the current environment within Christchurch and the surrounding districts in the wake of the earthquakes, it was anticipated that many families may have moved or relocated into different suburbs or even satellite towns. To combat this, different options were used to contact potential participants and their families. These included contacting agencies that provide assistance, advice and advocacy for families with children or adolescents living with disabilities. A list of agencies and groups was researched and established (see Appendix B) and an email was sent to the groups explaining about the research and requesting their assistance in either sending an email to people on their emailing lists or placing an approved advert in the next group newsletter that would be sent out to members (see Appendix C).

This process also generated further interest from other agencies and groups that provided different services to families of children and adolescents with disabilities who then contacted the researcher for further information about the study. This method of recruitment utilised the ‘snowball effect’ whereby one person contacted could send on the email to other people who might be interested in participating or knew people who might be. This method of recruitment is often used to generate interest and participation from groups who are known to be hard to access or find for research purposes (Spreen 1992). Those families with children and adolescents who have disabilities are often cited as respondents who fall under the ‘hard to access/find’ title and the snowball effect recruitment method has been used in research with similar respondents to good effect in earlier research (Albrecht & Devilieger 1999).

### Survey Procedures

The study was conducted via an online survey administered through the Qualtrics website (Qualtrics Online Surveys, http://www.icts.canterbury.ac.nz/qualtrics/) with a University of Canterbury interface. Once a participant opened the link to the survey, they were taken to the University of Canterbury’s Qualtrics website and were prompted to enter a password (‘coping’) which was included in the email. This was to safeguard the integrity of the survey and data by ensuring that no one could access the survey without being contacted by an agency or the researcher. This then opened the webpage with details explaining the study and they were asked to agree to the anonymous approval rubric before proceeding with the survey. The participant could click ‘yes’ to proceed. If they clicked ‘no’, they were taken to the final page of the survey. The participants were able to exit the survey at any time by simply closing the browser.

If the participant chose to complete a paper copy, they were required to read through the first pages with the same information as available on the information/consent page of the online version before having to tick ‘yes’ to indicate their consent and understanding of the procedures. They could then proceed to answer the questions as per the online survey. On completion of the paper survey, the participant could return it to the researcher with the pre-labelled envelope provided. It was expected that the survey would take no more than 10 minutes to answer unless they wanted to add additional comments on a particular area of the survey.

## Data Summarisation and Analysis Procedures

The data was entered into Statistical Package for the Social Sciences (SPSS) programme for analysis. To ensure that all data was assessed together and to maintain the anonymity of the participants, the completed paper copies (N=10) were assigned a number according to the order-of-entry and entered into the online survey rubric. The data entered by the researcher was double-checked against the respectively numbered paper copies to ensure that it was clean and no errors had been entered. The raw data set was then downloaded into the SPSS programme for further analysis.

**Recoding of demographic variables.** The raw demographic data was reviewed and recoded for ease of use. Because of the wide range of answers to the nature of the child or adolescents' disability (Q3), a new column was added in SPSS and each disability was assigned to a new code based on the Statistics New Zealand Disability Survey categories (see Table 1), 1 -  Sensory, 2 – Intellectual, 3 – Psychological, 4- Physical and 5 – Other.

The demographic variable of age was also separated into two groups; younger children (2-12 years inclusive) and adolescent (13 – 20 years). These were further checked against the respondents answers to "what level of school does the child attend" primary (5-12 years inclusive) and secondary school (13 years and older).

The responses to the geographic area was also broken into three groups determined by the areas frequently reported to have sustained significant damage in the major EQs of 2010 and 2011.  These were North and West Christchurch (no red-zoned properties), the rest of Christchurch including East, South and Other (Central

Christchurch City) including all red-zoned areas and the Outer districts of Selwyn and Waimakariri which sustained damage in September 4, 2010 EQ and includes the town of Kaiapoi which has red-zoned areas (CERA, 2012).

**Recoding of Other Variables.** It was discovered that the answer order to some questions was reversed from the majority of the remaining questions where 5 equalled a positive or good response and 1 was a negative or not so good response. Where this was noted, the questions were recoded to ensure uniformity of answers and the data was re-checked to determine if the reverse response had adversely affected the responses by the participants.

After running frequency analysis on different questions, it was decided to recode variables to enable better analysis of the responses. This was due to the number of responses. The 5-point Likert scale spread out the responses and it was transformed into a 3- point Likert scale. When a response was recorded as a “4” or “5”, it was recoded as a “5”; a response of “3” remained as a “3” and a response of “2” or “1” was recoded as a “1”.

**Analysis of Results.** Due to the exploratory nature of this study and the low response rate, statistical analyses were in general restricted to frequency counts and percentages. Statistics were calculated using IBM SPSS Statistics (version 20). However, where possible further crosstabulation analysis of the results were investigated by for effects by gender, age groups and geographic location resident in Christchurch region. However, because of the expected small cell sizes, the Fisher’s exact test was included instead of a Chi-square to ensure a more exact result. Scores suggesting a statistically significant relationship were been included. The scores have been included.  Confidence levels for percentages were omitted due to the small sample who responded.

The results of the closed questions described by the use of frequency tables were presented by the domain of QOL that they related to including QOL: Physical health, QOL: psychological health – stress, QOL: psychological health – coping, QOL: Social belonging – friendships, QOL: Social belonging – socialising, QOL: Community belonging – community access and QOL: Community belonging – Schooling and QOL: Leisure becoming – recreation and Overall QOL.

The responses given to the open-ended question in QOL: Leisure becoming – recreation were analysed by the distinction of different types of activities as either social, recreational or leisure as measured in Solish, Perry and Minnes (2010). The responses given were analysed by the type of activity and recorded by the number of respondents who reported that their children engaged or participated in such an activity.

Responses to the question, “Thinking back over the months since the earthquakes began, what are your child's strengths especially in regards to coping?” were analysed and arranged to show development of coping styles by individual children. Any additional information provided by the respondents was included where possible to further clarify or give an example that supported or in some cases contradicted the results of the open-ended questions.

# Chapter 4 Results

## Response Rate

The response rate of the survey is unknown because of the nature of the recruitment. A total of 20 agencies were contacted by email or in person and it is not known how many actually distributed the information or, if they did, the total number contacted.

## Profile of the Respondents

A total of 31 participants responded to the survey. Of the 31 respondents, 21 completed the survey online and 10 completed the survey in paper format. Most of the respondents answered each question. When they did omit to answer a question it was just one or two. Some respondents did not answer a question if they did not consider it relevant to their child. For example the question on the effects of the EQs on the return to school were not relevant for some participants as they were not in school (i.e. home-schooled) This type of information was conveyed in the open-ended comment part of the survey segment related to each topic domain. One respondent completed only the first half of the survey, however, because of the low number of participants the answers of the "partial-completer" have been included. Of the 31 respondents, all but one (96.5%) indicated they were the parent of the child, with the other respondent indicating they were a caregiver. Three respondents indicated that their child or adolescent assisted in answering some of the questions.

The large majority of the respondents' children and adolescents were male (N=22) (See Table 7). The children ages ranged from 2 years, 5 months to 20 years with a mean of 12 years and 6 months.

Table 7
Characteristics of Respondent's Children

| Characteristic | N (%) |
|---|---|
| Gender | |
| Male | 22 (70.9) |
| Female | 9 (29.0) |
| Age | |
| 0 – 4 years | 2 (6.5) |
| 5 – 12 years | 16 (51.6) |
| 13 – 18 years | 8 (25.8) |
| 19 years plus | 5 (16.1) |
| Mean age: 12.6 years | |
| Disability Type | |
| Sensory (Vision) | 3 ( 9.7) |
| Physical | 5 (16.1) |
| Intellectual | 11 (35.5) |
| Psychological | 7 (22.6) |
| Other | 5 (16.1) |
| Area Resident | |
| East Christchurch | 11 (35.5) |
| North Christchurch | 3 (9.7) |
| West Christchurch | 7 (22.6) |
| Selwyn District | 3 (9.7) |
| Waimakariri District | 4 (12.9) |
| Central City | 2 (6.5) |
| No response recorded | 1 (3.2) |

As the majority of respondents were the parents, all subsequent references will use the words parent/s and their child or children to refer to the child or adolescent. Thirteen children were recorded as living in areas that received significant damage or were negatively affected by the main EQs including eastern and central areas of Christchurch (See Figure 2).

The respondents were asked to describe the diagnosed disability or impairment of their child. The answers were grouped into broader categories as defined by Statistics New Zealand in their Disability Survey of intellectual disability, psychological or psychiatric disability, physical disability, sensory (vision) disability and other disability. Over a third of the children had an intellectual disability (see Table 7). Four of the children were reported as having Down syndrome, four as having global developmental delay and one with Williams syndrome. Another child was reported to have a unique chromosomal condition which causes intellectual and minor physical impairments. One of the children with Down syndrome was reported as having a comorbidity of ASD. Of these eleven children, nine were considered high or very high needs (see Table 8).

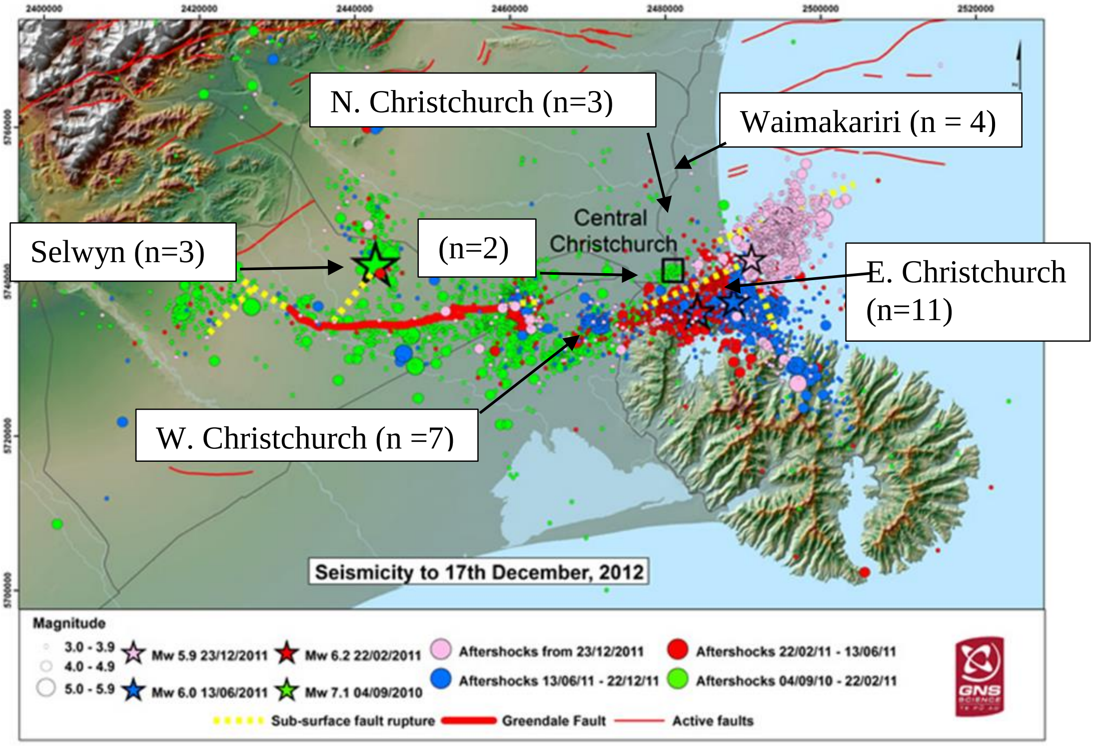


*Figure 2 Residential location of respondent overlaid the seismic activity map from September 4, 2010 until 17 December 2012. (GNS Science, http://www.gns.cri.nz/Home/Our-Science/Natural-Hazards/Recent-Events/Canterbury-quake/Recent-aftershock-map. Accessed 1 July 2014).*

More than twenty percent of the children had a psychological impairment (see Table 7). Of these, three children were recorded as having Asperger syndrome and four were recorded as having ASD along with comorbidities of ADHD or development dyspraxia. Two of these children were considered high or very high needs by the Ministry of Education (MOE) (see Table 8). Five of the children had a physical disability (see Table 7). All of these children were reported as having CP. Two of these children had comorbid conditions of an intellectual disability or ASD. All of these children were considered high or very high needs level by the MOE (see Table 8). Nearly ten percent of the children had a sensory impairment (see Table 7). All of these children were reported as having a visual impairment. All of these children were considered high or very high needs level by the MOE (see Table 8).

Five of the children were reported to have a disability that was categorised as Other disability. Three of these children were reported as having a disability that affected their learning or speaking. Of these children, two were reported to have ADHD and one was reported to have ADHD, developmental dyspraxia and a non-verbal learning disability (NLD). One child (3 years) was reported as having global developmental delay. The other child was reported as being extremely premature at birth and having a chronic lung disease. None of the children were considered high or very high needs by the MOE.

Almost all the children for which there were responses were receiving school services (see Table 8). Half of the children were attending a primary school (Years 0-8). Eleven of the children were receiving secondary education (Years 9-13+). These included two attending educational units providing specialist educational services for students with different educational needs attached to state (government funded) secondary schools and one was recorded as being home-schooled.

Table 8
Schooling Profile of Children of Respondents

| Characteristic | N (%) |
|---|---|
| School Level (n=31) | |
| Preschool | 2 (6.5) |
| Primary | 15 (48.4) |
| Secondary | 11 (35.5) |
| Post-Secondary/ Not attending | 2 (6.5) |
| No response | 1 (3.2) |
| School Support (n=31) | |
| Ongoing Resourcing for High Needs | 19 (61.3) |
| Teacher Aide | 2 (6.5) |
| Other | 4 (12.9) |
| Does not receive school support | 5 (16.1) |
| No response | 1 (3.2) |

Two of the children were involved in pre-school services. The remaining two children were reported as no longer receiving school services. It was reported that both had been in school during the period of the 2010/2011 EQs but had subsequently left school.

Nearly two-thirds (N=19) of respondents indicated that their child received the Ongoing Resourcing Scheme for students with high or very high needs to support them with their education (see Table 8). Of the children reported to receive ORS funding, 60 percent (N=11) were aged between 13 and 20 years. Of the other children, two respondents indicated that a teacher aide was employed or was about to be employed to assist their child. Four respondents reported that their child received services for moderate needs support. One respondent indicated ‘yes’ to the question “Does your child / adolescent receive some form of assistance with their education” but did not give any further indication of what type of assistance so was classified as other assistance type. Of the five parents whose child did not receive any form of educational assistance, one respondent noted that their child had in the past been supported by a teacher aide.

## Impact of Earthquakes on Quality of Life

This next section reports on the results of the findings on how the earthquakes impacted on different areas of the respondents' children QOL. It is divided into the ten subsections, physical health, psychological health: stress and coping, physical belonging, social belonging: friends and visiting and socialising, community belonging, schooling and leisure becoming. Each subsection reports on the findings from the questions asked in the survey of the respondents regarding their children's experiences through the EQs concerning the corresponding domain of QOL. Each section will review the questions that asked the respondents to rate how the child feels about that area of their lives. Then the questions that look at how the EQs affected that area of their lives are reported on. When the respondents offered further relevant information to support their answers this was included when it further gave a more detailed picture of the survey questions. Further analysis was carried out looking at the effects of gender, the age of the children along with the geographic location that the child was reported to reside in. A final subsection reports on the overall QOL questions that were asked.

**QOL: physical health.** The domain of Physical Being was addressed by questions concerning physical health of the children in this study. Additional information was provided by 15 of the respondents. Physical health was rated by more than eighty percent of respondents to be extremely important (N=16) or very important (N=10) to their child (see Table 9).

Two thirds of respondents reported that their child was "happy" (N=16) or "very happy" (N=4) with their current physical health.

Table 9
Summary of Responses for Quality of Life: Physical Health

| Survey Item | Mean (SD) | N (%) |
|---|---|---|
| Importance of physical health (n=31) | 4.3 (1.0) | |
| Physical health is very/extremely important | | 26 (83.9) |
| Happiness with current physical health (n=31) | 3.7 (0.9) | |
| Very happy/happy with current physical health | | 20 (64.5) |
| Effect of the EQs on physical health (n=31) | 2.3 (1.4) | |
| EQs had very little/little effect | | 18 (58.1) |
| EQs had some effect | | 5 (16.1) |
| EQs had quite a bit/a lot of effect | | 8 (25.8) |
| Change in physical health (n=31) | 3.2 (0.8) | |
| Physical Health much better/better | | 4 (12.9) |
| Physical Health is about the same | | 18 (58.0) |
| Physical health is worse/much worse | | 8 (25.8) |
| No response | | 1 (3.2) |

Potential limitations to this assessment was, however, indicated by one parent who added that their child,

> "only talked about [their] physical health when [they] have specific issues such as a sore knee preventing [them] from engaging in physical activity. I don't think [they] are especially concerned about [their] physical wellbeing unless it hinders [their] activity". *Adolescent aged 19*

The EQs had varying impact on the respondents' children's physical health. Sixty percent of parents reported their children had "little" (N=4) or "very little" (N=14) change in their health after the EQs. The mean for this question was 2.3 (*Quite a bit*) (SD 1.4) which would suggest that the EQs did have a negative effect on physical health, there was some variation in the responses. However, the EQs did have "quite a bit" or "a lot" of effect on around a quarter of children in the study and this translated into extra medical centre visits. Of these eight children, seven respondents indicated that their child required extra medical visits as a result of the EQs. One parent observed that;

> “a few months after February 22nd 2011, my [child] was ill with several viruses and generally run down. This went on for about 3 to 4 months.”
>
> *Adolescent aged 14*

Although how much of it was related to physical illness was unclear as another parent noted that;

> “[their] health is good, but more talking [themselves] into pain, eg...... admitted into hospital a couple of times.” *Child aged 9*

One child who was in hospital for surgery during the February 22nd EQ was reported to have a potentially detrimental reluctance to go to hospital afterwards;

> “[the child] has since had two more operations but is very unclear about where the pain is. I think due to the earthquake [the child] doesn't want to stay in hospital any longer than needed and therefore doesn't complain about the pain until it is unbearable.” *Adolescent aged 15*

When asked to compare their child’s health after the EQs with before the EQ series started, three parents rated their children’s health as “better” (N=3) or “much better” (N=1) than before the EQs. In all instances this was noted to be because of factors beyond or despite the EQs including moving into a new home (unrelated to the EQs) or physical therapy and “ongoing developmental progress”. However, for the majority of children (60%) the parents reported little change in their health from prior to the EQs.

The impact of the EQ on the physical health domain of the respondents’ children was analysed by gender, geographic location within the region and by age category.

Table 10
Comparison of Change in Physical Health after Earthquakes between Younger Children and Adolescents

| Health change comparison after EQs | Younger children (2 -12 years) | Adolescents (13 -2- years) |
|---|---|---|
| | n (% within age group) | n (% within age group) |
| Worse or Much Worse | 2 (11.8) | 6 (46.2) |
| About the Same | 12 (70.6) | 6 (46.2) |
| Better or Much Better | 3 (17.6) | 1 (7.7) |
| Total | 17 (100.0) | 13 (100.0) |

The age group analysis did reveal that there was a higher probability that the adolescent group experienced a negative impact on their health (38.5 %, N=5) compared to younger children (N=3, 16.7%). Although it was also reported that similar numbers of adolescents (N=5) had “little” or “very little” impact on their health.

Similar analysis of the question comparing the physical health of the child after the EQs found that nearly half of the respondents reported that their adolescent’s physical health was “worse” or “much worse” (see Table 10). This could be a potential area of concern especially when compared to the same category of the younger age group (N=2). However, no statistically significant relationship (p= 0.12) between age group and the effects of the EQs was observed.

The analysis by gender found that 50 percent (N=4 of 8) of female children or adolescents were “worse” or “much worse” which compared with less than 20 percent of males (N=4 of 22), however, the small number of female children (N=8) makes this result tentative at best. The health of the majority (N=14) of male children was reported to be about the same after the earthquakes when compared with before the sequence started. However, there was no statistically significant relationship (p= 0.16) between gender and the effects of the EQ.  Analysis by geographic location failed to find any identifiable patterns or observations.

Overall, the survey identified that physical health was considered to be a very important area for the majority of the respondents' children and it was observed to be a relatively satisfied area of QOL for around three-quarters of the children. It was reported that the EQs did not have a pronounced impact on the physical health of almost sixty percent of the children.  However, for a quarter of the children there has been some detrimental effect on their QOL physical health.

**QOL: psychological health: coping.** Psychological being was also addressed in questions that asked about how the children coped with things or events in their lives that bothered or upset them. Additional information was supplied by 11 of the respondents.  Around a third of the respondents reported that their child coped with things in their lives that bothered or upset them "quite well" (N=4) or "sometimes" (N=7). However, as shown in Table 11, nearly two-thirds of respondents felt that their child did not cope "at all well" (N=14) or only "a little bit" (N=6) with difficult situations that arose in their lives.

These results would suggest that the children in this study may not be completely satisfied with their ability to cope with things or events in their lives that bother them or cause them to become upset.

Table 11

Summary of Responses for Quality of Life: Psychological Health - Coping

| Survey Item | Mean (S.D) | N (%) |
|---|---|---|
| Level of coping with things that bothers or upsets them (n=31) | 2.0 (1.1) | |
| Does not cope well/ a little | | 20 (64.5) |
| Coping with immediate effects of EQ (n=31) | 2.0 (1.3) | |
| Coping quite well | | 6 (19.4) |
| Coping some | | 2 (6.5) |
| Not coping at all or a just a little | | 23 (74.2) |
| Change in level of coping with things that bother or upset after EQ (n=31) | 2.4 (0.8) | |
| Coping better | | 3 (9.7) |
| Coping about the same | | 11 (35.5) |
| Coping worse or much worse | | 17 (54.8) |

Many of the children (N=14) did not cope at all with the immediate effects of the EQs. A further nine children coped “a little bit” with any immediate effects of the earthquakes.

Frequently parents mentioned reactions to the ongoing aftershocks in the aftermath of significant earthquakes. One respondent noted that their child,

> “becomes quite unsettled when we have experienced aftershocks since the February earthquake.” *Adolescent aged 19*

Another parent explained how their child struggled with coping to sleep alone;

> “After Sept 4th, 2010, my [child] slept in our bedroom for nearly 3 months... After Feb 22nd, 2011 [the child] slept in our room up until just before Christmas. [The child] would not go to bed until we did, preferring to go to sleep on the couch in the lounge where we were.”
>
> *Adolescent aged 14*

However, a quarter of the children did cope “some” (N=2) or “quite well” (N=6) indicating they had unexpected resilience to the effects of the EQs.

When asked to consider if there had been any changes in coping ability since the pre-EQ period,  forty five percent of respondents felt that the long term coping with the effects of upsetting events “better” (N=3) or “about the same” (N=11) as that at the time of the EQs. However, more than half of the respondents believed their children had become worse at coping with difficult situations that arose than pre-quake. This was supported by the mean score of 2.4 (SD .8) which suggests that the EQs had a negative effect on this area of QOL. Some parents have observed specific long term issues from their children such as not wanting to being separated from close family and support even at home (N=2) or other regular places they attend such as their school (N=2). One parent reported;

> “[After September 4, 2010] in the first few weeks [my child] followed us like a shadow as [the child] was too afraid to be on [their] own. [After February 22, 2011] Again [the child] followed us around like a constant shadow but this time it lasted for much longer. We could not leave [the child] with anyone else...[My child] has asked us not to travel outside of Christchurch ... while at school. Even now although sleeping in … own room, [the child] is reluctant to go to bed unless someone else is at that end of the house - some nights are better than others.”
>
> *Adolescent aged 14*

Similarly, another parent observed that their child,

> “will not be in any room by [themselves] - this includes the toilet, bathroom and [their] bedroom. [They] did have their room upstairs but …will not go upstairs now, so we have moved [them] into a downstairs bedroom. [They] need to know if I go out and leave [them] with the family, [they] need to know where I am and how long I will be. [They]

> will ring me about every 20 minutes to check where I am. If I am running late - I will also get a call." *Adolescent aged 15*

Other responses indicated that some children struggled to cope with activities or events they had engaged with or enjoyed prior to the EQs. Two respondent particularly noted that their children needed more reassurance to engage with activities they had previously been alright with. One child was found to have withdrawn from previously enjoyed activities and had significantly lost confidence.

The other parent wrote about how difficult it was for their child to engage in regular activities because of constant reminders of the sound and feel of EQs;

> [Child] still struggles with any quake movement - he 'passes it off' by saying it was a big truck going past, which is ok when at home or at grandparents as we agree with him (to some extent) - kids at school tell him otherwise and [child] gets upset at this. [Child] also struggles with air-conditioning noise in some malls and especially the large "the warehouse" stores - gets very uptight/ on edge and can't focus on what we are there to look at/buy. [I] have had to quickly grab essentials and leave the store so that he can calm down again on more than one occasion. (Air conditioning noise and the rumble - earthquake sound [the same] to him). *Child aged 8.*

Further analysis looking at the effects of age, gender and geographic area were carried out on the questions that asked about how the child coped with the effects of the EQs. No significant relationship was found between the age groups, gender of the child and geographic area and the effects of the EQs on the QOL: psychological health – coping.

Table 12
Comparison of Change in Level of Quality of Life: Psychological Health - Coping - after Earthquakes in Male and Female Children

| Change in level of coping skills after earthquakes | Female | Male |
|---|---|---|
| | N (% within group) | N (% within group) |
| Worse or Much Worse | 7 (77.8) | 10 (45.5) |
| About the Same | 2 (22.2) | 9 (40.9) |
| Better or Much Better | 0 (0.0) | 3 (13.6) |
| Total | 9(100.0) | 22 (100.0) |

No significant relationship was found when the effects by the different age groups, 0 - 12 years and 13 – 20 years were compared (p = 0.12). The results revealed that all children between 13 and 20 years reported the lowest mean score of 1.00 (SD .000) which would indicate that they did not cope at all with the effects of the earthquakes. When asked whether there was any change in ability to cope from pre-EQs, 11 of 13 respondents indicated that they rated their child “worse” or “much worse” than before the EQs started.

When the results were examined for any relationship between gender and changes in coping skills no statistically significant relationship was observed, however, as Table 12 shows, over three-quarters of females were rated to be worse or much worse in coping skills than compared to pre-EQ levels. No significant findings were found for analysis by geographical area.

The answers to the survey questions concerning the quality of life domain, psychological being focusing on coping with upsetting things or events consistently revealed the sizable effect that the EQs had on children with disabilities and how the unexpected events caused considerable disruption in psychological QOL for many of the children.

**QOL: psychological health: stress.** The QOL domain of psychological being was also addressed in a series of questions that asked about the levels of stress experienced by the children participating in this study. Nine parents contributed additional information. The results indicated that the levels of stress experienced by the children in this study was notable. One of the results presented in Table 13 reveals that nearly half of the children were reported as struggling with stress "quite often" (N=15) or "all of the time" (N=1) (see Table 13).

One parent observed that their child, aged 11, "had always been anxious," so the stress may have been present before the EQ. Although another parent acknowledged that it was,

> "hard to tell because [the child] does not usually talk about what is bothering [them] underneath, but focuses on the external (tidy room, etc.)."
>
> *Young adult aged 20*

When asked about how their child or adolescent dealt with stressful events in the days or weeks after the major EQs, over 60 percent of parents reported that their child dealt with stress "very little" or "not at all well" as shown in Table 13. One parent reported that their adolescent "has become incontinent due to raised anxiety, stress [and] fear" during the EQ period. Two other respondents noted similar regressive responses with their children or adolescents.

Table 13
Summary of Responses for Quality of Life: Psychological Health - Stress

| Survey Item | Mean (SD) | N (%) |
|---|---|---|
| How often child is stressed or nervous (n=31) | 2.4 (0.6) | |
| Is stressed or nervous quite often /all the time | | 16 (51.6) |
| Is stressed sometimes | | 15 (48.4) |
| Is never stressed | | 0 (0.0) |
| Ability to deal with stressful events in days or weeks following notable EQ (n=31) | 2.2 (1.3) | |
| Quite well or very well | | 8 (25.8) |
| Some | | 4 (12.9) |
| A little | | 6 (19.4) |
| Not at all | | 13 (41.9) |
| Change in ability to deal with stressful events now after EQs (n=31) | 2.4 (0.8) | |
| Better | | 3 (9.7) |
| About the same | | 16 (51.6) |
| Worse or much worse | | 12 (38.7) |

Other respondents reported symptoms of stress disorders in their children including heightened anxiety and nervousness (N=5), somatic complaints (N=2), appetite change (N=2) as well as avoidance of former activities (N=2) and a general “unsettledness” (N=4). One parent observed that their child now, post EQ;

> “seemed to be troubled by everything. When [the child] is at home [the child] wants to go out. When [the child] is out [the child] wants to go home”. *Young adult aged 20*

However, seven respondents indicated that their children dealt with any stress in the aftermath of the major earthquakes “quite well”. These children ranged in ages from 5 to 9 years and lived in various geographic locations around the affected region. All but one of these children was attending a primary school at the time of the major events with the other recorded as attending Kindergarten at the time of the major EQs. Another parent of a preschool aged child reported that their child dealt with the stress ‘very well’, noting

> “I think he is more upset by our response than the earthquakes. If we get scared he runs to us so we make a huge effort to stay calm” *Child aged 3*

The potential long term effect of the EQs on the respondents’ children ability to deal with stress did appear positive with over 50 percent reporting it to be “better” (N=3) or “about the same” (N=16) compared to pre-EQ levels. One parent noted that effects of attending counselling sessions with a child psychologist had a positive effect on their child;“much better at talking things through.” *Adolescent aged 14*

One parent believed that other factors may have contributed to their child’s improved response to the stressful events post-EQ including puberty and natural development and a greater self-awareness unrelated to the earthquakes. Another parent noted that the heightened stress only seemed apparent for immediate weeks after each significant EQ;

> “the distress caused by the earthquakes only seemed apparent for the initial weeks after a major quake. This was stress felt each time an aftershock happened - my [child] was scared and needed to be held at each aftershock.” *Child aged 3*

However, almost 40 percent of parents believed that their child had less ability to deal with stress than prior to the EQs. One parent noted that;

> “Overall I believe my [child] is more anxious than …pre-earthquakes. There has been some improvement but [the child] is not back to where [the child] was pre-earthquakes.” *Adolescent aged 14*

Table 14
Comparison of Means of Immediate Effect of Earthquakes and Pre-Earthquake Comparative effects by Age-group

| Effect of stress from earthquakes on Children and Adolescents | Children (2-12 yr.) (n=18) | Adolescents (13-20 yr.) (n=13) | Overall (n=31) |
|---|---|---|---|
| | Mean (SD) | Mean (SD) | Mean (SD) |
| Immediate effects of earthquakes [a] | 3.11 (1.875) | 1.15 (.555) | 2.29 (1.755) |
| Effects compared to before earthquakes [b] | 2.7 (1.14) | 1.92 (.751) | 2.42 (1.285) |

a Likert Scale where 1 (*Not at all*), 2 (A little). 3 (Some), 4 (Quite well), 5 (Very well)
b Likert Scale where 1(Much worse), 2 (Worse), 3 (Same), 4 (Better), 5 (Much better)

The impact of the EQ on the psychological being domain of the respondents' children were analysed by crosstabulations of age, gender and the geographic location within the region. The geographical factors were not significantly related (p = 0.15). A statistically significant relationship was found when the effects of age on the QOL domain of psychological health – stress were measured. The results for the question # 3.2; "Ability to manage stressful events in days or weeks following notable EQ" were p = 0.003. The relationship between age group and the comparison of ability to handle stress to pre-EQ was also very significant, p = 0.001. The relationship was evident in that children in the 0-12 year age group appeared on average to have less issues with any stress resulting from the earthquakes than those in the older age group (see Table 12). With an overall mean score of 1.15 (*not at all well*; SD: .555), 10 of the 13 children for whom it was reported did not deal with the stress of the EQs were aged between 13 and 21 years.

Furthermore, as Table 14 indicates, there was a higher probability that adolescents scored "worse" (Mean = 1.92, SD 0.751) for Q# 3.3 "*Change in ability to handle stressful events now compared to pre-EQs*" than children in the younger age category.

Similarly, all of the children (N=8) who were reported to have dealt “quite well” (See Table 13) with the stressful events immediately after the earthquakes were in the 0-12 year age group. Of the 12 children for whom it was reported were less able to deal with stress than before the EQs sequence, 9 were in the 13-21 year age group.

There was no statistically significant relationship between gender and the effects of the EQs on psychological health – stress (p = 0.8). All female adolescents (13-20 years) (N=6 of 9) scored were noted to score either “very little” or “not at all” while 85 percent (N=6) male adolescents scored the same. At the same time, the children (0-12 years) who scored as dealing with the stress “quite well” were male. This would support the suggestion that the QOL was less effected by EQ-related stress for younger (>13 years) male children.

The answers to the quality of life domain, psychological being focusing on the effects of stress revealed that for many children, significant stress and anxiety was inevitable since the EQs started. These results indicate that there is a potentially strong relationship between the age of the child and their capacity to handle stressful events.

**QOL: physical belonging: area of residence.** The QOL domain of physical belonging was covered in questions that addressed how the children felt about the neighbourhood where they resided. Eleven respondents gave additional responses. The results shown in Table 15 show that more than three-quarters of respondents reported that the neighbourhood where they lived was “important” (N=7) or “very important” (N=16) to their child. Eighty percent of respondents also reported that their child was “happy” or “very happy” with where they lived. Although one parent observed;

> “my [child] says [they] like living here but I don't know that [the child] comprehends just how lucky we are to live out of earthquake affected areas.” *Adolescent aged 19*

Table 15
Summary of Responses for Quality of Life: Physical Belonging - Area Resident

| Survey Item | Mean (S.D) | N (%) |
|---|---|---|
| Importance of where they live (n=31) | 4.2 (1.1) | |
| Where they live is very important/important | | 23 (74.2) |
| No Response | | 1 (3.2) |
| Happiness with where they live (n=31) | 4.0 (1.1) | |
| Very happy/ happy with where they live | | 25 (80.6) |
| Effect of EQs on happiness with where they live (n=31) | 2.5 (1.4) | |
| Not at all or a little | | 18 (58.0) |
| Sometimes | | 6 (19.4) |
| Quite a lot or a lot | | 7 (22.6) |

These results would suggest that the QOL domain of area of residence is one in which the respondents children are quite satisfied with. Although this should be carefully considered along with the age of the children and the high probability that they live in the area that their family chose to suit their needs.

When asked to evaluate the effects of the EQs on their child's level of happiness with where they lived, nearly 60 percent of respondents observed that there was "little" or "none at all" impact. One parent noted,

> "an undamaged house and friendly neighbours have made life easier"
>
> *Young Adult aged 20*

However, the EQs did effect some areas of Christchurch significantly and this had a negative impact on nearly a quarter of the respondents' children who indicated they came from one of those areas. As one parent explained;

> "our home is our [child's] security - it is where [they] have always felt safe. This has changed with the earthquakes. Our home is damaged but thankfully liveable but we have lost the use of our sewer system on three occasions and this has really thrown our [child]. [They] refused to use a chemical toilet and we had to take [them] to other people's homes for [them] to do no. 2s.

> [They are] very aware of the damage to the area we live in - shops [they] went to are shut and due to be demolished, people [they] knew have moved away, damage to the roads and footpaths make cycling hazardous (and [the child] liked to ride his bike to his grandmas who lives a few streets away). Grandma is also moving away as she is red-zoned; we don't know where yet and this worries my [child]. [They] used to cycle in Porritt Park and along the Avon river, but we don't go there anymore - our [child] finds it too sad."
> *Adolescent aged 14*

Another parent residing in the eastern suburbs noted,

> "[Child] wants to move away from Christchurch but financially and because of accessibility issues it is impossible" *Adolescent aged 19*

However, the effects of the EQs were widespread across Christchurch as one parent residing in the western suburbs of Christchurch noted;

> "[They] will not go upstairs. [They] cannot go to the toilet unless the door is open. When [the child] is in the shower, I have to be in the bathroom. We live near the airport [west of CBD] so if [they] hear a big plane take off [or] land [they] will jump up or grab the closest person to [them]."
> *Adolescent aged 15*

The effect of the EQs on the child's happiness with the area they reside in was further analysed by crosstabulation in relation to the age, gender and geographic location within the greater Christchurch area. The results showed that there was no significant relationship ($p = 0.44$) between the geographical area that the children were residing in at the time of the earthquakes and the effect on the child's happiness with the area they live in.

While more than half of the children reported that the EQs did not affect their happiness with where they lived, it was noted that children who lived in the east of Christchurch were more likely to report '*a lot'* (N= 3 out of 4) of effect on their happiness. For one of these children, it was reported that where they lived was important (Q# 4.1) but was also unhappy with where they lived (Q# 4.2) which could indicate that the EQs has had a significant effect on the QOL domain of residence for that individual child. Another child for whom it was reported the EQs having ‘quite a lot’ of an effect on their happiness, lived in the west of Christchurch, and struggled to feel safe in their own home and refused to be in parts of the home by themselves. Further analysis looking at the effects of gender (p = 0.56) and age (p = 0.10) were run but no significant results were observed.

Where there had been additions made to properties such as ramps or hoists, most (N=6) respondents indicated that there had been little impact, however for one adolescent access was more complicated after the EQs as their parent pointed out,

> “[The] footpath dropped so [they] was unable to get to the Pandex Hoist in [their] wheelchair by [themselves] to get inside. From the van [they] had to go down the driveway, out the gate and up the footpath, then onto the grass the back up onto the footpath to access [the] Hoist”
>
> *Adolescent aged 19*

In a related situation, another parent noted some of the effects for their visually impaired child where, “damaged footpaths outside the house took a long time for council to fix. It was dangerous.” *Adolescent aged 19*

The answers to the quality of life domain of physical belonging were varied and can be seen as indicative of the wide range of effects of the EQs on the region and on children living with disabilities.

**QOL: social belonging: friendships.** The questions concerning the QOL domain of social belonging: friendships examined the relationship that the respondent’ children had with their friends. Eleven respondents gave additional information.

Table 16
Summary of Responses for Quality of Life: Social Belonging – Friends

| Survey Item | Mean (S.D) | N (%) |
|---|---|---|
| Happiness with their friends (n=31) | 3.8 (0.7) | |
| Very happy or happy with friendships | | 22 (70.9) |
| Importance of keeping contact with friends following EQs (n=31) | 3.7 (1.1) | |
| Very important or important to keep contact | | 15 (48.4) |
| Neutral on importance to keep contact | | 13 (41.9) |
| Unimportant or Very unimportant | | 2 (6.5) |
| No Response | | 1 (3.2) |
| Effect of EQs on relationship with their friends (n=30) | 3.2 (0.6) | |
| Friendships much better or better after EQ | | 6 (19.4) |
| Friendships are about the same after EQ | | 22 (70.9) |
| Friendships are worse after EQ | | 2 (6.5) |
| No Response | | 1 (3.2) |

The results presented in Table 16 reveal that around 70 percent of their children were reported to be "happy" or "very happy" with the friends that they had. However, five parents added that friends and friendships was a difficult area for their children with a number pointing out that the friends were often schoolmates or family. One parent observed;

> "making friends is a challenge for [adolescent]. [They have] one friend [adolescent] sees at school and does things with after school. That friendship is important to [adolescent]." *Young adult aged 20*

Other parents indicated similar situations; with one observing,

> "our child does not have friendships other than those at school".
>
> *Adolescent aged 16*

While another reported that their adolescent;

> "… does not really understand about relationships other than those of his parents or siblings." *Adolescent aged 16*

The importance of family for the relationships of their children was noted by two of the parents, with one pointing out;

> "Our [child] has no friends in the normal use of that word – [they have] some acquaintances at school. But family is very important to my [child] - in particular [they] love visiting one of my sisters because she has a [child] who is 2 years older than my [child]. They are the only people that our [child] feels comfortable enough with to stay a night although [they have] not done this since the Feb 22nd quake." *Adolescent aged 14*

The results revealed that all of the children that were reported to be "neither happy nor unhappy" with their friends (N=8) or "unhappy" (N=1) were recorded as male. This could indicate an area of concern for male children with disabilities and the development of relationships with their peers. All female children were reported as being "happy" (N=6) or "very happy" (N=3) with their friends and friendships.

It was reported that half of the children or adolescents felt it was "important" or "very important" to keep in contact their friends after the EQs (see Table 16). One parent observed about their adolescent;

> "After an aftershock, [the child] will ring [their] friends to check on them. [The child] spends heaps more time on the phone talking to [their] friends now than before the earthquakes. [Their] friends that live outside of Christchurch will get a phone call as well - to see if they are ok as well. "
>
> *Adolescent aged 15*

While another adolescent was "always wanting to know that they are safe."

*Adolescent aged 14*

Two respondents noted their children using various technologies to maintain contact with friends in the aftermath of the EQs. One family identified the different means including,

> "We have ensured that we have maintained regular contact with my [child's] friends through the disruptions caused by earthquakes (and snow) with visits, and SKYPE. This has been a way to maintain some sense of normality." *Adolescent aged 19*

Another family mentioned the usefulness of Facebook "…for communication, especially with non-verbal children." *Adolescent aged 19*

When the effects of the EQs on the children's relationships with their friends were considered, the majority (70%) indicated they were about the same with another twenty percent indicating some level of improvement (N=6). As one parent found the decision to evacuate their child in the aftermath of the EQs to another city for a while was a positive move;

> "[The child's] friendship circle grew because of time in Wellington. [The] new friends didn't know of [child's] disability - loved being "normal."
>
> *Adolescent aged 14*

Another observed other positive changes in the wake of the EQs,

> "My [child] does not have friends as such, which ties in with [child's disability]. [The child] does have a [other child] at school [the child] talks to and this came in handy after the June aftershocks. At that time my [child] was busing to school across town and when [the child] refused to go to school, the school asked this [other child] to sit with our [child] on the bus which was fantastic." *Adolescent aged 14*

Further analysis by age, gender and geographic area was carried out. A very significant relationship ($p = 0.003$) was observed between the age groups when it was measured for the importance of keeping in touch with friends after the EQs (see Table 17) although none was observed when friendships were compared to pre-EQ.

*Table 17*

Comparison of Importance of Keeping in Contact with Friends between Younger Children and Adolescents

| | Younger Children (0-12 years) | Adolescent (13 -20 years) |
|---|---|---|
| Importance of keeping in contact with friends | N (% within group) | N$^a$ (% within group) |
| Unimportant/Very Unimportant | 1 (77.8) | 1 (45.5) |
| Neither Unimportant nor Important | 12(22.2) | 1 (40.9) |
| Important/Very Important | 5 (0.0) | 10 (13.6) |
| Total | 18(100.0) | 12 (100.0) |

a This a total count of 30 responses. There was one recorded No response.

It was thought there might be a significant relationship between the gender of the children and the importance of keeping in touch after the EQs but none was observed ($p = 0.18$). No relationships were observed when geographic location was tested.

The results for the QOL domain of social belonging – friendships indicate that there are a wide range of experiences for children and adolescents with disabilities. The majority of respondents indicated that the children were happy with their friends although a number mentioned that male children were less likely to have friends outside of school or family. The responses indicated a minimal effect on friendships or in some instances an improvement.

**QOL social belonging: visiting and socialising.** The QOL domain of social belonging was also covered in the survey by questions that asked about how the children felt about visiting and socialising with friends and family. Eight respondents gave additional information. Over two-thirds of the respondents reported that their children thought it was "important" or "very important" to visit and socialise with friends and family and that they enjoyed it "quite a lot" or "a lot" (see Table 18).

Table 18
Summary of Responses for Quality of Life: Social Belonging – Socialising

| Survey Item | Mean (S.D) | N (%) |
|---|---|---|
| Importance of visiting/socialising with family or friends (n=31) | 4.0 (1.0) | |
| Very important or important to visit/socialise with family or friends | | 20 (64.5) |
| Likes visiting/socialising with friends and family (n=31) | 4.0 (1.0) | |
| Likes visiting a lot or quite a lot | | 20 (64.5) |
| Sometimes | | 8 (25.8) |
| A little or very little | | 1 (3.2) |
| No Response | | 2 (6.5) |
| Effect of EQ on willingness to GO and visit or socialise with friends or family (n=31). | 4.2 (1.1) | |
| Had very little effect on willingness to visit | | 20 (64.5) |
| Had some effect on willingness to visit | | 7 (22.6) |
| Had quite an effect on willingness to visit | | 3 (9.7) |
| No Response | | 2 (6.5) |
| Effect of EQ on willingness to have friends or family visit their own home (n=29). | 4.6 (0.8) | |
| Had very little or little effect | | 25 (80.6) |
| Some effect | | 3 (9.7) |
| Quite a lot of an effect | | 1 (3.2) |
| No Response | | 2 (6.5) |

The respondents reported on the various places or sites that their child enjoyed visiting or socialising with friends with the family home being the most popular with over three-quarters of children followed by meeting at a friend’s home (66%) and at school (52%). Shopping malls and other community sites were also recorded as popular sites for 24% percent of children. Other sites included, on holiday, the family’s place of worship, youth groups, playgrounds, community sites and visiting friends in other cities.

The earthquakes appeared to have had a very limited impact on the willingness of the respondent’s children to visit or socialise with friends and family. When asked about the effect of the EQs on having friends or family come and visit the child in their own home, 80% indicated that there was “very little” or “a little” effect. One parent who reported their child was affected “sometimes” did, however, note,

> “it is hard for some of [their] friends to get here.” *Adolescent aged 19*

There was a slight difference in the overall impact of the earthquakes on the children’s willingness to go and visit friends and family after the earthquakes. Around 65 percent of respondents indicated that the EQs had “very little” or “a little” effect on their children’s willingness to go and visit or socialise with friends or family. Over a third (N=10) of children were reported as being “sometimes” or “quite” reluctant to go out and socialise compared to just four children who were uncertain or “quite” unwilling with people visiting their own home . One parent noted,

> “[the child] doesn't want to go to the mall the same, movies or large buildings. Would rather be at home than out and about.”
>
> *Adolescent aged 14*

Reluctance to go to malls and other large community sites was noted by two other parents of adolescents.

Another respondent reported changes in their child’s willingness to socialise but was uncertain if this was EQ related or not;

> “[the child] is inclined to want to stay more at home - but not sure if this is EQ related or not. [Child] does not share a lot of his inner state, getting info about feelings into words is very hard for him. He's certainly minimised outings, but

> at same time, is doing lots of things with school as in final year now - and having to take risks, go places, etc”
>
> *Young adult aged 20*

One parent though, noted that little had changed from before the earthquakes with their child,

> “[The child] has never gone to anyone else's home on [their] own apart from family - this was a pre-earthquake attitude and it hasn't changed. We have suggested inviting children from school to our house but our [child] has never wanted this before or after the quakes.”
>
> *Adolescent aged 14*

One parent also observed that the EQs may have affected their child’s need to stay in contact with their family, noting;

> “Since the earthquakes my [child] has made more requests to see members of our family - I don't know if [child] is trying to reassure [themselves] that they are okay or that [child] feels more secure in a larger group of people that care about [child].”
>
> *Adolescent aged 14*

Further analysis by age group (p = 0.06), gender (p = 0.57) and geographic location (p = 0. 94) of the children did not reveal any statistically significant relationships. The QOL domain of social belonging visiting and socialisation for children with disabilities can be viewed as an area of reasonable importance to them the EQs appears to have had a minimal impact for the majority of the children.

**QOL community belonging: community access.** The QOL domain of community belonging was surveyed through questions on the level of community access for the children of the respondents. Seven respondents gave additional information. Three quarters of respondents reported that it was “important” or “very important” for their child to have access to different places in the community (see Table 19). However, just 52% considered their child to be "happy" or "very happy" with the level of community access.

Table 19
Summary of Responses for Quality of Life: Community Access

| Survey Item | Mean (S.D) | N (%) |
|---|---|---|
| Importance of community access (n=31) | 4.1 (1.2) | |
| Very important or important to have access to different places in community | | 23 (74.2) |
| Happiness with community access (n=31) | 3.4 (1.1) | |
| Very happy or happy with access to different places in community | | 16 (51.6) |
| Reasonable access to community places after EQ (n=31) | 2.8 (1.3) | |
| A lot or quite a lot of access | | 10 (32.3) |
| Some access | | 9 (29.0) |
| A little or very little access | | 11 (35.5) |
| No Response | | 1 (3.2) |
| Compared access to usual community places after the EQ (n=31) | 2.3 (0.7) | |
| Better access | | 1 (3.2) |
| About the same access | | 9 (29.0) |
| Worse or much worse access | | 19 (61.3) |
| No Response | | 2 (6.6) |

When asked about the level of access to community sites following the EQs just one-third of respondents reported a continued reasonable level of access. The loss or closure of popular community sites such as libraries, pools and museums and popular attractions including the city tram and gondola featured in all the additional responses. One parent observed,

> "many of the city libraries have been closed, my [child] visited a library weekly, now it is more difficult to access, having to travel further. Our local swimming pools have been closed (one to earthquake, the other to snow)."
> *Adolescent aged 19*

This sentiment was echoed by other parents who also cited the difficulty in accessing new sites due to EQ related damage to city infrastructure,

> "construction works and street closures make it worse in some areas."
>
> *Child aged 7*

The reduced level of access to the usual places after the EQs was notable with two-thirds reporting worse or much worse access. One parent commented that,

> "we don't go to places we used to go to." *Adolescent aged 19*

Another noted the difficulties in the constantly changing sites for popular community facilities and the impact this has on some children with disabilities;

> "We no longer have access to QEII where my [child] liked to go. Our local shops are closed and to be demolished - they are red zoned. Our local library is closed and there is no date given for re-opening. Our local shopping mall is open but has been partly demolished. It is very difficult to my [child] to adapt to this situation – [the child] likes routine and the security of going to the same places. I have not been able to convince [them] to visit other libraries, etc. It doesn't help that some of these facilities are now very busy which is a difficult situation for [them] to be in." *Adolescent aged 14*

However, some parents noted that the limited access was only temporary in some instances and other alternatives were found. One parent pointed out that;

> "initially the community venues were closed but now they have reopened. Swimming was at QE2 so we had to find a new venue for this." *Child aged 2 ½ years*

While another respondent commented that while their child;

> "really misses the trams, and the gondola, [their] favourite places to go pre EQ. [The] Museum and library [being] reinstated has made [them] happy. [It] has focused [their] attention on what remains, and only occasionally mentions what

> is temporarily lost. But it does affect [them]."
>
> *Young adult aged 20*

Further crosstabulation analysis of this domain by age, gender and geographic area did not reveal any statistically significant relationships. Although it is notable that the majority of the respondents who commented noted the struggles that their adolescent or young adults had with the loss of familiar recreation sites. The results indicated that it is important for the QOL of children with disabilities to have good access to different activities and places in their community. The EQs have had a considerable impact on the access and QOL domain of the children and adolescents.

**QOL practical becoming: schooling.** The QOL domain of practical becoming was surveyed with questions looking at schooling. Nearly half (N=15) of the respondents added additional comments. The responses revealed that it was an important area in the majority of children's lives. More than three-quarters of respondents indicated that their child felt it was "important" or "very important" to attend school (see Table 20).

Four respondents (13.8%) indicated that they believed their child felt it was very unimportant to attend school.  It was indicated that three of these children were also "unhappy" or "very unhappy" with attending school. However, as Table 20 shows, over 60 % of respondents reported their children were "happy" or "very happy" with going to school. Six parents recorded that their child was neutral in their happiness with attending school which might be a reflection that school is something that is simply seen as part of the daily routine rather than anything particularly important. However, a number of the respondents emphasised that their child's school provided a source of friends, activities and daily routine for the child without which they would struggle. This could emphasise how important schooling is for children with disabilities and their families.

*Table 20*

Summary of Responses for Quality of Life: Practical Becoming – Schooling

| Survey Item | Mean (S.D) | N (%) |
|---|---|---|
| Importance of attending School (n=31) | 4.1 (1.4) | |
| Very important or important to attend school | | 22 (70.9) |
| No Response | | 2 (6.6) |
| | | |
| Happiness with attending school (n=31) | 3.7 (1.2) | |
| Very happy or happy with attending school | | 19 (61.3) |
| No Response | | 1 (3.2) |
| | | |
| Happy to return to school after EQ (n=31) | 3.3 (1.3) | |
| Very happy or happy to return after EQ | | 15 (48.4) |
| Neutral about return after EQ | | 5 (16.1) |
| Very unhappy or unhappy to return after EQ | | 9 (29.0) |
| No Response | | 1 (3.2) |
| | | |
| School Change after EQs (n=31) | | |
| Same school, same location. | | 22 (70.9) |
| Same school, different location | | 2 (6.6) |
| Had to go to different school | | 5 (16.1) |
| Other | | 1 (3.2) |
| No Response | | 1 (3.2) |

The impact on the EQs on the happiness of the respondents' children to return to their school was mixed. Half of the respondents indicated that their child was "happy" or "very happy" to return to school after the major EQs which saw schools closed even temporarily. One parent said;

> "[the child] was desperate to get back to school to check on [their] friends but due to [their] health [they] couldn't so [they] spent hours on the phone."
> *Adolescent aged 15*

Another identified how school assisted with their child's ability to cope with the disruption caused by the EQs, saying,

> "Going to school is a very important part of [the child's] routine and [the child] was most happy once school was back up and running after 22/2 [February 22

> 2011 EQ]. School routines have probably kept [them] calm more than anything else. Very grateful for teachers and their hard work in keeping things 'as normal as possible'." *Young adult aged 20*

Although not all children were happy to return to school after some of the larger EQs as one parent noted;

> After the June 13th aftershocks [the child] refused to go to school (off school for a week) until some changes were made at the school, most importantly a buddy to walk to classes with (at this time [the child] was attending another school on the other side of town as [child's school] was closed). *Adolescent aged 14*

However, other parents noted the issues that arose from the timing of some of the major EQs and about the fears associated with being at school while experiencing major EQs and the effects this had on their child. One parent thought that their adolescent;

> "was anxious about returning to school after the February and June quakes as they were experienced at school and it was pretty traumatic…[the child] loves school and was keen to get back to see [their] teachers and friends but that eagerness was tampered with the anxiety of possible future aftershocks."
> *Adolescent aged 19*

Another noted that their child,

> "did not like being on the other side of town - for [child's school] was too far away from us if something went wrong. Even though we got there quickly in June, [the child] was not convinced that [they] were safe. In fact one of [their] first comments after the 23rd December 2011 aftershocks was that [they] were so pleased [they] were not at school." *Adolescent aged 14*

The majority of children returned to the same school site after each EQ enforced closure (see Table 20), although as one parent of a child with high needs indicated, for some schools this was sometimes for quite a while,

> “same school but it was closed for quite a while after the February earthquake and it was a challenge organising care.” *Child aged 7*

Five parents indicated that their child attended another school after the EQs although for most of the children (N=3) this was temporary and only for the immediate weeks after the February 22, 2011 event. Two primary-aged children attended another school for two months after the February EQ and then returned to their original school. Three of the children were also affected by the school site sharing set up in the wake of the February 22, 2011 EQ. For one of these children, it was quite a difficult time with the school hosting another school so the child was starting much earlier in the morning which according to the respondent, caused considerable tiredness for the child.

> “[Their] school had another school sharing their site so that meant a change of school hours and leaving home at 6:45 am each morning. My [child] became very tired as a result of the change in hours.”
>
> *Adolescent aged 19*

Two respondents also indicated that their adolescent children did return to school after the major February 22, 2011 EQ but were unhappy and had since left school.

Further crosstabulation analysis of this domain by age, gender and geographic area did not reveal any statistically significant relationships. It was notable though that children in both age groups demonstrated a reluctance to return to school (see Table 20), although two-thirds of primary school aged children appeared happy to return. The adolescent group, however, appeared to be reasonably divided.

Table 21
Comparison of Happiness to Return to School after Earthquakes between Younger Children and Adolescents

| Happiness to return to school after the earthquakes | Younger Children (5-12 years: n=15[a]) | Adolescents (13-20 years: n= 13[b]) |
|---|---|---|
| | N (% within group) | N (% within group) |
| Very unhappy or unhappy | 4 (26.7) | 5 (38.5) |
| Neither happy nor unhappy | 2 (13.3) | 3 (23.0) |
| Very happy or happy | 9 (66.7) | 5 (38.5) |
| Total | 15 (100.0) | 13 (100.0) |

[a] Total of children who indicated they were in formal (i.e. primary) schooling. Two children were recorded as being in early childhood and were excluded from this table.
[b] There was one no recorded response to this question.

The questions that have looked at schooling revealed that the EQs did have a significant impact on the children even if only temporarily. That two significant EQs were experienced during scheduled school hours may have contributed to this. The loss of a number of school sites also contributed even though none of the children themselves had to move sites permanently. This was one QOL area that the EQs did affect with very few children unaffected in some way.

**QOL: leisure becoming: recreational and fun activities.** The QOL domain of recreation becoming was addressed by questions that asked about the recreational and fun activities that the children regularly engaged in. Ten respondents gave additional information. The respondents were asked to list the various recreational activities that their children liked to engage in for fun. These were then collated and organised in Table 22 using the activity categories defined in Solish, Perry and Minnes (2010), social, recreational and leisure.

Table 22
Summary of Responses for Quality of Life: Leisure Becoming

| Survey Item | Mean (S.D.) | N (%) |
|---|---|---|
| Type of activity: Social<br>Socialising, visiting friends, visiting malls with friends, sleep overs, going to the movies, going out for meals. Holiday programmes, Youth groups, Cubs | | 13 (44.8[a]) |
| Type of activity: Recreational<br>Badminton, basketball, swimming lessons, dance group, choir, cricket, boccia, bowling, horse riding | | 15 (51.7[a]) |
| Type of activity: Leisure<br>Television, computer games, PlayStation, watching movies, listening to music, walks to the park, cycling, visiting local attractions, playing games, puzzles, trampolines, reading, quad biking, hunting, crafts, drawing. | | 26[b] (89.6[a]) |
| Effect of EQ on recreational and fun activities (n=31) | 3.6 (1.2) | |
| Very little or little effect | | 16 (51.6) |
| Some effect | | 9 (29.0) |
| A lot or quite a lot of an effect | | 5 (16.1) |
| No Response | | 1 (3.2) |

[a] This is a percentage out of a total of 29 responses.
[b] This indicates the number of respondents who recorded such leisure activities.

Nearly 90 percent of children were reported as engaging in some form of leisure activity while just over half of the children engaged in some form of organised recreational activities including sports. Fewer children were reported as regularly engaging in social activities (see Table 22).

Further analysis of the activities listed for children in this study found that just 5 children were reported as engaging in regular activities that included all three types. Thirteen respondents reported their child as participating in two different types of activities (N=5, social and leisure; N= 8, recreational and leisure). Further comparison also found that almost all of the female children (8 of 9) were reported as participating in social activities compared with 5 (16.7%) males.

Over 50 percent of respondents reported that there was little or very little effect from the EQs on the activities their child enjoyed (see Table 22). Thirty percent of respondents noted some disruption to activities. One activity that was mentioned frequently, was swimming with four of the parents noting again the loss of local swimming pools which resulted in further travel and disruption.

Another respondent noted,

> "We seem to have involved our [child] in more outdoor activities since Feb 22nd - I think partly because some of the places we used to go to are now closed and partly because of our own need to get outdoors more."
>
> *Adolescent aged 14*

Five respondents reported a "quite a lot" or "a lot" of effect on the activities their child liked to do. No additional information was given in further explanation for this answer. Analysis of this domain by age, gender of the child and geographic area did not reveal any statistically significant relationships.

The loss of community facilities as a result of the EQs appears to have had some impact on the different recreational activities that the children in this study enjoyed doing. However, it appeared for the majority these were only minor issues and they were still able to engage in regular activities that they enjoyed, and the EQs had little impact on the QOL of the children for this area.

**Overall QOL**. The results to the questions related to the overall QOL of the child and the respondent were presented in Figure 3.

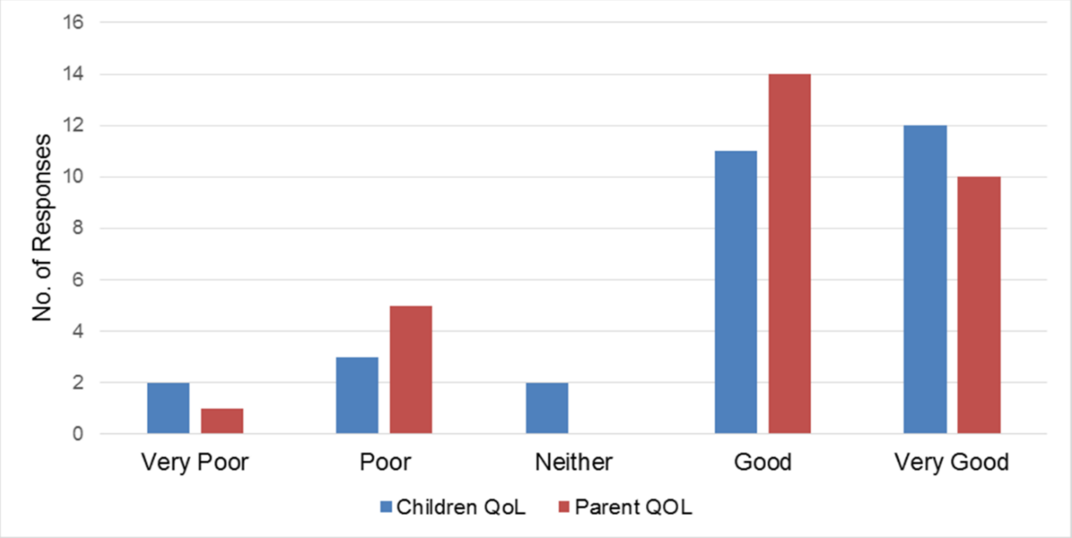


*Figure 3 A comparison of overall quality of life of the child and parent responses*

A total of 30 responses were recorded for this question with one no response. There was one additional comment. Respondents were asked to assess their children's overall QOL as well as rating their own QOL. With identical mean scores of 3.9 (standard deviation = 1.2) the majority of respondents rated both their children (N=23) and their own (N=24) QOL as either "very good" or "good". One respondent of a primary school aged child with a significant physical disability reported the child's QOL as "good" but suggested that while their child was happy,

> "comparing their quality of life to an uninjured person, it is very poor."
>
> *Child aged 7*

However, more of the respondents believed their own QOL to be more negatively affected than that of their children with 20 percent of respondents reporting their overall QOL as "poor" or "very poor" compared with 17 percent of their children. Although no additional information was given to further develop on this topic. The findings on overall QOL would suggest that for the majority of children was good or very good.

## Summary of Earthquake effects on QOL

After reviewing the reports for the different areas of QOL, the results suggest that the Christchurch EQs did affect different areas of QOL for the children of the respondents. As seen in Figure 4, when the effects of the EQs on the different QOL domains are compared, the areas of measuring social belonging; children's friendships and social relationships, were reported as been the least negatively affected by the majority of respondents. Friends was also an area where it was indicated that there was minimal impact from the EQs on the children's frienships from pre-EQ levels (N=22) with nearly 20 % indicating an improvement in the overall quality of friendships.

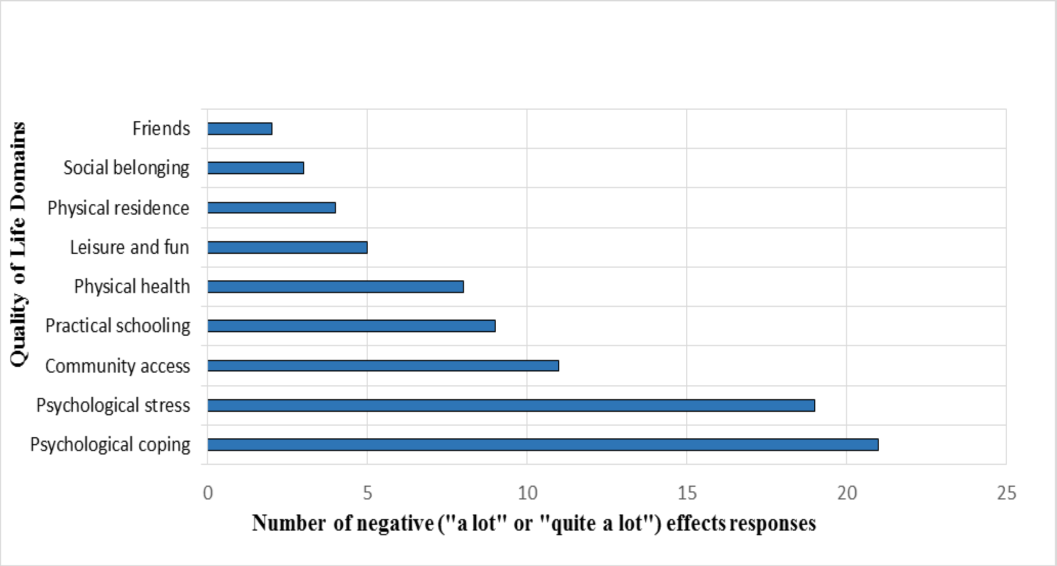


*Figure 4 Reported negative effects of Christchurch earthquakes by quality of life domains.*

However, in the QOL domain of psychological health; coping with difficult events (N=21) and psychological health (N=19) over 60 percent of the respondents indicated that their children had a negative response in both areas. This would suggest that EQs had a substantial impact on the QOL domain of psychological health for the children. Similar numbers of respondents (N=11; N=12) indicated that there had was little change in their child's ability to deal with stressful events since before the EQs began but this may not actually indicate a good result rather just support pre-existing anxieties. Community access was also noted to be an area of concern as a number of respondents indicated that the access to favourite facilities was severely restricted as a result EQs. This will contribute to a negative impact on the overall QOL of the child through the loss of favourite places and activities they enjoyed doing pre-EQ.

### Development of Coping Skills and Resilience in the Aftermath of the Earthquakes

Given the considerable effect that experiencing and living through a natural disaster can have on one's ability to cope with different events that occur in everyday life, the respondents were asked to reflect over the previous 15 month period since the EQ series began and to report on what strengths their child had developed or gained especially when considering coping skills. The responses were mainly positive with just two respondents out of a total of 27 indicating that they did not believe there had been any real development or improvement in their child. However, as one parent noted, coping can be changeable: "Changeable, sometimes he can cope better than me and other times he can panic!"(*Parent of 19 year old).*

Many of the children were reported to use or developed various emotion-focused coping strategies. These would also reveal a level of engagement coping where they have chosen to seek support with the situation in order to better cope with it (Pfefferbaum et al., 2014).

> "She communicates her fears to me and when comforted is ok (*Parent of 11 year old*)"
>
> "Very good at expressing feelings and asking questions particularly of parents (*Parent of 7 year old*)"

> “He has responded to counselling and been able to articulate his fears and took advice on board about how to deal with them (*Parent of 11 year old*)”
>
> “Being able to keep most regular routines. Earthquake drills at school have been great, our child knows exactly what to do and does not get upset. Teachers at school have been wonderful at maintaining a calm environment. We try and keep things calm at home too.” (*Parent of 6 year old*)
>
> “He is able to recognize when things are getting too much for him and takes himself off to bed for a rest. He does come to a parent for comfort at times but I am not sure he always expresses his need to be comforted.” (*Parent of 6 year old*)
>
> “She is very social and loves talking. I think she has helped her friends deal with the aftershocks just as much as they have helped her.” (*Parent of 15 year old*)

Two male children were noted to engage in problem-focused coping strategies which saw them actively seek out information that could help them understand their situations:

> “Gathers information about things that bother [them] and works [their] way through that (*Parent of 20 year old*)”
>
> “Gathering information (why it happened, how it happened) and processing the information (*Parent of 10 year old*)”

Other respondents indicated that they believed their children had developed coping strategies that would be classified as secondary control coping where they have appeared to adjust to their changed reality;

> “She has learnt to cope because it has been quite some months the quaking has been going on for (*Parent of 20 year old*)”

Of some concern though were the number of respondents who indicated that their child had exhibited signs of disengagement or passive coping by withdrawing from the situation or trying to ignore the impact of the EQs on them. One parent of an adolescent noted that they "shut himself up for a bit with his PlayStation to cope with his anxiety after 22/2" although, they had also developed a number of other coping strategies including information gathering and primary control strategies where they monitored and controlled their emotional responses. Another parent believed their adolescent could only cope if he had a distraction,

> "We take his PSP out or music ipod to help him cope" (*parent of 16 year old)*

While another would "laugh it off nervously" (*parent of 15 year old*)

Some of the children developed a better understanding of how to manage the stress and anxiety that came with the EQs and the uncertainty and fear they created.

> "He is able to calm himself with minor reassurance from parents that everything is fine. (parent of 9 year old) "

Others were noted to have developed a better ability to express their emotions and how they are feeling in the wake of the EQ series:

> "She communicates her fears to me and when comforted is ok (*parent of 11 year old*)."
>
> "Very good at expressing feelings and asking questions particularly of parents" (*parent of 7 year old*)
>
> "He has responded to counselling and been able to articulate his fears and took advice on board about how to deal with them" (*parent of 11 year old*)

Quite a number of respondents indicated a growing awareness and understanding of other people's emotions and developing sense of empathy in their children that they had not seen before:

> “There have been times when my son was so concerned about others that he was no longer thinking of his own situation (*Parent of 14 year old*)”
>
> “Going back to school and learning about doing the "turtle" gave him a good sense of understanding and that everyone else was affected too. (*Parent of 7 year old*)”

In some instances, parents identified the emergence of personal strengths in the period since the earthquakes.

> “He is a positive person, he is able to re-focus fairly fast on what is possible and cut out the things that he can't do. He has more freedom in ChCh than he had living in a small town (pre 2010).” (*Parent of 20 year old*)
>
> Another parent noted a number of coping strategies their child engaged in and noted the ones the child initiated themselves,
>
> “Coping strategies - exercise/pilates**; fun holidays, relaxation CDs**, breathing skills**, time alone** (** strategies the child uses independently).” (*Parent of child aged 8*)

In particular, the parent of a adolescent described in detail how her son’s personality affected his coping and post-disaster growth.

> My son is very strong-willed which at a time like this has been an asset. He tries very hard to find solutions to problems and while not always having an answer brings up some interesting ideas. His lovely sense of humour has also come to the fore, turning what have been rather stressful situations into shared laughter. I have read so many times that those with Asperger’s do not have empathy - well, my son proves them wrong. There have been times when my son was so concerned about others that he was no longer thinking of his own situation. (*Parent of 14 year old*)

Similarly, another parent remarked that their son was “Very brave at carrying on with day to day life - Asperger’s and being very routine person keeps the days rolling by (*Parent of 8 year old*).”

The results from the different coping strategies developed or used since the EQs started, reveal that the children and adolescents with disabilities in this study have developed strong resilience to the effects the EQs have had on them and their lives. While a small number continued to struggle with negative effects on them personally, the majority had grown in confidence, learned self-management techniques and developed a sense of trust in the adults around them. The wide range of coping strategies indicated by the parents also potentially reveals that a number of the children have significant adaptability skills. This would suggest that the development of the QOL domain, growth becoming through coping and being adaptable to changes is an area where the EQs have had a positive impact on the QOL of the children in this study.

# Chapter 5 Discussion

The results of this study indicate that the Christchurch earthquakes (EQs) did have an impact on the Quality of Life (QOL) of children with disabilities. All of the domains of QOL measured in this study; physical health, psychological health in coping and stress management, physical belonging, social belonging through friends and socialising, community access, practical becoming through schooling and leisure becoming (Raphael, Brown & Renwick, 1999) were found to be affected by the EQs. Some more significantly than others. However, of note, the overall QOL of the children was reported to be "very good" or "good" by three out of four parents.

The Christchurch EQs had the most impact on psychological health: stress as most respondents indicated that their children were stressed as a result of them. Near two-thirds of parents reported that their children displayed signs of stress disorders in the weeks and months following the earthquakes. There were significant results that supported the idea that the younger the child, the less they were reported to show stress-related behaviours. While one in three parents reported that their child coped "quite well" or "sometimes" with things or events that bothered or upset them, three out of four children were reported as not coping well with the effects of the earthquakes. The ongoing aftershocks and the uncertainty they generated were reported as being a constant source of concern for many children in this study and was noted as a significant factor in over half of the parents reported that their children coped much worse with upsetting or difficult events than when compared to before the earthquake sequence. This was especially noticeable in older children and adolescents.

On the other hand, the Christchurch EQs were reported to have had a much smaller impact on social belonging. One in five parents indicated that their children's relationships with their friends were better following the EQs than beforehand while nearly three-quarters indicated little or no effect on their child's friendships. These responses would indicate that there was a minimal disruption to the children's friendships and in some situations had a positive impact in some children's lives. There was also a positive relationship between the age group and importance of keeping in touch with their friends post-EQ. However, these results may need to be treated with caution as some respondents reporting that their children, notably all male, struggled to establish friendships outside of family or only interacted with their peers while at school. Just one parent indicated that the EQs had any significant effect on having friends or family come and visit them. However, a third of parents reported there was "some" or "quite a bit" of an impact on their child when they went out and visited or socialised with friends and family after the EQs. This also supported reports that some older children were less enthusiastic to go and meet up with friends than before the EQs which reveals that the EQs did still cause considerable disruption in this area of some of the children's lives.

The Christchurch earthquakes also had a notable impact on community belonging. Two-thirds of respondents reported reasonable or some access to regular community places for their children in the aftermath of the earthquakes. However, just one in three reported "better" or "similar" community access when compared to before the earthquakes began. Frequently, the closure of regular recreational facilities or attractions and the constant disruption to roads were reported as adding to travel and removing access to sites for the children. While these closures and disruptions were not always permanent, it did add to the impact of the EQs on the children's ability to attend their regular activities and enjoyment of their local community. It also impacted on other areas of their QOL in recreation and leisure activities.

The QOL category of recreation and leisure, was also impacted on by the Christchurch earthquakes for children with disabilities primarily through the closure of community sites. The loss of recreational facilities including swimming pools was a regular theme throughout the report with nearly half of the parents indicating swimming as a regular recreational activity for their child. Despite this, over half of the respondents indicated there was “little” or “no effect” on what their child liked to do for leisure with just five parents adding additional information. However, there was some indication from some parents that other factors including impact on the psychological health of some children, especially adolescents, may have contributed to some children being more reluctant to go to some activities that they previously enjoyed or engaged in.

The EQs also had a considerable impact on schooling as it was reported by almost all parents to play an important part in the children’s lives. However, the impact was quite varied as responses ranged from “desperate to get back to school” to “refusal to return”. While half of the respondents indicated that their child was happy to return, the timing of major EQs occurring at school was a noted concern for a number of children and it was seen to impact on their schooling. Other stressors in the EQs aftermath including separation anxiety were also observed to impact on the schooling of the children. Added concerns were bought about by the need for some schools to share sites which placed additional pressures on the children involved. Despite this, many respondents noted that their children appreciated the routine and support that their schools provided.

The earthquakes also had a varying impact on the children’s physical health. Over half of the respondents indicated that there was little impact of the earthquakes on their children’s physical health. However, for one in four children, the impact on their health resulted in more medical visits and had a reasonable detrimental effect on their overall physical health when compared to before the earthquakes. With physical being considered an important area in the lives of the majority of the children it was necessary to look at this area closely. While some potential concerns were found especially when looking at the effects on the physical health of older children and that of the small number of female children represented in this study, for the majority of children, their health remained the same as it was before the earthquakes started.

The results to the QOL questions that looked at the area the children lived in, indicated that the EQ had a reasonable impact as one respondent in four reported their children as being unhappy with where they lived. Children who were reported as living in areas known to have endured the most damage from the EQs were more likely to report a negative response to their neighbourhood. Yet further analysis did not indicate any significant relationship. However, other results indicated that individual circumstances were more of a catalyst as to whether there was a greater impact by the earthquakes in this domain than by the area where one lived. This echoed the findings of other studies into the experiences of populations in post-disaster disaster environment. When the child no longer felt safe in their own home or neighbourhood regardless of damage, they indicated unhappiness with where they lived irrespective of where that was in the Christchurch area.

One other domain of QOL,  growth becoming which looks at an individual’s ability to grow and develop, while not directly measured in the questionnaire was also found to have been affected by the EQs. A number of parents indicated positive changes in how their children responded to the effects of the EQs of 2010 and 2011. Over half of the respondents noted their children had developed stronger relationships with their families, improved communication skills and were learning to rely on and trust the important adults including parents and teachers in their lives to make the right decisions. A small number (N=4) of parents observed an increase in the awareness and empathy of their children for the plight or feelings of other people around them. Some of the children were reported as developing and engaging in different forms of coping methods for themselves and recognised when they needed to remove themselves from situations. Two respondents noted how their children used the opportunity to develop their understanding of the EQs and why they happened and what to expect in the future. However, other parents (N=4) reported that there was little or no positive improvement, including behavioural regression or the development of negative coping skills such as avoidance coping behaviour. Overall the area of growth becoming was positively affected for many of the children who appeared to have a heightened development of the sense of “self”.

The existing literature that addressed the post-disaster QOL of victims of earthquakes has frequently focused on the adult population (Wang et al., 2000; Chou et al., Wu et al.,), older adults (Ardalan et al., 2011) or children and adolescents without disabilities (Ceyhan & Ceyhan., 2007; Goenjian et al., 2011), therefore this study presents a small but important perspective. While the small number of participants has not allowed for significant analysis, when the findings are reviewed in light of the existing literature it presents aspects that both support and enhance the field of QOL research for populations who have experienced disasters or other trauma. A key point that has been identified indicates that the psychological wellbeing of the respondents’ children was the most affected area of QOL while social belonging was the least affected area for the majority of the children and some evidence given by some parents would even suggest that this is an area of growth and development in their children in the aftermath of the EQs. These findings are in line with earlier studies which looked at the QOL of adult survivors of EQs where levels of social support have a distinct advantage in overcoming long-term negative effects of such a disaster (Chou, F., Chou, P., Su, et al., 2004, Ke et al., 2010)

One area believed to be of concern for the children and adolescents in this study was that of physical health. However, the results for physical health were reasonably positive with the majority of respondents indicating that there was little effect or no change to the physical health of the child. Many of the scenarios or situations experienced in other disasters in similar developed countries, such as Hurricane Katrina in the USA as recorded in Abramson and Garfield, (2006) that saw large populations evacuated and relocated simply did not occur in Christchurch. Children who were reported as leaving the city, did so for short periods of time to “get away” from the EQs and therefore were not at risk of health care disuption. The reported issues experienced by the Louisiana children with disabilities in Abramson and Garfield including loss of medical records, difficulties getting prescriptions along with accessing needed medical treatment were not noted by any of respondents in this study. Medical services including, hospital services, general practices and pharmacies were only temporarily disrupted as other District Health Boards from around NZ assisted the CDHB where they could. Just one respondent noted any direct potential health risk in the immediate aftermath of the EQs where their child’s oxygen supply had to be switched from electric (compressor) to a cylinder supply to offset problems with the power supply in the weeks following the EQs but with no ill-effect on the child. From the results of this study, it could be concluded that the physical health area of QOL was considerably positive in spite of the EQs for the majority of the children in this study.

The parents that did report a negative effect on their child's physical health almost always noted considerable anxiety issues that their child was exhibiting as evidence of a physical health problem(s). As psychological health conditions can and frequently do represent as physical complaints this is not surprising (Carson & Stone, 2013). The reports of nervousness, anxiety, somatic complaints, appetite changes and incontinence could all be described as physical indicators of psychological distress (Carson & Stone 2013). Furthermore, all of these children were found to have significantly reduced psychological health in both stress and coping areas which supports the link between reduced psychological health and physical health issues (Waters, Davis, Nicholas, Wake & Lo, 2008). The evidence would suggest that physical health was less of an issue for the majority of the children with psychological health being a greater concern.

One area of concern observed in this study was that over half of the respondents indicated that their children frequently struggled with stress or nervousness. While this study did not have a baseline score to determine the stress experienced by the children prior to the EQs, the literature which addresses levels of stress in children with disabilities, does indicate that some children with disabilities are more at risk of experiencng higher levels of stress than their peers (Lee et al., 2008; Waters et al., 2008). Existing studies into the effects on psychological health in the aftermath of a disaster frequently noted that all children who already had a pre-existing mental health condition or stress-related concerns were more susceptible to stress and anxiety disorders including PTSD in the aftermath of a disaster (Asarnow et al., 1999; Norris et al., 2002 Peek & Stough, 2010; Shaw et al., 2012). This suggestion is perhaps confirmed by a similar number of respondents indicating that the children's ability to handle or deal with stressful situations and nervousness were about the same as before the earthquakes. Of these, over half had indicated that their child struggled with stress quite often. This could be tentatively an indicator that the current study's results supports earlier researchers including Shaw and colleagues (2012) reflecting that pre-existing mental health issues indicate a greater risk of psychopathology in the aftermath of a disaster.

When the results of the domain of Psychological Being were analysed in more depth, it was telling that both areas which evaluated stress levels and coping with negative events were found to be the most substantially affected by the EQs. Every study that measured the QOL of communities or groups that had experienced EQs noted significant decreases in psychological wellbeing in the immediate months after the main event (Wang et al., 2000; Chou et al., 2004a,b; Wu et al., 2006, Ceyhan et al., 2007; Tsai et al., 2007; Tian et al., 2013; Ardalan et al., 2011 and Goenjian et al., 2011). The unpredictable and ongoing nature of the EQs were cited by nearly all respondents as contributing to their child's lowered psychological wellbeing although one parent observed, perhaps wryly, that their child had begun to adjust as "[the aftershocks] had been going on for some time now". These sentiments were echoed by large number of respondents to the CERA wellbeing survey. The myriad of literature that has examined the psychological effects of EQs and other traumatic events on children (Asarnow et al., 1999; Norris et al., 2002; Shaw et al., 2012) found that repeated exposure to traumatic events was a significant contributing factor in an increased level of risk for long-term stress related conditions including PTSD in children and adolescents. While this study did not set out to measure and evaluate for the likelihood of PTSD, the symptoms of significant stress–related psychopathology including those for PTSD (Murray 2011) were mentioned by a number of respondents.

It was evident from information provided that a small number of the children in the study were mentioned to exhibit behaviours that would suggest a significant psychological impact from the EQs on their mental health. An important note to make here is the continued experiences of EQs were exacerbated by the continuing exposure to stressful events through the length of time that the Christchurch EQ series lasted (17 months). Every time a significant aftershock occurred, the children were re-exposed to the stress experienced in previous aftershocks. Even when there was no shaking, the children who lived in or came into Christchurch city were unavoidably exposed to the significant damage caused by the EQs to buildings and infrastructure around the city and thus frequently reminded of the physical effects of the EQs. Many of the psycho-biological responses reported in Shaw et al. (2007) were recorded by the respondents. In the more severe cases, respondents noted considerable behavioural regression including bedwetting and extreme separation anxiety. A number of parents also noted that sleep disturbances, while not assisted by ongoing aftershocks occurring during the night, continued in a couple of cases, for months after the major EQs. Female children were of particular risk to exhibit increased stress and long-term coping issues. Other children appeared to lose their motivation and willingness to participate in activities they had previously enjoyed. Many of the behaviours and actions recorded would be considered symptoms of chronic stress disorders and early warning signs of PTSD (Shaw et al., 2012).

The loss of motivation was particularly evident in adolescents. The literature that looks at the stress reactions of adolescents to trauma or disaster has indicated an increased level of anti-social behaviour and engaging in negative risk-taking activities (Shaw et al., 2007, 2012; Murray 2011). This, however, does not necessarily discuss the effects on adolescent with disabilities. Some of the respondents indicated that some of the changes could have been influenced by the effects of puberty which may disrupt and unsettle an adolescent's moods as the body experiences hormonal and physical changes (Murray 2006). Maybe of concern is the fact that all adolescents were reported as not coping at all with the EQs. Furthermore, while some improvement was noted, all adolescent females were all reported as having less coping skills post-EQs. However, other QOL studies did not necessarily observe a significant difference between males and females (Goenjian et al., 2011). While this was not a direct focus of the current study, it is a feasible argument that adolescents with disabilities may be more at risk of psychological health issues in the aftermath of a disaster especially if they struggle to communicate their thoughts and feelings, thus isolating them from family and other social groups who might otherwise be able to provide support.

However, one interesting feature that did emerge from the psychological wellbeing domain was that a third of parents believed that their child did not experience overly significant stress or nervousness in the immediate days and weeks following each significant EQ. Some of these children were also reported to be stressed or nervous quite often and yet the parents stated that the EQs did not appear to have to significant effect on their nervousness nor did they become more stressed. Of note, all of these children were under the age of 10 years and therefore their younger age may have impacted on how they experienced the consequences of the EQs (Murray et al 2011; Shaw, et al., 2007). One parent commented that their preschool aged child appeared to be more upset by the parents' response to the shaking than that the EQ itself. A case could be made that younger children were less likely to find the events of the EQs stressful, other than the immediate situation of the shaking itself. Once the event itself is over, the response of those around them at the time such as a parent or other significant adults is able to guide their continued reaction if any. This supports, in part, arguments put forward by Peek and Stough (2008) and Murray (2011) and suggests a strong connection and link between the mental health of the caregiver and that of the younger child with a disability.

The area of psychological health was seen to affect nearly all areas of QOL for the children in this study including dealing with the changed physical environment. Some respondents indicated that their children were unhappy with where they lived because of the constant daily reminders of the EQs including damaged and demolished buildings, being unable to go to places they had previously enjoyed such as local attractions or having easy access to family members who had moved because of damage to properties. The physical environment was also a constant reminder of the EQs as the demolishing of unsafe or damaged buildings was mentioned by one parent as “quite upsetting” for their child even when there was no apparent connection to the building itself. This could suggest a loss of security as well as a loss of familiarity and connection with the built environment that the child previously had. It might also indicate that each demolished building brought back reminders of the EQs and thus acts as a form of “re-traumatisation” as indicated in Goenjian and colleagues (2011) and Shaw et al., (2007). Currently there is no literature on the effects of disasters on how children with disabilities feel about their neighbourhood and where they live.

Similar reports were made about changes to familiar routine, which while many parents observed they attempted to keep to the same routines as much as possible, some changes were unavoidable especially when it came to schooling or community access. Schools attempted to re-establish classes as soon as possible as the MOE recognised in response to disaster literature the essential nature that schools can play in helping communities to rebuild in the aftermath of catastrophic events (Murray, 2011, McAdams-

Ducy & Stough, 2011). A number of parents noted how effective the schools and teachers were in contributing to the reestablishment of routine and reassurance for their children which was also observed in McAdams and Stough 2011. However, nearly all the children experienced a major EQ at school and this did cause problems for at least three of the children. Alongside the disruption to schooling in the region children were noted to experience tiredness, school refusal, separation anxiety and a general unease with everyday activities. All of which could suggest the child is at a heightened risk of longer term mental health issues. Other studies of older populations (Ceyhan & Ceyhan 2007; Ardalan et al., 2011) also observed these long-term psychological effects in individuals as much as four or five years after the event.

One QOL area often reported by respondents as being considerably affected was community access, however, there was little literature to provide background to the impact of a disaster on community access for children with disabilities (Peek & Stough, 2010). The lack of existing research places the information provided by the respondents in this study in an important position. The loss of swimming pools, venues for activities, local attractions and in some instances, schools were mentioned frequently by respondents as having a marked impact on their children’s wellbeing. This was echoed in the CERA wellbeing survey, 2012 where respondents rated the loss of recreation, leisure and cultural facilities as the most negative outcome of the EQs While these were only temporary losses in most cases, the requirement for ongoing changes to routine and regular schedules and the pressure this placed on their child was often noted by the respondents as contributing a part in how their child felt and experienced the EQs. Since routine activities are often the first events to be affected in the aftermath of a disaster it is not surprising that this would have a negative effect on children and adolescents who rely on them for social interaction and entertainment.

One positive aspect that did come through this study was the indication from almost all parents that their children have developed skills and demonstrated increasing signs of resilience and adaptability as result of the earthquakes. Social and personal growth were the most common areas of development but also a recognition of family connections and a growing awareness of their place in the community were highlighted. The study by Phibbs, Woodbury, Williamson and Good noted similar observations by their participants who found a greater awareness of their own strengths and resilience through the EQ period (2012). Valenti and colleagues (2011) also noted similar developments in the survivors of the L'Aquila EQ. In the current study, while the children have been considerably effected by the EQs, the observations on behalf of the parents would suggest that for most of the children represented in this study, positives experiences have evolved because of and despite the EQs.

The study has established that the overall impact of the EQs on different areas of QOL of life of the children, was considerable particularly on the area of psychological health. Despite this, many parents have felt that their children's overall QOL is good. The ongoing development in the social belonging domain for a number of children along with evidence of increased resiliency suggests that there is a strong likelihood of long-term positive outcomes for the QOL of the children and adolescents with disabilities in post-EQ Christchurch.

## Limitations of the study

This study was particularly limited two factors which are related to the other; the low number of respondents and the overall design of the study.

With so few respondents to the survey, any findings must be moderated in view of the small sample size and treated with caution as not necessarily reflective of a larger population's experiences and outcomes. In saying that, the information gathered is still valuable given the current lack of research on the experiences of children and adolescents with disabilities in the aftermath of earthquakes and other disasters. The findings around gender differences are particularly questionable as there was a skewed difference in numbers (2:1). The results that indicated differences in outcomes between male and female children in the QOL areas of health, psychological health and friends, while perhaps of importance, cannot be relied on and require further investigation with a larger sample size.

The limited number of respondents also restricted the level of analysis that was able to be carried out because of small sample sizes in different variables. This restricted any detailed analysis to cross-tabulations. While the majority of the investigated relationships of age, gender and location were found to be statistically non-significant, it is possible that the study was under-powered to detect them, that is, the sample size was too small to detect them, hence it is not clear if the relationship exists but the study was under-powered to detect it or that the relationship really does not exist and hence even if there was an adequately powered sample size it is not certain to have detected the relationship. Given the small sample size this is an expected result.

Further analysis could have also strengthened the findings of this study. Limiting the analysis to age, gender and location, while useful, did not necessarily give a true reflection of all the issues that could have been addressed. Analysis looking at disability type, level of educational assistance perhaps could have given a clearer or more developed picture of how children with disabilities respond to disaster and traumatic events. This was in part, limited by the small sample sizes that did not easily allow for such analysis. It is likely that any results would have been too small to indicate any significant relationships.

The limited response to the survey may have been in part as a response to the design and structure of the survey itself. In revising the survey, questions on some areas of QOL from the QOL-PD-SV (Raphael, Brown & Renwick, 1999) were left out for reasons including time restraints, difficulty in explaining them and uncertainty of relevance to the target population. This may have inadvertently led to the survey potentially lacking questions of relevance to some respondents. Similarly no questions were included that addressed the level of control the child or adolescent had over different areas of their lives. The decision not to include all the questions in the final version of the survey has limited the ability to measure and determine a score for each child or adolescent's overall QOL. This in turn may have allowed for better comparison of this study with other research that has used the full questionnaire or has carried out a full QOL score.

In a related aspect, some of the domains of QOL had questions on the importance of that area and satisfaction with it while other domains had only a question on importance or a question on level of satisfaction. The outcome of this was that the study may have felt disjointed to some respondents. The survey itself did not include an explanation of the CHP approach to QOL which may have given respondents a greater insight into why the questions were structured in that particular manner. This exclusion also contributed to difficulties in measuring overall QOL of the children and adolescents.

Another aspect of the design that may affect the findings was the use of parent or proxy responses. While respondents were asked to include their child if possible in answering the questions, this relied entirely on parental willingness to take the time to do so. A few parents commented that they felt their child or adolescent would not have understood the questions and without the capacity to rephrase the questions in an appropriate format to suit the individual needs of each participant, this limited the survey to most parents or caregivers. As discussed earlier, research suggests that parents or caregivers of children with disabilities do produce very similar QOL scores to their child when compared, however, there can be discrepancies when emotional or psychological health is rated (Wallender et al., 2001). With the focus on psychological health and parental evidence that the EQs significantly affected a number of children in this study, the proxy assessment may not always be the most satisfactory option for this type of research and the focus needs to be obtaining self-report when possible so to have a more clear picture of how the children and adolescents see the EQs affecting them personally.

Here, the study could have been significantly improved with a mixed methodology approach, with interviews with children and their caregivers to develop areas that were identified in the survey. This would have allowed for more in depth discussions on QOL, understanding of it and how it applied to each individual child as well as its relationship to the effects of the Christchurch EQs. A mixed methodology approach gives a much more detailed understanding of the personal impact and allows people to express themselves in different style of language (e.g. verbal, non-verbal and written) which accommodates a diverse population . However, despite using a qualitative approach, a number of parents did in fact provide additional and very detailed information that not only explained their respective situations but also gave an important insight into the experiences of their children throughout the EQ period. This additional information has been invaluable in adding greater depth and understanding to the results generated from the survey.

## Implications for future research

While this study has not been able to achieve a complete analysis of the effects of EQs on the QOL of children and adolescents with disabilities, the results reported on have clearly shown a relationship between the effects of the EQs and different domains of QOL for children and adolescents with disabilities. This has been particularly evident in the domain of psychological health and wellbeing. This would strongly imply that future studies should continue to follow and measure the QOL of survivors in the aftermath of disasters and other tragedies to assist in the development of plans and policies that can be put into action to aid long-term rehabilitation for children and adolescents with disabilities. More importantly though is the need to further the study of children and adolescents with disabilities and their families. How they determine their QOL to be and what they want to see happen to rehabilitate their own lives and their community. Peek and Stough (2010) lamented the dearth of research around children with disabilities in the aftermath of disasters and there is still a critical shortage of appropriate literature and directions for future research. While this study attempts to give a small insight into the effects on children and adolescents with disabilities in the aftermath of the Christchurch EQs, it is by no means an adequate or complete reflection of every child who has a disability in Christchurch and experienced the EQ or indeed has experienced any other disaster and thus further study is needed. QOL research provides an insight into personal lived experiences and can help guide future policies and programmes for rebuilding and growth.

This study has also shown that it is vital that the families of children and adolescents with disabilities are included in other studies. The impact of any disaster is often felt by all in the family and therefore it is important to determine how they have or are coping with any effects in order to ascertain how this might impact on the child/adolescent. As this research has shown, children and adolescents disabilities are often very close to their parents or caregivers and anything that negatively or strongly effects a parent or caregiver often has significant consequences for them.

On a positive note, many parents talked about how they worked with their child to help them overcome or at least accept the EQs which also supports the idea the inclusion of the families of children with disabilities in future studies. Strategies and ideas to overcome fears and reduce anxiety, practicing different coping methods and developing positive outlooks are all essential in learning to adjust to a changed situation. Future research with families of children with disabilities should help to formulate, test and analyse different approaches to work with other families and children with disabilities who may have experienced disasters or trauma.

### Implications for practice

One area that has come from this research is the need to provide appropriate assistance to aid children and adolescents with disabilities and their families prepare for and to assist them in the aftermath of any disasters. It is especially important that their voices are heard at a planning level to assist in the design of systems that meet their specific needs. In 2012, a disability-inclusive emergency preparedness and response symposium was held in Christchurch to discuss the experiences of people with disabilities and evaluate what could be done to improve the emergency response in the event of another disaster. Specific issues were identified including the lack of or inability to access appropriate communication and the lack of transport. These are critical to people with disabilities as it can isolate and potentially endanger them. Families with children who have disabilities can be equally disadvantaged and therefore it is imperative that any future emergency planning response includes provision to meet their needs. These needs may include for example; housing, medical, nutritional and psychiatric support just to mention a few. Many areas can be especially difficult for a family with a child who has a disability as there maybe additional factors to calculate for, therefore it is important that families feel they are acknowledged and recognised as having specific needs in emergency situations. The importance of keeping children with their families was exemplified in this study as many children found strength and resilience through their families. Therefore any provision of assistance needs to focus on supporting families to stay together and to enable and encourage them to assist their children within the family environment.

## Conclusion

This study set out to explore how the greater Christchurch earthquake series of 2010 and 2011 impacted on the quality of life (QOL) of children and adolescents with disabilities. Since no previous research in the area of children with disabilities and the effects of a natural disaster had used a quality of life approach, the current research gives a small but important viewpoint. The results indicated the earthquake caused considerable disruption and impact to each child. The area of psychological health for the children was the most significant area affected by the EQs. With most children reported as significantly affected even if only for the immediate weeks after the significant earthquakes. It was also evident that the ongoing nature of the Christchurch earthquake series had a long-term impact on children’s stress levels, friendships, social interactions, recreation and enjoyment of life. This appeared to have the greatest effect in the lives of older children/adolescents although this study was limited in its capacity to further investigate the extent of these findings. Yet, there is evidence from the findings that many children have grown and developed personally in the aftermath of such difficult events. The evidence of coping skills including self-awareness, improved family relationships, increased communication and self-reliance, all pointing to long-term positive outcomes. A few parents identified a growing empathy for others in their family and those outside of their child's immediate circle. This could indicate that the adversity they have experienced has afforded opportunities for personal development. Many children have shown strength and courage despite the challenges that came with the earthquakes.

"I believe my son is a hero - living in a non-Asperger's world before the quakes was never easy for him and certainly life after the quakes has been much more difficult but he has kept trying to make sense of it all and to make a success of his life."

*Parent of 14 year old*

# References

Abramson, D. M., & Garfield, R. M. (2006). *On the edge: Children and families displaced by Hurricanes Katrina and Rita face a looming medical and mental health crisis*. Retrieved from: http://academiccommons.columbia.edu/download/fedora_content/download/ac:148107/CONTENT/Abramson_-_Louisiana_on_the_Edge_-_Full_Report.pdf.

Abramson, D. M., Garfield, R. M., & Redlener, I. E. (2007). *The recovery divide: Poverty and the widening gap among Mississippi children and families affected by Hurricane Katrina.* Retrieved from: http://academiccommons.columbia.edu/download/fedora_content/download/ac:148117/CONTENT/Abramson_-_Mississippi_Recovery_Divide_-_Full_Report.pdf.

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine*, *48*(8), 977-988.

Allerton, L. A., Welch, V., & Emerson, E. (2011). Health inequalities experienced by children and young people with intellectual disabilities: A review of literature from the United Kingdom. *Journal of Intellectual Disabilities*, 1744629511430772.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Ardalan, A., Mazaheri, M., Vanrooyen, M., Mowafi, H., Nedjat, S., Naieni, K. H., & Russel, M. (2011). Post-disaster quality of life among older survivors five years after the Bam earthquake: implications for recovery policy. *Ageing and Society*, 31(02), 179-196.

Asarnow, J., Glynn, S., Pynoos, R. S., Nahum, J., Guthrie, D., Cantwell, D. P., & Franklin, B. (1999). When the earth stops shaking: Earthquake sequelae among children diagnosed for pre-earthquake psychopathology. *Journal of the American Academy of Child & Adolescent Psychiatry*, 38(8), 1016-1023.

Bauman, M. L. (2010). Medical comorbidities in autism: challenges to diagnosis and treatment. *Neurotherapeutics*, *7*(3), 320-327.

Baxter, P., Morris, C., Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., ... & O'Shea, T. M. (2007). The definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*, *49*(s2), 1-44.

Brown, I., Renwick, R., & Raphael, D. (1997). *Quality of life Instrument Package for Adults with Developmental Disabilities*. University of Toronto, Toronto: Quality of Life Research Unit.

Buttimer J. & Tierney E. (2005) Patterns of leisure participation among adolescents with mild intellectual disability. *Journal of Intellectual Disabilities*, 9, 25–42.

Carson, A., & Stone,J. (2013). Considering Depression and Anxiety. In C. Burton (ed.) *ABC of Medically Unexplained Symptoms*, Oxford: Wiley-Blackwell, pp. 10-13.

Ceyhan, E., & Ceyhan, A. A. (2007). Earthquake survivors' quality of life and academic achievement six years after the earthquakes in Marmara, Turkey. *Disasters*, 31(4), 516-529.

Chou, F.H.C., Chou, P., Lin, C., Su, T. T. P., Ou-Yang, W. C., Chien, I. C., ... & Chen, M. C. (2004). The relationship between quality of life and psychiatric impairment for a Taiwanese community post-earthquake. *Quality of Life Research*, 13(6), 1089-1097.

Chou, F.H.C., Chou, P., Su, T. T. P., Ou-Yang, W. C., Chien, I., Lu, M. K., & Huang, M. W. (2004). Quality of life and related risk factors in a Taiwanese village population 21 months after an earthquake. *Australian and New Zealand Journal of Psychiatry*, *38*(5), 358-364.

Chou, Y-J., Huang, N., Lee, C-H., Tsai, S-L., Chen, L-S., & Chang, H-J. (2004). Who is at risk of death in an earthquake? *American Journal of Epidemiology*, 160(7), 688-695.

Christ, G. H., & Christ, T. W. (2006). Academic and behavioural reactions of children with disabilities to the loss of a firefighter father: The New York World Trade Centre attack 9 ⁄ 11 ⁄ 01. *The Review of Disability Studies*, 2(3), 68–77.

Christchurch City Council. (2014). *Community Profile: Aranui/Wainoni/Bexley*. Retrieved from: http://resources.ccc.govt.nz/files/cityleisure/statsfacts/statistics/communityprofiles/2014/burwoodpegasus/communityprofile-burwoodpegasus-aranuiwaionibexley.pdf

Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H., & Wadsworth, M. E. (2001). Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. *Psychological Bulletin, 127*(1), 87.

Cramm, J. M., & Nieboer, A. P. (2012). Longitudinal study of parents' impact on quality of life of children and young adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 20-28.

Cummins, R.A. (1995). On the trail of the gold standard for subjective well-being. *Social Indicators Research, 35*, 179-200.

Dey, M., Landolt, M. A., & Mohler-Kuo, M. (2012). Health-related quality of life among children with mental disorders: a systematic review. *Quality of Life Research*, *21*(10), 1797-1814.

*Disability-inclusive emergency preparedness and response symposium 28 to 29 May 2012* accessed from http://www.odi.govt.nz/resources/guides-and-toolkits/emergency-preparedness-and-responsiveness/symposium-may-2012/

Dyson, L. L. (1996). The experiences of families of children with learning disabilities: Parental stress, family functioning, and sibling self-concept. *Journal of learning disabilities*, *29*(3), 280-286.

Education Counts. (2014). Ongoing Resourcing Scheme (ORS): Number of students by time series 2005-2014 dataset. *Statistics*. Wellington, NZ: Ministry of Education. Retrieved from http://www.educationcounts.govt.nz/statistics/special-education/ongoing-resourcing-scheme

Education Review Office. (2010). *Including Students with High Needs (June 2010).* Wellington, NZ: Author. Retrieved from http://www.ero.govt.nz/National-Reports/Including-Students-with-High-Needs-June-2010/Overview

Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, *191*(6), 493-499.

Environment Canterbury Regional Council. (2014). *Liquefaction information.* Christchurch, NZ: Author. Retrieved from http://ecan.govt.nz/advice/emergencies-and-hazard/earthquakes/pages/liquefaction-information.aspx

Eriksson, L., Welander, J., & Granlund, M. (2007). Participation in everyday school activities for children with and without disabilities. *Journal of Developmental and Physical Disabilities*, *19*(5), 485-502.

Expert Advisory Group on Solutions to Child Poverty. (2012). *Working Paper no.21: Child Poverty and Disability*. Wellington, NZ: Office of Commissioner for Children. Retrieved from http://www.occ.org.nz/assets/Uploads/EAG/Working-papers/No-21-Child-poverty-and-disability.pdf

Fauci, A. J., Bonciani, M., & Guerra, R. (2012). Quality of life, vulnerability and resilience: a qualitative study of the tsunami impact on the affected population of Sri Lanka. *Annali dell'Istituto Superiore di Sanità*, 48(2), 177-188.

Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, 16(1), 51-74.

Giuliani, A. R., Mattei, A., Santilli, F., Clori, G., Scatigna, M., & Fabiani, L. (2014). Well-being and perceived quality of life in elderly people displaced after the earthquake in L'Aquila, Italy. *Journal of Community Health*, 39(3), 531-537.

Gluckman, P. (May 2011). *The Psychosocial Consequences of the Canterbury Earthquakes: A Briefing Paper.* Wellington, NZ: Office of the Prime Minister's Science Advisory Committee. Retrieved from http://cdn.cera.govt.nz/sites/default/files/common/christchurch-earthquake-briefing-psychosocial-effects-2011-05-10.pdf

GNS Science. (2010). *Canterbury fault had not ruptured for at least 16,000 years - 06/09/2010*. Retrieved from http://www.gns.cri.nz/Home/News-and-Events/Media-Releases/16000-years

Goenjian, A. K., Roussos, A., Steinberg, A. M., Sotiropoulou, C., Walling, D., Kakaki, M., & Karagianni, S. (2011). Longitudinal study of PTSD, depression, and quality of life among adolescents after the Parnitha earthquake. *Journal of Affective Disorders*, 133(3), 509-515.

Greenhill, M. (7 August, 2014). Family forced to move nine times. *The Press*. Retrieved from http://www.stuff.co.nz/the-press/news/christchurch-earthquake-2011/10357917/Family-forced-to-move-nine-times

Halpern, A. S. (1993). Quality of life as a conceptual framework for evaluating transition outcomes. *Exceptional Children, 59*(6), 486.

Ham V, Cathro G, Winter M, Winter J (2012). *Evaluative study of co-located schools established following the Christchurch earthquake.* Retrieved from: www.educationcounts.govt.nz/publications/schooling/115174

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418.

Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: the lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*, 74(1), 38-47.

Heyne, L. A., Schleien, S.J., & McAvoy, L.H. (1994). *Making Friends: Using Recreation Activities To Promote Friendship between Children with and without Disabilities.* Minneapolis, MN: College of Education, Minnesota University.

Holten-Jeffreys, W. (2011). *Agenda item No: 10; Metro Bus services since 22 February 2011*. Christchurch, NZ: Christchurch City Council.

International Federation of the Red Cross and Red Crescent Societies. (2014). *What is a disaster?*. Geneva, Switzerland: Author. Retrieved 10 July 2014 from http://www.ifrc.org/en/what-we-do/disaster-management/about-disasters/what-is-a-disaster/

Jia, Z., Tian, W., He, X., Liu, W., Jin, C., & Ding, H. (2010). Mental health and quality of life survey among child survivors of the 2008 Sichuan earthquake. *Quality of Life Research*, 19(9), 1381-1391.

Kampert, A. L., & Goreczny, A. J. (2007). Community involvement and socialization among individuals with mental retardation. *Research in Developmental Disabilities*, *28*(3), 278-286.

Ke, X., Liu, C., & Li, N. (2010). Social support and quality of life: a cross-sectional study on survivors eight months after the 2008 Wenchuan earthquake. *BMC Public Health*, 10(1), 573.

King, G., Lawn, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Paediatrics*, 23(1), 63-90.

Kohane, I. S., McMurry, A., Weber, G., MacFadden, D., Rappaport, L., Kunkel, L., Bickel, J., Wattanasin, N., Spence, S., Murphy, S. & Churchill, S. (2012). The co-morbidity burden of children and young adults with autism spectrum disorders. *PloS One, 7*(4), e33224.

Landgraf, J. M., Abetz, L., & Ware, J. E. (1996). *The CHQ User's Manual*. Boston: The Health Institute, New England Medical Center, 235-9.

Lee, L-C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: quality of life and parental concerns. *Journal of Autism and Developmental Disorders, 38*(6), 1147-1160.

Lewis, John (2010, 5 March). "1010 refugee pupils swell schools' rolls". *Otago Daily Times*. Retrieved from http://www.odt.co.nz/regions/otago/150423/1010-refugee-pupils-swell-schools-rolls

Liang, Y., Chu, P., & Wang, X. (2014). Health-related quality of life of Chinese earthquake survivors: a case study of five hard-hit disaster counties in Sichuan. *Social Indicators Research*, 119(2), 943-966.

Liptak, G. S., O'Donnell, M., Conaway, M., Chumlea, W. C., Worley, G., Henderson, R. C., Fung, E., Stallings, V.A., Samson-Fang, L., Calvert, R., Rosenbaum, P. & Stevenson, R. D. (2001). Health status of children with moderate to severe cerebral palsy. *Developmental Medicine & Child Neurology*, *43*(6), 364-370.

Livingston, M. H., Rosenbaum, P. L., Russell, D. J., & Palisano, R. J. (2007). Quality of life among adolescents with cerebral palsy: what does the literature tell us?. *Developmental Medicine & Child Neurology*, *49*(3), 225-231.

McKenzie-McLean, J. (24 August, 2011). Quake stress may cause hair loss. *The Press.* Retrieved from http://www.stuff.co.nz/national/health/5495896/Quake-stress-may-cause-hair-loss

McLean, I., Oughton, D., Ellis, S., Wakelin, B., & Rubin, C. B. (2012). *Review of the Civil Defence Emergency Management Response to the 22 February Christchurch Earthquake*. New Zealand Ministry of Civil Defence and Emergency Management. Retrieved from http://civildefence.govt.nz/assets/Uploads/publications/Review-CDEM-Response-22-February-Christchurch-Earthquake.pdf

Masten, A. S., & Osofsky, J. D. (2010). Disasters and their impact on child development: Introduction to the special section. *Child Development*, 81(4), 1029-1039.

Matheson, C., Olsen, R. J., & Weisner, T. (2007). A good friend is hard to find: Friendship among adolescents with disabilities. *American Journal on Mental Retardation*, *112*(5).

Mathewson, N, (18 May, 2013). Quake take toll on the young. *The Press*. Retrieved from http://www.stuff.co.nz/the-press/news/christchurch-earthquake-2011/8689572/Quakes-take-toll-on-young

Middleton, D., & Westlake, R. (2011). *Independent Review of the Response to the Canterbury Earthquake, 4 September 2010: Technical Report Commissioned by the Ministry of Civil Defence, May 2011*. Wellington, NZ: New Zealand Ministry of Civil Defence and Emergency Management. Retrieved from http://canterbury.royalcommission.govt.nz/documents-by-key/20111003.55

Ministry of Education. (1996). *Special Education 2000*. Wellington, NZ: Author.

Ministry of Education. (2014). *Special Education Policy Guidelines*. Retrieved 6 July 2014 from http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/AboutUs/ContextOfOurWork/SpecialEducationPolicyGuidelines/Introduction.aspx

Ministry of Health. (2001). *The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga*. Wellington, NZ: Author.

Ministry of Health. (2001). *New Zealand Guidelines for the Assessment and Treatment of Attention-Deficit/ Hyperactivity Disorder*. Wellington, NZ: Author.

Ministries of Health and Education. (2008). *New Zealand Autism Spectrum Disorder Guideline.* Wellington: Ministry of Health.

Mokhtari, A. (2008). *Listening to the Voices of Adolescents with Intellectual Disabilities: Friendship Experiences* (Master of Science, Queen’s University, Kingston, Ontario, Canada). Retrieved from http://qspace.library.queensu.ca/handle/1974/975

Moos, R. H. (1988). Coping Responses Inventory Manual. Palo Alto, CA: Stanford University and Department of Veterans Affairs Medical Centre.

Morrow, B. H. (1999). Identifying and mapping community vulnerability. *Disasters, 23*(1), 1-18.

Murray, J.S. (2006). Addressing the psychosocial needs of children following disasters. *JSPN*, 11(2), 133-137.

Murray, J. S. (2011). Disaster preparedness for children with special healthcare needs and disabilities. *Journal for Specialists in Pediatric Nursing*, 16(3), 226-232.

Murrell, R. (1999). Quality of life and neurological illness: a review of the literature. *Neuropsychology Review, 9*(4), 209-229.

New Zealand College of Clinical Psychologists. (2011). *Christchurch Earthquake: Taking Care of Yourself*. Retrieved from http://www.nzccp.co.nz/assets/Uploads/ShrinkRAP-Autumn-2011.pdf

Norris, F. H., Friedman, M. J., Watson, P. J., Byrne, C. M., Diaz, E., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I. An empirical review of the empirical literature, 1981–2001. *Psychiatry: Interpersonal and Biological Processes, 65*(3), 207-239.

Osofsky, J. D., Osofsky, H. J., & Harris, W. W. (2007). Katrina's children: Social policy considerations for children in disasters. *Social Policy Report*, *21*(1), 3-18.

Papanikolaou, V., Adamis, D., & Kyriopoulos, J. (2012). Long term quality of life after a wildfire disaster in a rural part of Greece. *Open Journal of Psychiatry*, 2(02), 164.

Peek, L., & Stough, L. M. (2010). Children with disabilities in the context of disaster: A social vulnerability perspective. *Child Development*, 81(4), 1260-1270.

Petal, M. (2008). *Disaster Prevention for Schools: Guidance for Education Sector Decision-Makers. Consultation Version, November 2008*. Geneva, Switzerland: International Strategy for Disaster Reduction Thematic Platform for Knowledge and Education. Retrieved from http://www.preventionweb.net/files/7344_DPforSchoolssm.pdf

Pfefferbaum, B., Noffsinger, M. A., Wind, L. H., & Allen, J. R. (2014). Children's coping in the context of disasters and terrorism. *Journal of Loss and Trauma*, 19(1), 78-97.

Priestley, M., & Hemingway, L. (2007). Disability and disaster recovery: A tale of two cities? *Journal of Social Work in Disability & Rehabilitation*, *5*(3-4), 23-42.

Quality of Life Research Unit. (n.d.) *Centre for Health Promotion Quality of Life Model*. Toronto, Canada: University of Toronto. Retrieved 10 April 2014 from http://sites.utoronto.ca/qol/qol_model.htm.

Radio New Zealand. (Tuesday 22 Feb 2011). *Checkpoint: Canterbury Earthquake – Mark Wilson*. [Radio broadcast]. Wellington, NZ: Author. Retrieved from http://www.radionz.co.nz/national/programmes/checkpoint/audio/2464493/canterbury-earthquake-mark-wilson

Raphael, D., Brown, I., Renwick, R., & Rootman, I. (1996). Assessing the quality of life of persons with developmental disabilities: Description of a new model, measuring instruments, and initial findings. *International Journal of Disability, Development and Education, 43*(1), 25-42.

Raphael, D., Brown, I., & Renwick, R. (1999). Psychometric properties of the full and short versions of the Quality of Life Instrument Package: results from the Ontario province-wide study. *International Journal of Disability, Development and Education, 46*(2), 157-168.

Raphael, D., Renwick, R., Brown, I., Steinmetz, B., Sehdev, H., & Phillips, S. (2001). Making the links between community structure and individual well-being: community quality of life in Riverdale, Toronto, Canada. *Health & Place*, *7*(3), 179-196.

Reliefweb Project. (2008). *Glossary of Humanitarian Terms*. Retrieved 10 July 2014 from http://www.who.int/hac/about/definitions/en/

Renwick, R., Fudge Schormans, A., & Zekovic, B. (2003). Quality of life for children with developmental disabilities: A new conceptual framework. *Journal on Developmental Disabilities*, *10*(1), 107-114. Retrieved from http://29303.vws.magma.ca/publications/journal/issues/vol10no1/download/renwick_etal.pdf

Rosenbaum, P. L., Livingston, M. H., Palisano, R. J., Galuppi, B. E., & Russell, D. J. (2007). Quality of life and health-related quality of life of adolescents with cerebral palsy. *Developmental Medicine & Child Neurology*, *49*(7).

Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. *Quality of Life*, *1*, 123-139.

Schalock, R. L. (2000). Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities*, *15*(2), 116-127.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Journal Information*, *40*(6).

Shaw, J. A., Espinel, Z., & Shultz, J. M. (2007). *Children: Stress, Trauma and Disasters*. Tampa, FL: Disaster Life Support Publishing.

Shaw, J. A., Espinel, Z., & Shultz, J. M. (2012). *Care of Children Exposed to the Traumatic Effects of Disaster*. Washington, DC: American Psychiatric Pub.

Shirlaw, N. (2014). *Children and the Canterbury Earthquakes*. Auckland, NZ: Child Poverty Action Group. Retrieved from http://www.cpag.org.nz/assets/Backgrounders/140227%20CPAG%20Children%20and%20the%20Canterbury%20Feb2014.pdf

Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, *71*(2), 257.

Solish, A., Perry, A., & Minnes, P. (2010). Participation of children with and without disabilities in social, recreational and leisure activities. *Journal of Applied Research in Intellectual Disabilities,* 23(3), 226-236.

Spreen, M. (1992). Rare populations, hidden populations, and link-tracing designs: What and why?. *Bulletin de Methodologie Sociologique*, *36*(1), 34-58.

Stanley, E., Muntner, P., Re, R. N., Frohlich, E. D., Holt, E., & Krousel-Wood, M. A. (2011). Quality of life in hypertensive clinic patients following hurricane Katrina. *The Ochsner Journal*, *11*(3), 226-231.

Stanley, K. (2007). *Child Poverty causes Disability and Disability causes Child Poverty, Press Release.* United Kingdom: Institute for Public Policy Research. Retrieved from http://www.ippr.org/pressreleases/111/2540/child-poverty-causes-disability-and-disability-causes-child-poverty

Statistics New Zealand. (2007), *Disability Survey: 2006*. Wellington: Author. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey2006_HOTP06.aspx

Statistics New Zealand, (2010). *Subnational Population Estimates: At 30 June 2010*. Wellington, NZ: Author. Retrieved from http://www.stats.govt.nz/browse_for_stats/population/estimates_and_projections/SubnationalPopulationEstimates_HOTP30Jun10.aspx

Statistics New Zealand. (2011). *Re-enrolment of Christchurch School Students, at 13 September 2011*. Wellington, NZ: Author. Retrieved from http://www.stats.govt.nz/browse_for_stats/education_and_training/earthquake-schools.aspx

Statistics New Zealand. (2012). Canterbury Labour Market: A snapshot after the 22 February 2011 earthquake. Retrieved July 7, 2014, from http://www.stats.govt.nz/browse_for_stats/income-andwork/employment_and_unemployment/Canterbury-suffers-after-quake.aspx

Statistics New Zealand. (2014), *Disability Survey: 2013*. Wellington, NZ: Author. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx

Stylianou, G. (04 September 2014). EQC battle felt like the 'twilight zone'. *The Press.* Retrieved from http://www.stuff.co.nz/the-press/news/christchurch-earthquake-2011/10457263/EQC-battle-felt-like-the-twilight-zone

Tian, W., Jia, Z., Duan, G., Liu, W., Pan, X., Guo, Q., ... & Zhang, X. (2013). Longitudinal study on health-related quality of life among child and adolescent survivors of the 2008 Sichuan earthquake. *Quality of Life Research*, 22(4), 745-752. doi: 10.1007/s11136-012-0201-z.

Tsai, K. Y., Chou, P., Chou, F. H. C., Su, T. T. P., Lin, S. C., Lu, M. K., ... & Chen, M. C. (2007). Three-year follow-up study of the relationship between posttraumatic stress symptoms and quality of life among earthquake survivors in Yu-Chi, Taiwan. *Journal of Psychiatric Research*, 41(1), 90-96. doi: 10.1016/j.jpsychires.2005.10.004

Turnbull III, H., Turnbull, A., Wehmeyer, M., & Park, J. (2003). A quality of life framework for special education outcomes. *Remedial and Special Education*, 24(2), p. 67-74.

Valenti, M., Ciprietti, T., Di Egidio, C., Gabrielli, M., Masedu, F., Tomassini, A. R., & Sorge, G. (2012). Adaptive response of children and adolescents with autism to the 2009 earthquake in L'Aquila, Italy. *Journal of Autism and Developmental Disorders*, *42*(6), 954-960.

Valenti, M., Masedu, F., Mazza, M., Tiberti, S., Di Giovanni, C., Calvarese, A & Sconci, V. (2013). A longitudinal study of quality of life of earthquake survivors in L'Aquila, Italy. *BMC Public Health*, 13(1), 1143.

Van Den Berg, B., Van Der Velden, P. G., Yzermans, C. J., Stellato, R. K., & Grievink, L. (2006). Health-related quality of life and mental health problems after a disaster: Are chronically ill survivors more vulnerable to health problems?. *Quality of Life Research*, *15*(10), 1571-1576.

Van Willigen, M., Edwards, T., Edwards, B. & Hessee, S. (2002). Riding out the storm: Experiences of the physically disabled during Hurricanes Bonnie, Dennis, and Floyd. *Natural Hazards Review*, August, 98-106.

Varni, James W, Seid, Michael, & Rode, Cheryl A. (1999). The PedsQL (TM): Measurement model for the pediatric quality of life inventory. *Medical Care, 37*(2), 126-139.

Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL™ 4.0 Generic Core Scales. *Health and quality of life outcomes*, *5*(1), 2.

Villemure, M., Wilson, T. M., Bristow, D., Gallagher, M., Giovinazzi, S., & Brown, C. (2012). *Liquefaction ejecta clean-up in Christchurch during the 2010-2011 earthquake*. Paper presented at New Zealand Society for Earthquake Engineering:

2012 Annual Technical Conference (NZSEE), 13-15 Apr 2012, Christchurch, New Zealand.

Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: issues, instruments, and applications. *Journal of Clinical Psychology*, *57*(4), 571-585.

Wang, X., Gao, L., Zhang H., Zhao, C., Shen, Y. & Shinfuku, N. (2000). Post-earthquake quality of life and psychological well-being: Longitudinal evaluation in a rural community sample in northern China. *Psychiatry and Clinical Neurosciences*, 54,427–433

Waters, E., Davis, E., Nicolas, C., Wake, M., & Lo, S. K. (2008). The impact of childhood conditions and concurrent morbidities on child health and well-being. *Child: Care, Health and Development*, *34*(4), 418-429.

Waters, E., Davis, E., Ronen, G. M., Rosenbaum, P., Livingston, M., & Saigal, S. (2009). Quality of life instruments for children and adolescents with neurodisabilities: how to choose the appropriate instrument. *Developmental Medicine & Child Neurology*, *51*(8), 660-669.

WHOQOL Group. (1997). *Measuring Quality of Life*. Geneva: The World Health Organization, 1-13.

Winn, S., & Hay, I. (2009). Transition from school for youths with a disability: issues and challenges. *Disability & Society*, *24*(1), 103-115.

World Health Organisation (2014) *Disabilities.* Geneva, Switzerland: Author. (Accessed April 15, 2014) Retrieved from http://www.who.int/topics/disabilities/en/

World Health Organisation. (2014). *Disability and Health*. *Fact Sheets*. Geneva, Switzerland: Author. Retrieved April 15 2014. http://www.who.int/mediacentre/factsheets/fs352/en/

Wu, H. C., Chou, P., Chou, F. H. C., Su, C. Y., Tsai, K. Y., Ou-Yang, W. C., ... & Chen, M. C. (2006). Survey of quality of life and related risk factors for a Taiwanese village population 3 years post-earthquake. *Australian and New Zealand Journal of Psychiatry*, 40(4), 355-361.

Zekovic, B., & Renwick, R. (2003). Quality of life for children and adolescents with developmental disabilities: Review of conceptual and methodological issues relevant to public policy. *Disability & Society, 18*(1), 19-34.

# Appendices

**Appendix A –** Human Ethics Approval Letter

**Appendix B -** List of Agencies or Groups Contacted by Email or in person

**Appendix C -** Copy of Email to Agencies

**Appendix D -** Information Sheet for Paper Survey

**Appendix E -** Information Sheet for Online Survey

**Appendix F –** Copy of Survey Form

## **Appendix A** – Human Ethics Approval Letter

UC
UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2011/129

16 December 2011

Megan Ryan
Health Sciences Centre
UNIVERSITY OF CANTERBURY

Dear Megan

The Human Ethics Committee advises that your research proposal "Living in a shakey city: how children and adolescents with disabilities have coped during the Canterbury earthquakes of 2010/2011 and their ongoing quality of life" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 8 December 2011.

Best wishes for your project.

Yours sincerely

Michael Grimshaw
***Chair***
***University of Canterbury Human Ethics Committee***

## **Appendix B –** List of Agencies or Groups Contacted by Email or in Person

Allenvale School
Arthritis New Zealand
Autism New Zealand, Canterbury Branch
BLENNZ: Blind and Low Vision Education Network NZ
The Blind Foundation
CPODC: Canterbury Parents of Deaf Children
Caring for Carers
CCS Disability Action
Cerebral Palsy Society of New Zealand
Cystic Fibrosis Association of New Zealand
The Champion Centre
Deaf Aotearoa
DPA
Epilepsy NZ
IDEA services
IHC New Zealand
Muscular Dystrophy Association of New Zealand
New Zealand Riding for the Disabled Christchurch Group
Special Needs Library
The Southern Centre

## **Appendix C –** Copy of Email to Agencies

Dear [Agency Name]

I am a Master of Health Sciences student at the University of Canterbury, and my study has been approved by the University of Canterbury Human Ethics Committee. I am writing to ask your assistance, which involves sending an email to your members or, alternatively, to put a notice in your newsletter.

About The Research: My research is a survey of parents and carers of children and adolescents with disabilities.  It is about the coping during the earthquakes and the quality of life post-earthquakes.  There has been very little research done looking at the impact of natural disasters on the quality of life of children with disabilities.

About the Researcher: I have a long-term interest in research involving the improvement of outcomes for children and adolescents with disabilities and their families. Primarily, this stems from assisting members of my extended family who live with the effects of progressive physical disabilities. My family also has a background of providing support for and working with people with disabilities.

My Request to Your Agency: I know that you are very busy but you are also a well-respected community support agency, which is why I am writing to you to ask:

Would you be willing to email a notice of this study to individuals on your emailing list or alternatively, place an advertisement of this study in your next newsletter?

The email you send will invite parents/caregivers to complete an online survey. A hard copy version of the survey is attached so you can see what I am asking.  There are no questions about your services or support or anything that might reflect on your organization.  No information that could in any way identify any participant will be included in my thesis or in any report or publication.

Please let me know, 'yes' or 'no' by replying to this email - as I need to know if this process will be acceptable as the first step in getting people interested in completing the survey.

If you reply 'yes', I will email you back with a suggested draft email that you can send to your mailing list, which will include the survey link and access password or, if you prefer, a draft advertisement of the study to go in your newsletter.

I am grateful for the time you have taken to consider my request.

If you wish you can also contact my supervisors: Assoc. Professor Kathleen Liberty: (03) 364 2545 ext 2645 or through email: kathleen.liberty@canterbury.ac.nz and Assoc. Professor Ray Kirk: (03) 364 3108 or through email: ray.kirk@canterbury.ac.nz

I am happy to email you a summary of my results, if you are interested. Just let me know in the email.

Many thanks,

Megan Ryan

Masters of Health Sciences candidate,
Health Sciences Centre,
University of Canterbury.
Email: megan.ryan@pg.canterbury.ac.nz

## **Appendix D -** Information Sheet for Paper Survey

# How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes and their ongoing Quality of Life

Megan Ryan
Masters of Health Sciences Candidate

Please read the following information before completing survey.

You are invited to participate in the research project, Living in a Shaky City: How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes and their ongoing Quality of Life by completing the following survey.

The aim of this project is to learn about how school-aged children and adolescents with disabilities have coped during the Canterbury earthquakes since September 2010 and their ongoing quality of life.

By completing and returning the survey to the researcher, it will be understood that you have consented to participate in the project and that you consent to publication of the results of the project with the understanding that anonymity will be preserved.

Please turn over the page for more information.

The project is being carried out as a requirement for the University of Canterbury Masters of Health Science thesis by Megan Ryan under the supervision of Associate Professor Kathleen Liberty and Associate Professor Ray Kirk. The results of this survey will be published as a thesis which will be available as a public document on the University's library website and maybe published in a professional publication or presented at a conference.

Participation in the questionnaire is anonymous, and you will not be identified as a participant without your consent. Any information presented will be confidential, and you are not asked to provide your name or email address, or any other information that could permit you or a member of your family to be identified. All results will be statistical summaries of responses to items, or else, if a written answer is used, any potentially identifying information will be removed.

You may withdraw your participation by not completing or returning a completed survey. However, once the survey has been submitted because it is anonymous, it cannot be retrieved after that.

THIS STUDY HAS BEEN REVIEWED AND APPROVED BY THE UNIVERSITY OF CANTERBURY HUMAN ETHICS COMMITTEE.

The Human Ethics Committees are responsible to the Vice-Chancellor of the University to ensure that researchers whose work involves human participants will conduct their work with appropriate regard for ethical principles and cultural values, and in accordance with the Treaty of Waitangi. These principles and values include: Justice, Safety, Truthfulness, Confidentiality and Respect. Researchers must also take into account the evolving understandings of how those principles and values are expressed in a society at a particular time.

It is expected that this survey will take between 10 - 15 minutes to complete, unless you wish to add any additional comments.
The finished thesis will be available on the University of Canterbury's Library catalogue (in around 12 months) as a public document if you are interested in reading this study's findings. This will be accessible at this website: http://library.canterbury.ac.nz/.

Questions about the Research
If you have questions regarding this study, you may contact Megan Ryan at megan.ryan@pg.canterbury.ac.nz.

Questions about your Rights as Research Participants
If you have questions you do not feel comfortable asking the researcher, you may email Dr Kathleen Liberty, kathleen.liberty@canterbury.ac.nz or Dr Ray Kirk, ray.kirk@canterbury.ac.nz. They will be pleased to discuss any questions you may have.

## **Appendix E -** Information Sheet for Online Survey

### LIVING IN A SHAKY CITY: How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes and their ongoing Quality of Life

Please read the following information before completing survey.

You are invited to participate in the research project, Living in a Shaky City: How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes since September 2010 and their ongoing Quality of Life by completing the following survey. The aim of the project is to learn about how school-aged children/teenagers with disabilities have coped during the earthquakes and their quality of life.

The project is being carried out as a requirement for the University of Canterbury Masters of Health Science thesis by Megan Ryan under the supervision of Associate Professor Kathleen Liberty and Associate Professor Ray Kirk. The results of this survey will be published as a thesis which will be available as a public document on the University's library website and maybe published in a professional publication or presented at a conference.

Participation in the questionnaire is anonymous, and you will not be identified as a participant without your consent. Any information presented will be confidential, and you are not asked to provide your name or email address, or any other information that could permit you or a member of your family to be identified. All results will be statistical summaries of responses to items, or else, if a written answer is used, any potentially identifying information will be removed

You may withdraw your participation by exiting the survey at any time. However, once the survey has been submitted because it is anonymous, it cannot be retrieved after that.

**By entering the survey and answering the questions, it will be understood that you have consented to participate in the project and that you consent to publication of the results of the project with the understanding that anonymity will be preserved.**

THIS STUDY HAS BEEN REVIEWED AND APPROVED BY THE UNIVERSITY OF CANTERBURY HUMAN ETHICS COMMITTEE.

The Human Ethics Committees are responsible to the Vice-Chancellor of the University to ensure that researchers whose work involves human participants will conduct their work with appropriate regard for ethical principles and cultural values, and in accordance with the Treaty of Waitangi.

These principles and values include: Justice, Safety, Truthfulness, Confidentiality and Respect.

Researchers must also take into account the evolving understandings of how those principles and values are expressed in a society at a particular time.

It is expected that this survey will take between 10 - 15 minutes to complete, unless you wish to add any additional comments.

Questions about the Research

If you have questions regarding this study or if you prefer to receive a paper copy, you may contact Megan Ryan at megan.ryan@pg.canterbury.ac.nz. (After answering your email, Megan will delete it.)

Questions about your Rights as Research Participants

If you have questions you do not feel comfortable asking the researcher, you may email Dr Kathleen Liberty, kathleen.liberty@canterbury.ac.nz. or Dr Ray Kirk, ray.kirk@canterbury.ac.nz. They will be pleased to discuss any questions you may have about participation in the project.

**I have read and understood the above consent form and desire of my own free will to participate in this study.**

● **Yes**

○ **No**

**Appendix E -** Copy of Survey

# Living in a Shaky City

## How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes and their ongoing Quality of Life

**Megan Ryan**

**Masters of Health Sciences Candidate**

The aim of this project is to learn about how school-aged children and adolescents with disabilities have coped during the Canterbury earthquakes since September 2010 and their ongoing quality of life.

By completing and returning the survey to the researcher, it will be understood that you have consented to participate in the project and that you consent to publication of the results of the project with the understanding that anonymity will be preserved.

Please turn over the page for more information.

**LIVING IN A SHAKY CITY: How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes and their ongoing Quality of Life.**

## Please read the following information before completing survey.

You are invited to participate in the research project, Living in a Shaky City: How Children and Adolescents with Disabilities have coped during the Canterbury Earthquakes and their ongoing Quality of Life by completing the following survey.

The project is being carried out as a requirement for the University of Canterbury Master of Health Science thesis by Megan Ryan under the supervision of Associate Professor Kathleen Liberty and Associate Professor Ray Kirk. The results of this survey will be published as a thesis which will be available as a public document on the University's library website and maybe published in a professional publication or presented at a conference.

Participation in the questionnaire is anonymous, and you will not be identified as a participant without your consent. Any information presented will be confidential, and you are not asked to provide your name or email address, or any other information that could permit you or a member of your family to be identified. All results will be statistical summaries of responses to items, or else, if a written answer is used, any potentially identifying information will be removed

You may withdraw your participation by not completing or returning a completed survey. However, once the survey has been submitted because it is anonymous, it cannot be retrieved after that.

THIS STUDY HAS BEEN REVIEWED AND APPROVED BY THE UNIVERSITY OF CANTERBURY HUMAN ETHICS COMMITTEE.

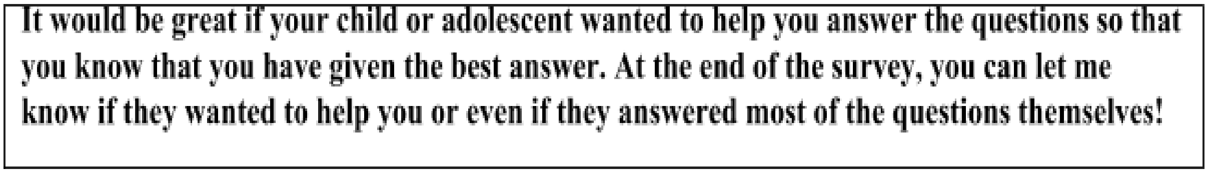
The Human Ethics Committees are responsible to the Vice-Chancellor of the University to ensure that researchers whose work involves human participants will conduct their work with appropriate regard for ethical principles and cultural values, and in accordance with the Treaty of Waitangi. These principles and values include: Justice, Safety, Truthfulness, Confidentiality and Respect. Researchers must also take into account the evolving understandings of how those principles and values are expressed in a society at a particular time.

It is expected that this survey will take between 10 - 15 minutes to complete, unless you wish to add any additional comments.
The finished thesis will be available on the University of Canterbury's Library catalogue (in around 12 months) as a public document if you are interested in reading this study's findings. This will be accessible at this website: http://library.canterbury.ac.nz/.

Questions about the Research
If you have questions regarding this study, you may contact Megan Ryan at megan.ryan@pg.canterbury.ac.nz.

Questions about your Rights as Research Participants

If you have questions you do not feel comfortable asking the researcher, you may email Dr Kathleen Liberty, kathleen.liberty@canterbury.ac.nz or Dr Ray Kirk, ray.kirk@canterbury.ac.nz. They will be pleased to discuss any questions you may have about participation in the project.



**It would be great if your child or adolescent wanted to help you answer the questions so that you know that you have given the best answer. At the end of the survey, you can let me know if they wanted to help you or even if they answered most of the questions themselves!**

## First some questions about your child/ adolescent:

1. How old is your child/adolescent? ________________________________
2. Is your child/ adolescent:

| | |
|---|---|
| 1 | 2 |
| MALE | FEMALE |

3. What is the nature of your child's/adolescent's disability?

   ____________________________________________________________

   ____________________________________________________________

4. What is your relationship to the child/adolescent (e.g. Parent/Main caregiver/Grandparent)? ________________________________________
5. Because different areas of Christchurch and surrounds have been affected differently by the earthquakes, the following question is to identify in which general area the child/adolescent reside: in no particular order

   *(Please circle which is most appropriate for you)*

1 = East Christchurch

2 = West Christchurch

3 = North Christchurch

4 = South Christchurch

5 = Banks Peninsula

6 = Selwyn District

7 = Waimakariri District

8 = Other Canterbury District

9 = Do not live in Canterbury at the moment

6. If “Don’t live in Canterbury at the moment” is selected: why did the child/adolescent leave?

   ____________________________________________________________

   ____________________________________________________________

   ____________________________________________________________

**These next questions are about your child's/ adolescent's physical HEALTH**

1. How <u>important</u> to your child/ adolescent is their physical health?
   *(Please rank how important you think this is to your child).*

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| Very Unimportant | Unimportant | Neither | Important | Very Important |

2. How <u>happy</u> is your child/ adolescent with their physical health?
   *(Please rank how important you think this is to your child)*.

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| Very Unhappy | Unhappy | Neither | Happy | Very Happy |

3. Have they had any extra doctor or hospital visits as a direct result of the earthquakes?

   YES NO

4. How much has the earthquakes affected their overall health?

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| Very little | A Little | Some | Quite a Bit | A Lot |

5. How would you rate their health <u>now</u> compared to before the earthquakes began?

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| Much Better | Better | About the Same | Worse | Much Worse |

Please add any further comments you may have below:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

These next questions are about how well your child/adolescent copes with things that bother or upset them

1. How well does your child / adolescent cope with things that bother or upset them?

| | | | | |
|---|---|---|---|---|
| Not at all Well | A Little | Some | Quite Well | Very Well |
| 1 | 2 | 3 | 4 | 5 |

2. How well has your child / adolescent been able to cope with the immediate effects of the earthquakes?
*Think about the first few days/weeks following the major earthquakes which may have caused significant disruption to normal routines such as going to school.*

| | | | | |
|---|---|---|---|---|
| Not at all Well | A Little | Some | Quite Well | Very Well |
| 1 | 2 | 3 | 4 | 5 |

3. How would you rate your child's / adolescent's ability to cope with things that bother or upset them now compared to before the earthquakes?

| | | | | |
|---|---|---|---|---|
| Much Worse | Worse | About the Same | Better | Much Better |
| 1 | 2 | 3 | 4 | 5 |

Please add any further comments you may have below:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

These next questions are about how often your child/adolescent is stressed or nervous:

1) How often is your child/ adolescent stressed or nervous about things in their life?

| | | | | |
|---|---|---|---|---|
| All the Time | Quite Often | Sometimes | Rarely | Never |
| 1 | 2 | 3 | 4 | 5 |

2) How was your child/ adolescent able to deal with stressful events in the immediate weeks following the earthquakes?

| | | | | |
|---|---|---|---|---|
| Not at all Well | A Little | Some | Quite Well | Very Well |
| 1 | 2 | 3 | 4 | 5 |

3) How would you rate your child's/ adolescent's ability to deal with stressful events now compared to before the earthquakes?

| | | | | |
|---|---|---|---|---|
| Much Worse | Worse | About the Same | Better | Much Better |
| 1 | 2 | 3 | 4 | 5 |

Please add any further comments you may have below:

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

**These next questions are about where your child/adolescent lives:**

1. How important to your child / adolescent is where they live?

| Very Unimportant | Unimportant | Neither | Important | Very Important |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

2. How happy is your child / adolescent with where they live?

| Very Unhappy | Unhappy | Neither | Happy | Very Happy |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

3. Have the earthquakes affected your child's / adolescent's happiness with where they live?

| Not at All | A Little | Sometimes | Quite a lot | A Lot |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

4. If additions were made to the house your child/adolescent lives in such as a wheelchair ramp or a modified bathroom; have the use of these been affected by the earthquakes?

| Yes | Some | No | Not Relevant |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

Please add any further comments you may have below:

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

These next questions are about your child/adolescent’s relationships with their friends

1. Is your child / adolescent happy with their friends?

| | | | | |
|---|---|---|---|---|
| Very Unhappy | Unhappy | Neither | Happy | Very Happy |
| 1 | 2 | 3 | 4 | 5 |

2. Is it important to your child / adolescent to keep in contact with their friends following the earthquakes?

| | | | | |
|---|---|---|---|---|
| Very Unimportant | Unimportant | Neither | Important | Very Important |
| 1 | 2 | 3 | 4 | 5 |

3. Thinking about your child's / adolescent' relationships with their friends, how would you rate them now compared to before the earthquakes?

| | | | | |
|---|---|---|---|---|
| Much Worse | Worse | About the Same | Better | Much Better |
| 1 | 2 | 3 | 4 | 5 |

Please add any further comments you may have below:

**These questions are about your child/adolescent socialising and visiting with their friends and family:**

1. Does your child/adolescent like getting together with friends and family?

| Very Little | A Little | Sometimes | Quite a Lot | A Lot |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

2. How important to your child / adolescent is visiting/socialising with friends?

| Very Unimportant | Unimportant | Neither | Important | Very Important |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

3. Where does your child/adolescent like to get together with friends?

*Circle all that apply*.

1 = At home
2 = At friend's house
3 = At the mall or other community site
4 = School
5 = Other
___________________________________

4. Have the earthquakes affected your child's/adolescent's willingness/happiness to visit other people outside of their home?

| A Lot | Quite a Lot | Sometimes | A Little | Very Little |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

5. Have the earthquakes affected your child's/adolescent's willingness/happiness to have other people visit or come over to their home?

| A Lot | Quite a Lot | Sometimes | A Little | Very Little |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

Please add any further comments you may have below:

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

**These questions are about your child/ adolescent's community access:**

1. How important is it for your child / adolescent to access places in their community such as libraries, swimming pools or shopping malls?

| Very Unimportant | Unimportant | Neither | Important | Very Important |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

2. How happy is your child / adolescent with their access to places in their community?

| Very Unhappy | Unhappy | Neither | Happy | Very Happy |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

3. Following the earthquakes, has there been reasonable access to the usual places in the community that they visit?

| Very Little | A Little | Some | Quite a Bit | A Lot |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

4. How would you rate your child's / adolescent's access to the usual community places that they visit now compared to before the earthquakes began?

| Much Worse | Worse | About the Same | Better | Much Better |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

Please add any further comments you may have below:

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

**These questions are about your child/adolescent’s schooling:**

1. What level of schooling is your child / adolescent at? *Please circle one*:

    1=Early Childhood/ Kindergarten
    2=Primary School
    3=Secondary School
    4=Other ______________________

2. Does your child / adolescent receive some form of assistance with their education *(e.g. Assistive technology, Supplementary Learning Support, ORS)*
    _________________________________________________________________

3. How <u>important</u> is it for your child / adolescent to attend school?

| | | | | |
|---|---|---|---|---|
| Very Unimportant | Unimportant | Neither | Important | Very Important |
| 1 | 2 | 3 | 4 | 5 |

4. How <u>happy</u> is your child / adolescent with attending school?

| | | | | |
|---|---|---|---|---|
| Very Unhappy | Unhappy | Neither | Happy | Very Happy |
| 1 | 2 | 3 | 4 | 5 |

5. Was your child / adolescent <u>happy</u> to return to school after the earthquakes?

| | | | | |
|---|---|---|---|---|
| Very Unhappy | Unhappy | Neither | Happy | Very Happy |
| 1 | 2 | 3 | 4 | 5 |

6. Was your child/ adolescent able to go back to the same school or was there a change of location of school?

| | | |
|---|---|---|
| Same School and Same Location | Same School but Different location | Had to go to Different School |
| 1 | 2 | 3 |

Please add any further comments you may have below:

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

These next questions are about what your child/adolescent likes to do for fun or leisure:

1. What sort of activities does your child or adolescent like to do for fun? *(e.g. watching movies, playing games, music, horse riding)*

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

2. How much has the earthquakes affected what your child or adolescent likes to do for fun?

| | | | | |
|---|---|---|---|---|
| A Lot | Quite a Lot | Some | A Little | Very Little |
| 1 | 2 | 3 | 4 | 5 |

Please add any further comments you may have below:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

**These questions are about overall Quality of Life of your Child/ Adolescent and your OWN Quality of Life:**

1. How would you rate your child's /adolescent's overall quality of life?

| Very Poor | Poor | Neither Poor nor Good | Good | Very Good |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

2. How would you rate YOUR overall quality of life? *(Parent, main caregiver)*

| Very Poor | Poor | Neither Poor nor Good | Good | Very Good |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

Thinking back over the months since the earthquakes began, what are your child's strengths especially in regards to coping?

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

Thank you for taking the time to fill out this survey.

Please indicate how much of the survey your child / adolescent were able to help you with: *(e.g. They did all of it; helped with some areas; I completed it for them)*

______________________________________________________________________

______________________________________________________________________

Please add any additional comments on any area that you or your child/ adolescent believe are relevant:

I appreciate the time you have given in completing this survey.

If you or your child/adolescent feel that you would like to talk to someone about aspects that this survey may have raised you can contact the:

Quake Support Counselling Services Helpline on 0800 777 846.

This service can help you with your questions, give information and put you in touch with free counselling services for you or any member of your family.

If you have any questions on any other aspect raised in this survey, please do not hesitate to contact me:

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