Quality of Life of New Zealand Families with Children who have Serious Brain Injury or Disorder

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Abstract

Children's brains can be affected by injuries, illnesses, genetic conditions or differences of development in ways that make it hard or impossible for them to meet society's expectations in various domains of life.

International research shows that raising such a child has an impact on family quality of life. While quality of life (QoL) is defined in numerous ways, reports show effects on emotional, social, psychological and financial levels, as well as impacts on family relationships.

Little is known about New Zealand families' experience of raising children who have these conditions. Initially, a study was planned of the QoL of families raising children affected by severe epilepsy. Later, the target group was expanded to include families raising children with serious neurological effects caused by any injury, illness, disorder or difference.

A survey was created, based largely on the Impact of Epilepsy on Quality of Life (IEQoL) measure (Cianchetti et al., 2015), and the Quality of Life in Children with Epilepsy (QOLCE55) (Goodwin, Lambrinos, Ferro, Sabaz & Speechley, 2015). Numerous opportunities for additional comments were provided for respondents. The survey was hosted online on Qualtrix, on a Massey University server, from 11 October to 22 November 2019.

Support organisations for families raising children with conditions which might include serious neurological effects were contacted and asked to invite their members to consider completing the survey. 98 responses were received, of which 21 were excluded and 77 analysed.

Almost all respondents had children with autism spectrum disorders (ASD). No other condition was represented in numbers large enough to permit comparisons between or among groups. Throughout this study, we refer to respondents' children as having a "serious brain

injury/disorder", which in retrospect is not an ideal term, but has been retained in discussion to maintain consistency with its usage in the survey.

Impacts on both child QoL and family QoL were reported. Extensive commentary was provided by many respondents. Cognitive effects on children most widely reported included difficulty with following complex instructions, with reasoning and with problem solving.

Social, emotional and behavioural effects on children included feeling frustrated, having limited social activities, encountering difficulty in keeping friends, and requiring a lot of attention.

Effects on family QoL included apprehension about the future, limitations on participation in/enjoyment of leisure activities, impacts on employment, and increases in conflict among family members.

Respondents also reported positive effects of raising a child with serious brain injury/disorder, including improved perspective on life, increased patience, and bringing the family closer together.

Qualitative analysis of respondents' written comments is planned for the future. Recommendations for future research are presented.

Acknowledgements

I am hugely indebted to my supervisor, Professor Janet Leathem, for her scholarship, her pragmatism and her endless optimism. To misquote E.B.White: "She was in a class by herself. It is not often that someone comes along who is a true friend and a good writer. [Janet] was both."

Thank you also to Dr Simon Bennett, who provided cultural advice for this project.

The respondents who completed the survey were extraordinarily generous in sharing their experience. The rich, moving data they provided is the heart of this thesis, and I hope their stories will encourage others to research further in this area.

I also appreciate the many support organisations throughout New Zealand for people with brain injury, disorders, and differences, which agreed to alert their members to the survey.

This thesis is dedicated to my children. Thank you, Donovan, Eleanor, Oliver and Naomi, for your love, support, and patience. It's also for my cousin Marie, in recognition of her entirely unjustified faith in me.

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Chapter One: Introduction

During postgraduate study, I became interested in neuropsychology, particularly in the measures used to assess individual experience of neurological and psychological phenomena. These measures are fundamental to diagnosis, to estimating outcomes and to selecting interventions and treatments. Yet they are subject to the complexities inherent in linguistic, cultural and personal variation - not only in the people being assessed but among the people who design them and those who administer them.

Some years ago, I completed an assessment form, aimed at determining whether my situation justified a surgery that was not medically necessary. The questions seemed to have little relevance to my experience. On completing the form, and re-reading it, I doubted that the surgery would seem justified so wrote a letter describing my experience in my own words, to accompany the form.

The surgery was approved, and subsequently, a health professional told me she had retained my letter to use as a tool in talking with other patients, as an adjunct to the assessment form. It was not because the issues I raised would be key to other people, but to demonstrate that personal experience could lie outside the assessment form, and still be relevant.

Neuropsychologists address this issue by using multiple measures with sound psychometric properties in their assessments accompanied by interview with the client, observing behaviours and talking with significant others in clients' lives.

Even where measures have high validity, it is always in relation to specific populations. An acceptable balance point has to be found between the imprecision of representing very large groups and the impracticality of representing very small ones. Applying a measure to a large population which includes considerable diversity means that effects can cancel one another out, or distinctive results can be lost in the crowd. Creating

measures for very small populations would require enormous resources, produce data based only on small samples, and reduce the possibility of identifying common features across different groups experiencing similar phenomena.

My interest in measures used in neuropsychology, coincided with an opportunity to work within a wider project on epilepsy. The Epilepsy Research Group (ERG), is exploring genetic factors in epilepsy and is seeking to isolate genes involved in different epileptic syndromes, with a view to eventually being able to develop precisely targeted therapies. Within this study, the ERG is interested in identifying and using neuropsychological measures of patient and family experiences with epilepsy that provide as much useful insight as possible.

To understand as fully as possible the experience of having a child with severe epilepsy, measures are needed that provide feedback about the family's quality of life, their needs and priorities, and which capture the experience of interacting with health care and support services. This will enhance clinicians' ability to support children and their families appropriately, to communicate clear and helpful messages, and to acknowledge and celebrate children's milestones without setting them up for apparent failure to reach goals in the order, and on the timescale, of typically developing children.

Dr Sadlier founded the ERG and is based at Wellington Hospital. Her studies involve exploring epileptic encephalopathies and examining family histories. Her view was that the measures currently available for assessment of family experience of severe epilepsy were not quite fit for purpose, in somewhat the same way as I had felt when completing the form for surgery. Thus a small piece of research around this was conceived.

While this research was going on, Dr Sadlier had to move ahead with her study, and selected an existing measure. This meant a change in focus for my thesis to include other families with a child who has acquired a severe brain injury, or who has a serious brain

disorder. These families may share similar effects on their quality of life, regardless of the specific cause of the injury or disorder. It is possible that a measure developed for one condition might be useful in other conditions. I therefore expanded my review of existing measures to explore the effects on families of non-epileptic severe brain injury and disorders as well. As background for the thesis a literature search of serious conditions was undertaken, which is reviewed in Chapter 2.

As it turned out, the majority of our survey respondents were parents/caregivers of children with autism spectrum disorders, and accordingly the literature around that condition was revisited.

The qualitative information provided by respondents was extremely rich, detailed and extensive. This connected with my own experience of raising a child who, while not formally diagnosed, has displayed many behaviours typical of autism.

Chapter 3 looks at existing knowledge about quality of life in families living with a child who has a severe neuropathy. A literature search produced some material directly focused on QoL in these families in other countries, but very little relating to New Zealand. The chapter also considers specific measures currently in widespread use in assessing family experience of severe pediatric neuropathy.

Chapter 4 draws together the research thread, and outlines the approach taken with specific aims and hypotheses. The study was exploratory, with a goal of understanding family experience after severe pediatric neuropathy.

Methodology and the results of the research are presented in Chapters 5 and 6, and a discussion of the results, with conclusions and recommendations, is presented in Chapter 7.

Chapter Two: Serious Conditions

Despite the original focus on epilepsy, and then changing to seeking participation from parents/caregivers of children with a wide range of severe health conditions, survey responses came overwhelmingly from parents/caregivers with children on the autism spectrum. Consequently, the information on ASD in this section was expanded. This chapter will present an overview of ASD and epilepsy, with a brief section on other health conditions which could produce serious brain injuries or disorders.

Autistic Spectrum Disorder (ASD)

Autism refers to a range of conditions which involves atypical neuropsychological development. Whether it is properly described as a disorder, or simply a different way of being human, is a matter of considerable debate. In the current social environment, however, it is clear that children with autism face difficulties in meeting society's expected social, emotional and behavioural standards, and may also risk having their strengths overlooked or undervalued.

Many diagnoses have been applied to people with autism since the condition was first described by Leo Kanner in 1943 and by Hans Asperger in 1944. The DSM-5 (American Psychiatric Association, 2013) introduced a single new category of "Autism Spectrum Disorder". This diagnosis replaced previous diagnoses including Asperger's Disorder, Autistic Disorder, Pervasive Developmental Disorder: Not Otherwise Specified; Childhood Disintegrative Disorder and Atypical Autism. There is ongoing discussion around whether the DSM-5 captures the same people who would have been diagnosed as having an autism spectrum disorder under DSM-IV-TR (American Psychiatric Association, 2000). Several studies suggest that the new criteria disproportionately exclude those with higher intellectual function, toddlers, and those who would have received diagnoses of PDD-NOS or Asperger's Disorder under the DSM-IV-TR (Harstad et al., 2015).

The DSM-5 offers two clusters of diagnostic criteria for ASD: difficulties with social interaction, and restricted or repetitive patterns of behaviour and/or interests. These criteria may manifest with three levels of severity in different individuals – (1) requiring support, (2) requiring substantial support and (3) requiring very substantial support.

Children with ASD may have social interactions which are perceived as lacking emotion and/or reciprocity (American Psychiatric Association, 2013). They may not understand social cues – my son, as a toddler, did not understand that he should follow with his eyes the direction a person was pointing: it was impossible to show him an airplane in the sky, for example. They may not imitate the behaviour they observe in others (the same child, presented with an ice-cream cone for the first time, stared at it in bemusement, watched other children licking their cones, and continued to stare at his own, making no attempt to eat). Speech may come late, early, or not at all. In some cases, existing language skills may be lost (Kumar, Karmakar & Mohanan, 2014).

Restricted or repetitive interests may be less noticeable in childhood than in adults – a fixation on dinosaurs, for example, is not unusual in childhood. The degree of focus, however, and often the unusual nature of the object of fascination (wheels, political polls) will tend to stand out.

Repetitive behaviours can include repeated body movements such as hand-flapping, ritualised movement of specific objects, and linguistic repetitions such as echolalia (Eckdahl, 2018a). My son when young repeated everything he said, immediately after he said it, in a soft whisper to himself. Routines can be very important for children with ASD, and change can be difficult to accept.

Many children with ASD are hypersensitive to sound, touch, and other sensory input (Chistol et al., 2018). This can limit the clothes they will wear, the food they will eat, or their ability to be in loud classrooms or sunny playgrounds.

These behaviours are likely to make a child seem odd to his or her peers, teachers, and even family members and can lead to social rejection and isolation. Children with ASD have high rates of psychological co-morbidities such as anxiety and depression (Mazefsky, Conner & Oswald, 2010). They also experience unusually high rates of auto-immune issues, sleep problems, and gastrointestinal disorders (Mannion & Leader, 2016).

The prevalence of ASD is estimated at 70 per 10,000, according to a review of 57 epidemiological studies published since 2000 (Hollander, Hagerman & Fein, 2018). The New Zealand Ministries of Health and Education noted in 2016 that there was no definitive prevalence rate for ASD in the country but estimated that there were likely more than 40,000 New Zealanders with ASD (diagnosed or not) across all ages.

The ratio of males to females with ASD has often been cited as 4:1, but a recent review of studies from 2000 onward suggests that 3:1 may be more accurate, with a tendency persisting for girls to be under-diagnosed (Loomes, Hull & Mandy, 2017).

Etiology

Current research suggests that ASD has no single cause, but arises from a complex interaction of genes, environment, immunology and neurology, prior to birth (Cheroni, Caporale & Testa, 2020). Many genes are implicated, and numerous environmental factors have been identified as potentially relevant. While certain risk factors can be mitigated – maternal diet, for example, has been found to have associations with levels of risk (Zhong, Tessing, Lee & Lyall, 2020) - many are not yet well understood.

Diagnosis

ASD can be diagnosed in children from the age of 18 months, but this seldom happens, because symptoms may not immediately be noticed, or their significance may be misunderstood (Eckdahl, 2018a). Most children are diagnosed after the age of 2. Eckdahl

notes that diagnosis is challenging, especially at the extreme ends of the spectrum. High-functioning children may have more subtle symptoms, and it may be hard to distinguish ASD from other conditions in non-verbal children with intellectual disability.

Franchini et al. (2019) found that children who at 12 months showed low rates of initiating joint attention – seeking to orient another person to an object the child is paying attention to – were significantly more likely to be diagnosed with ASD or language delays by age 3. Those children who still had low rates of initiating joint attention at 18 months were more likely to have ASD than to have simple language delays. This mechanism may help to identify the children for whom very early interventions may be helpful.

Treatment/management

ASD is not a curable condition, and indeed many people object to the idea that a "cure" would be desirable (Autistic Reader, 2016).

People with ASD do experience challenges, however, and can need a range of assistance to reach their potential (Bédard & Hecker, 2020). This can include tools to manage behaviours that cause difficulties, therapies to assist with learning key skills, treatment of co-morbidities and increased accommodation and acceptance of difference in the wider community.

Epilepsy

Epilepsy is a term describing a set of conditions which cause people to experience repeated seizures (Dlugos, 2018). Having epilepsy affects people's mental, physical and emotional well-being. It impacts on the individual's social life, educational and work prospects, and presents challenges to the significant others of affected people.

Refractory epilepsy is epilepsy which does not respond to treatment. It affects between 30% and 40% of patients with epilepsy (Schoenberg, Werz & Drane, 2011). The

term usually refers to cases where anti-epileptic drugs are not effective in controlling seizures, and consequently, the possibility of treatments other than medication should be considered.

Several different systems of categorising seizures and epileptic syndromes have been proposed at different times because there is considerable variation of etiology, seizure characteristics, and accompanying symptoms (Moshé et al., 2015).

In 2017 the International League Against Epilepsy (ILAE) published a new system for classifying epilepsies which aims to provide consistent descriptions which are clear to health professionals, patients and family members (Brodie, Zubari, Scheffer & Fisher, 2018). The system does not attempt to categorise non-epileptic seizures.

Under the ILAE approach, description follows three levels. The type of seizure is identified first, then the type of epilepsy, and finally, if possible, a specific epileptic syndrome. Emphasis is placed on assessing co-morbidities and etiology throughout the process (Brodie et al., 2018).

Types of seizure

Seizures categorised as focal can be seen to arise from a single point in one hemisphere of the brain. Generalised seizures may begin at a single point, but rapidly affect much or all of both hemispheres. If it is unclear whether seizures are focal or generalised – for example, when a patient has experienced only one or two seizures, or symptoms have not been carefully observed – the ILAE system describes them as being of unknown type, until further investigation may be able to draw a clear conclusion (Brodie et al, 2018).

Seizures arise from abnormal electrical activity in the brain and can affect any of the brain's activities. Consequently, seizures can take many forms. A focal seizure might involve only dizziness or could seem like a momentary loss of responsiveness. Equally, it might cause the random movement of a limb, or a sudden unintended vocalisation. Similarly,

generalised seizures can range from a brief blank stare to collapse, shaking and jerking, with loss of consciousness.

Types of epilepsy

Once the type of seizure has been assessed, the type of epilepsy can be decided: focal, generalised, comorbid focal and generalised, or unknown (Brodie et al., 2018).

There are many distinct epileptic syndromes, each consisting of a cluster of factors, from epilepsy type and co-morbidities to genetic abnormalities and distinctive EEG patterns. So, for example, West's syndrome is marked by infantile spasms, developmental delay and hypsarrhythmia (a chaotic interictal EEG pattern) (Schoenberg et al., 2011). Landau-Kleffner syndrome, on the other hand, usually begins with language dysfunction in a child who has been developing normally in motor and language skills. Seizures may begin at the same time or may appear later, and abnormal activity in the temporoparietal area is necessary for diagnosis (Schoenberg et al., 2011). To complicate matters, children with West's syndrome may go on to develop Landau-Kleffner, meaning that it is vital to keep accurate records of current and past diagnoses, and consider the treatment and prognosis implications of each.

A 2004 study by Dunn, Buelow, Austin, Shinnar and Perkins assessed the severity of the different Pediatric epileptic syndromes. The criteria used were a) responsiveness to treatment, seizure severity, and long-term prognosis. Their findings placed early encephalopathies such as Lennox-Gastaut and Dravet at the high end of the severity scale, compared to seizures only in the context of acute metabolic or toxic events, and simple febrile seizures, at the low end.

Diagnosis

There is no single diagnostic test for epilepsy (Prager, 2018). Diagnosis can be difficult because medical professionals are relying on descriptions of seizures as reported by

the individual concerned, and perhaps by a witness. If seizures have occurred only once or twice, or at extended intervals, there is limited likelihood of catching one on video-EEG even if the person is able to spend a week in hospital for observation – assuming the resources are available. In practice, most people are diagnosed without a video-EEG recording (Bergin et al., 2018).

Moreover, a high level of non-epileptic seizures is found among people initially thought to have refractory epilepsy. Non-epileptic seizures may appear similar to epileptic seizures, but they are not accompanied by the electrophysiological changes seen during epileptic seizures (Schoenberg et al., 2011). Some result from organic conditions such as cardiac disease, and others from psychological causes. The latter group is known as psychogenic non-epileptic seizures (PNES). Despite an estimated incidence in the general population of 1.5/100,000 people, a much lower rate than epilepsy (at around 37.5/100,000), epilepsy treatment centres report that 25-30% of those referred to them with refractory epilepsy are found to have PNES. A significant minority of these people, estimated between 5-40%, also have epileptic seizures, or have a history of an epileptic disorder that has resolved or been controlled (Bodde et al., 2009).

Diagnostic tools. The primary tool for diagnosing epilepsy is a complete history of the patient, with descriptions of seizures if possible. A recent study of inter-observer variability, in which physicians assessed patient scenarios, found "substantial" agreement among the doctors on whether the patient had epilepsy, and "fair to moderate" on the type of seizure and etiology (Bergin et al., 2018).

Electrical activity in the brain can be measured using an electroencephalogram (EEG). Electrodes placed at set points on the scalp record neuronal activity, before, during and after a suspected seizure, and this record can be compared with patterns known to occur in seizures.

Video-EEG gives medical practitioners more information about a possible seizure, since physical effects are seen as well as neuronal activity. This can be carried out in a hospital setting or at home, using Ambulatory Video-EEG Monitoring (AVEM). While some doctors prefer the control of an inpatient setting, AVEM has been found to capture useful data on video around two-thirds of the time, in a retrospective study of more than 9,000 patients (Syed et al., 2019). As it has advantages in cost, convenience and accessibility, using AVEM should be considered in the diagnostic process.

In children, particularly, video-EEG can be usefully combined with polysomnography (a type of sleep study) to assist in diagnosing nocturnal events, and distinguishing, for example, sleep disorders from parasomnias. (Jain, Dye & Kedia, 2019).

Treatments

Four approaches to treatment and management of epilepsy are currently available. They are medication, surgery, electrical stimulation and lifestyle adjustments.

Medications. During the 20th century, only a handful of anti-epileptic drugs (AEDs) were available for prescription (Rho & White, 2018). There are now more than two dozen, with more currently in trial (Goldenberg, 2010). Around 60-70% of people with epilepsy can eliminate or significantly reduce the frequency of their seizures through the use of AEDs. Identification of specific epilepsies is important because different AEDs are used for different epilepsies. For some conditions, but not all, several options are available. A process of trial and error is used to find the specific drug most effective for each case, but if three medications have been tried without success, further trials are unlikely to control seizures, and the person is said to have refractory or intractable epilepsy,

Recently, a machine-learning project by pharmaceutical company UCB Pharma and IBM produced a predictive model to help physicians select the most appropriate AED for individual patients (Devinsky et al., 2016). Use of the model was found to extend the time

before a change of medication was required, and to reduce the expected use of healthcare resources.

In June, 2018, Epidiolex (Cannabidiol) , the first AED derived from cannabis, was approved for use in the United States (U.S. Food & Drug Administration, 2018). It is the first drug to be approved by the FDA for the treatment of Dravet syndrome.

Surgery. Surgery tends to be a treatment of last resort in epilepsy (Cross et al., 2016). While an estimated four million people worldwide with medication-resistant epilepsy could be candidates for surgery, which might eliminate seizures in 60-80% of cases, the most recent worldwide survey found only around 8,000 surgeries were carried out in the four years from 1986 – 1990 (Engel, 2016).

For children, speed of treatment is especially important. Cross et al. note that early surgery, where appropriate, is associated with better psychosocial outcomes for children. A long-term study (Skirrow et al., 2015) of outcomes for children who had surgery for temporal lobe epilepsy found better memory outcomes in comparison to a control group treated with medications. Within the surgical group, better results were linked to earlier surgery and briefer exposure to seizures.

Further research is needed to assist specialists in balancing the risks against the benefits of all of these surgeries, and reluctance to perform surgery on the brains of children at all remains a significant hurdle, according to Cross et al.

Electrical stimulation. Vagus nerve stimulation (VNS) is a treatment which can be offered to people with focal epilepsy, to either eliminate or reduce the frequency of seizures (Schachter, 2016). A number of studies have found significant benefits from VNS to children with epilepsy. Orosz et al. (2014) found reductions of 50% or more in seizure frequency in 32.5% of children implanted with a VNS device, rising to 43.8% two years after surgery.

Notably, QOL was assessed, and over a third of the children showed improvement in alertness, mood, energy, concentration and progress with their schoolwork.

While VNS has usually involved surgical implantation of a device, a newer form of transcutaneous VNS has been developed, which may provide similar benefits less invasively (Ellrich, 2011). As of 2015, no full studies had been done using this technique in children, though one was being planned, and a small pilot study had found good efficacy and no severe adverse events (He et al., 2015).

Other forms of neurostimulation are also being investigated, including deep brain stimulation (DBS), transcranial direct current stimulation (tDCS) and repetitive transcranial magnetic stimulation (rTMS) (Bolden, Sandipan & Szaflarski, 2015).

Lifestyle adjustments. While adaptations to lifestyle are unlikely to resolve epilepsy, evidence is mounting for the effectiveness of a number of measures in reducing the frequency or severity of seizures in certain cases.

Edward, Cook, Stephenson and Giandinoto (2019) found some evidence for seizure reduction in adults, following a brief lifestyle self-management intervention, focusing on psychosocial changes. A review of self-management interventions for children found significant impacts on individuals, families, health care systems and community (Wagner et al., 2017). For individual children, different studies in this review found improvements in mental health, reduced behavioural problems, self-concept/efficacy, knowledge of epilepsy, quality of life, and social skills. None of the studies scored well on the American Academy of Neurology's categorisation of levels of evidence, however, which measures risk of bias, and only one of the studies which included a control group found a reduction in seizures.

Diet has been used to manage epilepsy since at least Hippocrates' day (Gildea, 2017). Over the last century, the ketogenic diet (high fat, with very restricted carbohydrates) grew in popularity as a treatment for children with refractory epilepsy (Kim, 2017). Randomised

controlled studies have found the diet to be approximately as successful as the newest anti-convulsant drugs in controlling seizures in children (Kelley & Hartmkanhan, 2011). Adherence to the diet may be more of a problem, though, than adherence to medication. Not all families are able to stick to it.

While some evidence suggests that better self-management leads to better quality of life, Quon et al. (2019) found that focusing on safety aspects of self-management correlated to poorer quality of life. The ideal may be to locate the balance between having the best tools to manage epilepsy and spending too much time ruminating on dangers. More research is underway in this area.

The effects of exercise on epilepsy are not entirely clear. While people with epilepsy who engage in exercise have fewer seizures than those do not, the cause and effect are far from certain (Arida et al., 2013). However, as with anyone, refraining from exercise can expose people with epilepsy to increased risk of numerous undesirable health outcomes, both physical and psychological.

Willis, Hophing, Mahlberg and Ronen (2018) found young people reported improvements in their physical and psychological health after taking part in a "motivated walking" programme (wearing an activity tracker and being encouraged by a coach via telephone calls). Some felt their seizure frequency had also been reduced, though this was not empirically tracked.

The specific type of exercise may be important. In a small study of children with refractory epilepsy, Kanhere, Bagadia, Phadke and Mukherjee (2018) found that practising yoga reduced seizure frequency in the treatment group, compared to the controls. This may be particularly relevant for children who have hyperventilation-induced seizures, who may benefit from gaining greater control over their breathing.

Other serious conditions

Many families in New Zealand are raising a child with a serious brain injury/disorder other than ASD or epilepsy. As the focus of this study expanded, other pediatric health conditions which might affect families' quality of life in ways similar to epilepsy and ASD were considered.

A brief review of a range of disorders and the domains which (according to the literature) could be affected by them was carried out. This produced an overwhelmingly consistent result that every domain which could be affected by epilepsy and ASD could also be affected by virtually all of the other disorders considered.

Consequently, a decision was made to widen the research to include any New Zealand family currently raising a child affected by a condition, of any etiology, which involved significant neurological impact, and the likelihood of long-term or permanent limitations in functioning. We sought families who had a child affected by traumatic brain injury, epilepsy, ASD, stroke, cancer, poisoning, infection or congenital conditions such as cerebral palsy, microcephaly or spina bifida. In the end, the vast majority of responses we received related to ASD, with a handful of families reporting on congenital and genetic conditions and on childhood injury. A brief discussion of these latter conditions follows. Conditions which were not reported among our respondents' children are not discussed. Several respondents did not give their child's diagnosis, or reported that their child's condition had not yet been diagnosed.

Congenital and genetic conditions and childhood injury

A number of congenital conditions can cause significant neurological impact, and there can be implications specific to the age-group. Congenital brain lesions, for example, can affect the functions associated with whichever part of the brain they occur in, but unlike older people who develop brain lesions, babies lack a developed sense of how their bodies move

and work, which is essential to sensorimotor integration (Ritterband-Rosenbaum, Justiniano, Nielsen, & Christensen, 2019). Congenital genetic conditions can affect multiple bodily systems: Down Syndrome, for example, is frequently associated with heart conditions and hearing conditions, as well as with intellectual disabilities ranging from mild to severe (Eckdahl, 2018b). The needs of such children may be very wide-ranging.

Similarly, injury either at birth or in childhood can result in very different outcomes, with children needing different management and treatment.

Amongst our respondents, we encountered two reports of genetic ADHD, two instances of a chromosome deletion, and one reference to a "doubling up" of a gene, in a child who was also identified as having ASD. One child had experienced a brain haemorrhage, three had suffered birth injures, and one's condition is thought to result from being dropped at 6 months.

Diagnosis of these conditions uses many techniques from pre-natal screening to genetic testing, observation, and parental questionnaires. Treatment depends on the individual diagnosis, the child's symptoms and the options available.

Chapter Three: Families' Experiences Raising Children with Serious Brain Injury/Disorder

Raising any child is challenging and brings stress, as well as joy, to parents' or caregivers' lives. Raising a child with a disability brings added complexities, which have been found to impact on parents' stress levels (Pinquart, 2018), and therefore on their quality of life (QoL). Discovering that a child is severely disabled produces significant physical and mental stress for some parents (Graungaard, Andersen & Skov, 2011). Brehaut et al. (2011) highlight the practical impacts of raising a child with a disability: greater demands on time, higher costs (both medical and other), constraints on employment and concomitant lower income, and greater complexities in the activities of caregiving.

This chapter examines the concept of QoL, and looks at how it is affected in families raising a child with a serious brain injury/disorder. International findings and the small body of New Zealand-based research are discussed. Finally, measures of QoL are examined.

Quality of Life

QoL lacks an agreed definition. The World Health Organisation (WHO) describes it as "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" (WHO, 1996). The study of QoL has expanded in several directions, so that research now focuses on FQoL (Family Quality of Life), HRQoL (Health-Related Quality of Life), and CRQoL (Care-Related Quality of Life).

Within these categories, researchers have identified numerous factors that contribute to the overall QoL, developed many measures to assess them, and produced a number of theories around which characteristics and behaviours promote good QoL, and which interventions can improve it. Having so many variables makes an agreed definition of QoL seem less achievable than ever, even before exploring any New Zealand-specific issues.

Studies of parents of children with disabilities have shown lower QoL than is found in parents of healthy children (Isa et al., 2016). There appears to be an association between parental HRQoL and the complexity of the child's disability (Brehaut et al., 2011; Werner & Shulman, 2013). In a study of physically and mentally disabled children Ganjiwale et al. (2016) found that QoL for parents of disabled children was affected by the nature of the child's disability. Weleerner and Shulman (2013) reported that internalised stigma associated with particular conditions impacted parental QoL: the greater the internalised stigma attached to the child's condition, the poorer the parents' QoL. Parents of children with ASD were found to have higher internalised stigma, and lower QoL, than parents of children with intellectual or physical disabilities. No study was found that showed parents/caregivers of disabled children having QoL the same as, or higher than, parents/caregivers of healthy children.

Hickey, Anderson, Hearps and Jordan (2018) describe the complexity of parental response to brain injury. Emotions can involve elation at a child's survival of an accident or illness, sorrow over changes in the child they've known, and grief at anticipated difficulties facing the child.

On the other hand, Myers, Mackintosh, and Goin-Kochel (2009) asked parents the open-ended question "How has your child in the autism spectrum affected your life and your family's life?" and received many positive responses as well as negative. Appreciation of small things, enrichment of experience, and increased patience and compassion were among the benefits described.

Factors impacting QoL in parents/caregivers of disabled children.

Lee and Shivers (2019, p. 627) identified the following factors which each contribute to parental/caregiver HRQoL in different ways in different families, depending on the nature and degree of a child's disability:

- Health
- Mental health
- Health information needs
- Emotional support needs
- Instrumental support needs
- Professional support needs
- Community support needs
- Involvement needs
- Subjective externalised strain (e.g. feeling angry at child)
- Subjective internalised strain (e.g. feeling tired, worrying)
- Objective externalised strain (e.g. missing work, disrupted family schedule)
- Adaptive coping
- Maladaptive coping

Studies of the factors listed above are very varied, using a wide range of measures, and a variety of interventions to assess either QoL, or specific aspects of it, (which are not always defined in the same way).

Sen and Yurtsever (2007) identified three stages of a typical parental response to the diagnosis of a child's disability. Initial shock, denial and depression give way to anger, guilt and shame, which eventually turn to bargaining, acceptance and adaptation. The point in this process which a parent is at, may influence their experience of caregiving and their QoL.

In cases where a serious brain injury is acquired partway through childhood, parents/caregivers may experience "disenfranchised grief" - defined as "the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported. Isolated in bereavement, it can be much more difficult to mourn and reactions are often complicated" (Doka, 1999, p.37). The child has survived a major illness or accident – surely the appropriate response is rejoicing? Yet the child the parent/caregiver has always known may be gone, along with hopes for his/her future, and an expectation of being

able to step back from the caregiving role eventually. The loss is "non-finite": there is no cut-off point, as with a death; their child still exists, but not as they have always known them (Collings, 2008). The opportunity to grieve – or lack thereof - may also impact on QoL.

Unempathic medical professionals have been found to contribute to "resource-deterioration" – that is, weakening of the parents' sense of hope and their belief in their own ability to cope and thrive along with their disabled child (Lee et al., 2009). On the other hand, Old, Adams, Foley and White (2011) reported that New Zealanders have high expectations that doctors will be compassionate, which may indicate that we have, in the main, experienced compassion from our doctors.

Stress arising from financial factors has been shown to be a significant issue for parents of children with life-limiting conditions (Cadell, Kennedy & Hemsworth, 2012).

QoL associated with Pediatric Epilepsy

Nearly two decades ago, the ILAE (International League Against Epilepsy) noted that the importance of HRQoL was leading to its inclusion as a consideration in growing numbers of clinical trials and published a report on HRQoL measures and the principles of assessment (Cramer, 2002). HRQoL in both children with epilepsy, and their caregivers or parents, has subsequently been investigated quite extensively (e.g., Soria et al., 2007; Cianchetti et al., 2015; Conway et al., 2016; Puka, Tavares, Anderson, Ferro & Speechley, 2018).

A study of the HRQoL of schoolchildren with epilepsy and their parents found that both parents and children had lower quality of life than a control group unaffected by epilepsy (Bompori, Niakas, Nakou, Siamopoulou-Mavridou & Tzoufi, 2014). Notably, HRQoL was lowest for parents and children when epilepsy was drug-resistant and accompanied by neurodevelopmental problems. Riechmann et al. (2019) found lower QoL in parents to be associated with lower QoL in their children, and also with disease duration, continuation of seizures, related disabilities, and their own unemployment if they were

primary caregivers. In children, factors associated with low QoL included an active sense of missing a time when one had been free from seizures, comorbidities, living in foster care, hospitalisation and degree of disability.

No research has been published on the QoL of New Zealand parents/caregivers raising children with severe epilepsy.

QoL associated with ASD

Globally, researchers in the field of ASD have similarly explored the QoL of children and their parents or caregivers. De Vries & Geurts (2015) found children with ASD had lower HRQoL than their neurotypical peers, and that lower executive function and stronger autistic traits were associated with the lowest levels of HRQoL. ten Hoopen et al. (2019) distinguished caregiver HRQoL from care-related QoL (CRQoL). They found pain to be a slightly more common issue for caregivers than depression, though both were at high levels. In terms of caregiving, problems in the relationship with the child with ASD was the most significant issue, followed by difficulty in combining care with other daily activities. Notably, 96% of all caregivers reported experiencing fulfilment from caring for their child. Two studies have been carried out in New Zealand into the QoL of parents of children with ASD. They are discussed at the end of this chapter.

The parent or caregiver of a child with ASD may not have to worry about physical injury from seizures, but may have fears around his or her child's social interactions which may be less applicable to the parent/caregiver of a child with epilepsy.

Lee and Shivers (2019) found that caregiver HRQoL was not significantly affected by the age of the child with ASD, in a study comparing young children to young adults. This suggests there may be no point at which caregivers can hope for their burden to lift. Greater severity in the child's condition has been found to predict poorer parental QoL (Ozgur, Aksu, & Eser, 2018).

In 2018, Willet, Dorstyn, Due and Li investigated the patterns of uptake of support and services by Australian parents of children with ASD, and the relationship of these patterns to HRQoL. They found that the strongest predictors of service use were having more than one child with ASD, and caregiver distress. Socioeconomic status also had a significant effect on the uptake of services.

Ganjiwale et al. (2016) acknowledge that the culture-specific family support structure in India is relevant to parental QoL; Wang et al. (2018) refer to a child's ASD imposing a heavy childcare burden on mothers in China but not on fathers, for cultural reasons.

Research in the New Zealand context

New Zealand-specific research is needed to test which of these findings apply here - which aspects of our physical and cultural environment affect parents' and caregivers' experiences, and which forms of support would be most valuable here. Little has been published on the QoL of New Zealand parents/caregivers of children with brain injuries/disorders.

Browne's (2010) Master's thesis compared the QoL of parents of children between ages 6-16 affected by ASD or intellectual disability (ID), with the QoL of parents whose children in the same age group were unaffected. She found that QoL was lower for parents of children with ASD or ID, with problem behaviour having a moderate negative effect on parents' QoL scores. Level of care required and combined socio-economic/marital status had no significant impact on QoL, while satisfaction with the support services provided produced a weak positive effect. As was the case in the present study, Browne's participants provided rich qualitative data about their experiences. Three key themes emerged: a need for respite, a desire for community acceptance of their child, and the challenges of accessing good services within the disability sector.

Landon, Shepherd and Goedeke (2017) reported on satisfaction with life (SWL) in New Zealanders raising children with ASD. SWL is a narrower measure than QoL, but has the advantage of allowing respondents to weight the different "life domains" according to their own values, thus tailoring the resulting SWL more individually. While the average SWL suggested "slight dissatisfaction", outcomes were widely distributed from "extremely dissatisfied" to "extremely satisfied" with no clear pattern emerging. The factors which impacted SWL most strongly were care-related health problems (negative effect) and care-related esteem (positive effect).

Both these studies focused on ASD, and the QoL of New Zealanders raising children with other brain disorders/injuries has not yet been explored.

Measures

QoL is measured objectively as well as from an individual's subjective perception, and involves assessment of numerous domains of life. Consequently, the challenge is to come to a broadly acceptable common understanding of what QoL is and how it can be measured in different settings (Eiser & Morse, 2001).

Early this century, QoL was a relatively new consideration in assessing outcomes of clinical trials and health interventions, which had traditionally been measured in such terms as survival rates and cure (Fayers & Machin, 2016). Patient-reported outcomes were not regularly measured. As researchers began exploring this perspective on treatments and experiences, emphasis was placed on different aspects of QoL, depending on researchers own interests and focus. Some measures stressed psychological impacts, others practical experiences, yet others spiritual effects, and so forth. For HRQoL, the effects of illness and its treatment are the focus, usually with consideration of social, emotional and physical functioning, and sometimes financial and/or employment impacts.

Measures of QoL can be categorised as disease-specific or as generic. Suites of measures, such as EQ-5D, offer both options: an all-purpose measure, and a version tailored to each of a number of diseases. Many QoL instruments are developed in response to a specific clinical group: adults with asthma (Eberhart et al., 2014), people living with HIV (Brown et al., 2018), people with acute myeloid leukemia (Buckley et al., 2020).

Popular measures of children's QoL include PedsQL and EQ-5D-Y, both of which have been in use (with updates) for over 20 years. A strong body of data is building around each of these measures. Each has multiple scales and modules, normed on a number of populations, and neither is freely available. Each has options for children to complete reports, and for parents/caregivers to respond on the child's behalf.

Proxy reports of QoL – such as those made by parents/caregivers assessing their child's situation – have been found to be biased, with both underestimation and overestimation sometimes occurring (Kreimeier & Greiner, 2019). In the case of children who are not able to complete a report on their own behalf, however, a proxy is the best available source.

Numerous measures of QoL have been developed in relation to specific child populations, commonly for groups of children with a particular health condition. Researchers have designed measures to capture the specific QoL issues of (for example) eczema, cancer, obesity, asthma and coeliac disease on children and adolescents.

In summary, QoL in children and their families has been studied in terms of the many factors listed above using a a wide range of measures, and a variety of interventions. The breadth of data is somewhat undercut, however, by the inconsistency of definitions across different studies and measures.

Chapter Four: The Present Study

The aim of this exploratory study was to examine the QoL of New Zealanders who are raising children with "serious brain injury/disorder". This was defined as conditions likely to have long-term or permanent effects which significantly affect a child's cognitive, emotional, behavioural, social and/or physical functioning. Responses were sought from people with such children, regardless of whether the cause were genetic, an injury or illness. In retrospect, "serious brain injury/disorder/difference" would have been more inclusive.

Given our initial focus, we examined the measures designed for children with epilepsy most closely. These are discussed in more detail in Chapter 5. For the current study, it was planned to measure parent/caregiver QoL both from the perspective of social and emotional functioning, as well as work and community effects. It was important to understand the QoL of the child in their care, to understand the situation they were living with. Two measures would be needed, one of the adult carer's QoL, and one of the child's HRQoL. In both cases, it was important to seek both quantitative and qualitative data, to allow for both statistical analysis and a richer understanding of parental/caregiver experience.

International research indicates that raising a child with brain damage can impact negatively on caregivers' quality of life, but little is known about the experience of parents/caregivers in the New Zealand context, i.e., which aspects of life are most affected, and in which ways. Certain factors specific to New Zealand may influence the experience for caregivers. Maori and Pacific cultural beliefs and customs would be one such potential factor, as would the opportunity (or inability) to access support from the Accident Compensation Corporation (ACC).

Documenting the challenges facing caregivers, with indications of their key concerns, is essential to ensuring that the best supports are made available to New Zealanders in this

situation. It is hoped that the research will lead to specific suggestions for ways to promote the QoL of caregivers by alleviating some of their burdens.

The following hypotheses were formed

1 Parents/caregivers will feel their doctors have given them good information, and that any gaps in information provided arise from limited current knowledge about a disorder and its impacts, rather than from poor communication by doctors

This hypothesis will primarily be tested by the responses to questions 5 and 6 of the survey (See Appendix 1). Responses in open questions throughout the survey would also give insights. The direction of the hypothesis is based on a study by Old et al. (2011) who reported that 91% of New Zealanders surveyed strongly agreed that they expected doctors to be helpful sources of health education and advice. While having an expectation does not prove that the expectation is necessarily always met, such a high response suggests a history of having found doctors to be helpful. Similarly, the State Service Commission's annual survey, Kiwis Count, shows good levels of satisfaction with the experience of taking a child to the doctor, but does not drill down to the level of satisfaction with information provided by doctors (State Services Commission, 2019).

However, there is no published evidence around the specific satisfaction with doctors of New Zealand parents/caregivers of children with severe disability. The Kiwis Count survey shows lower results from respondents with disability than from others. It is possible that a similar effect may apply to parents/caregivers of children with a disability. If results on questions 5 & 6 show parental/caregiver disappointment, this will be an area where improvement could be recommended.

2 Parents/caregivers will report sorrow about their child's condition and worry for their future

Questions 7 and 9 of the survey address this hypothesis directly, and again, written responses would likely provide more information. Hickey et al. (2018) refer to the "family trauma" surrounding a child's brain injury. Similarly, Jordan and Linden (2013) found a mixture of grief, anxiety, exhaustion and guilt in mothers of brain-injured children.

3 Parents/caregivers will regard the condition as being at least moderately serious

This hypothesis will be tested by question 8 and possibly informed by later written responses. If a parent or caregiver does not consider their child's condition to be serious, they may not be in the correct demographic for the survey.

4 Parents/caregivers will report significant deficits in their child's cognitive, social, emotional and physical function

Questions 19-78 seek to establish the parent's or caregiver's perception of how the child deviates from standard function in key domains. If few, or only slight deficits exist, the child's condition may not be severe, or the parent/caregiver's perception may be inaccurate.

5 Parents/caregivers will report negative effects on family life, levels of conflict and apprehension, work life, social life, extra-family relationships, and finances, with more negativity in those who report more extreme deficits in their child's functioning

This hypothesis is tested by questions 10-16, question 18, and questions 83-88 and is based on studies in numerous settings that have found that raising a child with a disability can

impact negatively on parental/caregiver QoL, and that more severe disability can correlate with poorer QoL (e.g., Ozgur et al., 2018; Bompori et al., 2014).

6 Parents/caregivers will report lower impact on some of these quality of life features if their child is being funded under ACC

The families of New Zealand children with serious brain injury/disorder may receive significantly different levels of support from the government, depending on whether the child's condition arises from an accident or from an illness. The Accident Compensation Corporation (ACC) can provide funding for services to children injured in an accident but not those whose disability results from an illness.

Financial stress can impact significantly on parents of children with major health issues (Cadell et al., 2012). ACC entitlement may result in better support for families. A comparison of satisfaction levels in respondents whose children qualify, and in respondents whose children do not, may be useful.

Question 82 will identify the respondents in receipt of ACC support, which will enable us to analyse other responses in light of this factor.

7 Parents/caregivers will report higher levels of negative impact if their child's disorder has caused sudden deterioration or loss of function, as opposed to having been chronic from birth (for example, an otherwise healthy child experiencing anoxia from a swimming accident, rather than as a birth injury).

A parent/caregiver whose child regresses from normal development may deal with the same practical issues as a parent whose child has always been disabled, but has also to cope with the loss of their relationship with the healthy child, and of some hopes for the child's

future (Youngblut et al., 2000). Questions 3 & 4 are intended to identify which respondents have dealt with a child's losing existing capacity.

8 Parents/caregivers will occasionally identify positive effects that have come from the experience of living with a child with severe neuropathy, possibly in terms of perspective, valuing small successes, or building stronger relationships within the family.

Question 17 offers the opportunity for parents/caregivers to detail positive outcomes of dealing with a child's severe illness. Myers et al. (2009) detailed parents' reports of enrichment in their lives from parenting a child with autism.

9 Parents/caregivers will report negative emotions arising from completing the questionnaire, such as sadness and frustration.

This hypothesis is based on Lindblad et al's (2007) finding that recounting their experiences with their child produces sorrowful feelings in parents, particularly in the context of insufficient support. Question 79 seeks to identify such feelings in respondents, and to encourage them to seek support if needed.

Chapter Five: Method

Recruitment

In order to reach people who would be qualified to participate in the survey, a list of conditions or events which might result in serious brain injury or disorder was generated and matched with New Zealand support groups for these conditions list (see Table 1).

Table 1

NZ Support Organisations and the Conditions they Cover

Organisation	Condition		
	Congenital /inherited[1]	ASD	Acquired[2]
Arnold-Chiari Malformation Support Group	✓		
Autism NZ		✓	
Brain Injured Children Trust			✓
Cerebral Palsy Society			✓
Cri du Chat Support Group	✓		
Cure Kids	✓	✓	✓
Down Syndrome Association	✓		
Epilepsy NZ	✓	✓	✓
Fragile X NZ Trust	✓		
IHC NZ[3]	✓	✓	
Immune Deficiencies Foundation NZ	✓		
Learning & Behaviour Trust	✓	✓	✓
NZ Federation for Deaf Children	✓	✓	✓
Parent to Parent NZ	✓	✓	✓
Prader-Willi Syndrome Assoc NZ	✓		
Rett NZ	✓		
Tourette's Association NZ	✓		
Williams Syndrome Association	✓		

1 e.g., cerebral palsy, spina bifida, microcephaly
2 e.g., TBI, stroke, infections, poisoning, cancer
3 A major provider of support services to the intellectually disabled in NZ

Organisations were initially telephoned by the researcher and asked if they would consider a request to distribute the survey to their members. SWAN NZ (Syndromes Without A Name) and Tetrasomy 18p were not reachable, but all others agreed to read an email about the survey (see Appendix 2 for an example). Minor variations were made to reflect both the organisation being contacted, and any specific details which had arisen during the telephone conversation.

Respondents

The survey was completed by 98 respondents. This number was reduced by 21 due to people beginning the survey (spending less than a minute with the survey open) but not progressing beyond the questions as to whether their child had a serious brain injury/disorder.

Of the 77 respondents remaining, 73 were parents, (70 mothers and three fathers) three grandmothers and an aunt. Most respondents (79.2%, *n*=62) identified as Pakeha, 6.5% (*n*=6) and 3.9% (*n*=3) as Māori and Pacific Peoples respectively. Two others were of mixed ethnicities.

Not all of the 77 respondents chose to answer every question. Some respondents (47%; *n*=36) did not answer the question regarding the cause of the child's condition or said that they didn't know. Of those who did specify, (53%; *n*=41),[4] autism accounted for 81% (*n*=33), acquired injury, 12% (*n*=5) and genetics 7%; (*n*=3). Some respondents noted multiple diagnoses although the secondary causes primarily grew from the cause mentioned first, e.g., autism accompanied by dyspraxia, speech/global developmental delay and ADHD.

[4] One respondent noted autism with epilepsy.

Measures

Development of Survey

A wide range of measures was considered in the preparation of the survey. Initially, general and epilepsy-specific measures were considered but as the study broadened to include all causes of serious brain injury/disorder, other more general measures were also considered.

Several specific issues were of importance in the selection. Firstly, it was important to understand parental/caregiver QoL, but also to know what challenges or limitations each respondent's child lived with. Consequently, a measure of QoL and a measure of child health/capacity was sought. As it was unlikely that the children concerned would be able to complete measures, a parental/caregiver assessment of child health was necessary. It can also be argued that the parents' or caregivers' perception of their child's health may be more relevant to their QoL than an external, medical and psychological assessment.

Some publicly available measures, such as the Impact of Child Illness Scale (ICIS), the Impact of Pediatric Epilepsy Scale (IPES), and the Kingston Caregiver Stress Scale (KCSS) were rejected for being too brief or covering issues in insufficient depth. Others, such as the Neuro-QoL, and the Quality of Life in Epilepsy Inventory (QOLIE-89) were so lengthy that it was felt that they might discourage online participation. Several measures were designed with adults rather than children in mind (e.g., the Epilepsy Outcome Scale, EOS).

Ultimately, the Impact of Epilepsy on Quality of Life (IEQoL) measure (Cianchetti et al., 2015), and the Quality of Life in Children with Epilepsy (QOLCE55) (Goodwin et al., 2015) were selected as these could be modified fairly easily to include other forms of disability.

The strength of the IEQoL was that it explored parents' or caregivers' emotional and practical experience of caring for a child with a serious brain injury/disorder in relatively few questions. With only 13 questions, and using a Likert scale, the IEQoL covers interaction

with health providers, grief, perception of severity, concern for the child's future, family conflict, worry, effects on parents'/caregivers' work and relaxation, community connections, and finances. The wording of the IEQoL was adjusted to remove epilepsy-specific terms and generalise the questions to include neurological difficulties arising from any type of injury, illness or disorder.

The QOLCE55 was chosen because it examined the parent/caregiver's perception of the affected child's abilities and limitations comprehensively. The questions cover cognitive, social, behavioural, emotional and physical domains. Again, a Likert scale provided an easy response mechanism. For each domain, we also added an open-ended question where respondents could add detail about their child if they wanted to.

One concern about QOLCE55 was that it asks a respondent to assess their child against healthy children in 55 different ways. It could be dispiriting for a parent/caregiver to repeatedly think about and report limitations on their child. It was acknowledged that this could be the case and a question was added asking the respondent's state of mind after this section of our survey. Details of support services available if needed were listed. Eight open-ended questions then followed to gain detailed information about the personal experiences of our respondents. These could be answered at any length, and respondents could choose to answer some but not others.

The Survey

The survey opened with an information sheet introducing the researchers, explaining the study, and defining the characteristics of suitable respondents. These were: proficiency in English, New Zealand residency, and being currently engaged in raising a child with a serious brain injury or disorder. A copy of the survey is included as Appendix 1.

The term "serious brain injury/disorder" was chosen in order to clarify that respondents were eligible to complete the survey regardless of the cause of their child's

condition. The phrase was defined in the information sheet as meaning a condition "which is likely to have long-term or permanent effects which significantly affect a child's functioning in at least one of the following areas: cognitive, emotional, behavioural, social or physical. The injury or disorder may be genetic, or may have resulted from an accident or illness, or as a side-effect of medical treatment."

In the responses to the survey, we found that not all respondents were happy with this choice of terminology. It is difficult to identify a term which covers the status of all the children we sought to reach, without being at least partially inaccurate or perceived as stigmatising for some children. With ASD in particular, even the term "disorder" was not welcome to those who view the condition as a difference, rather than a disability. In retrospect, "serious brain injury/disorder/difference" may have been a better choice.

In total, the survey consisted of the following sections:

- Consent and introductory questions
- Impact on the family
- Child's health and wellbeing
    - Cognitive functioning
    - Emotional functioning
    - Behaviour
    - Social functioning
    - Physical functioning
- Written response section
    - Cause of injury/disorder
    - ACC status
    - Challenges
    - Forms of support
    - Public understanding

The survey was completed anonymously online. No identifying data was sought, and respondents were informed that any data they provided in written answers would be

anonymised before analysis. Those respondents who were interested in receiving a summary of the research findings were asked to provide an email address, but this was stored separately from the main data and was not connected to the specific response it had come from. Respondents were advised that the survey was likely to take at least 25 minutes to complete, if they did not choose to add extra detail on their own experience.

The survey was hosted on Qualtrix, on a Massey University server. The survey data could be accessed only by Harvey Jones, a School of Psychology programmer/analyst who manages student and staff use of Qualtrix, and by the primary researcher, using a specially created ID and password.

Respondents were advised that they could choose not to answer any question, and could leave the survey at any point. They were able to navigate back and forth in the survey if they wished to revise an answer.

Ethics

An ethics application was completed and submitted to Massey University Human Ethics committee, which approved the study and the survey (application NOR 19/34).

Data analysis

It was planned that both quantitative and qualitative analysis would be carried out on the survey data. However due to the unexpected length and detail of the free form responses, full qualitative aspect of the project was curtailed. This will be conducted separately in the future.

Chapter Six: Results

Prior to launching the survey online, the researcher completed it herself as a proxy for the fastest anyone was likely to finish it (given her familiarity with the content). All questions could be answered (without adding comments) in 20 minutes. Accordingly, respondents were advised in the information sheet that the survey was likely to take them a minimum of 25 minutes to complete, and as much as 45 minutes if they chose to add written responses. In reality however, some respondents took much longer, (range 52 seconds-5 hours 42minutes; mean 32 minutes). Many respondents wrote long passages in the sections inviting written response. In supervision it was decided that analysis of so much material was beyond the scope of a Master's thesis. Instead, quantitative results are reported for each hypothesis in this chapter, with selected examples corresponding to some general themes (and sub-themes) presented relating to relevant hypotheses. More thorough analysis of the qualitative data will be conducted separately at a later date with a view to submission for publication.

It had been hypothesed that parents/caregivers would:

1. **Feel their doctors had given them good information.**

Although more (52.6%; *n*=40) felt that what their doctors had told them about the nature and future of their child's brain injury/disorder seemed sufficiently clear, a considerable proportion disagreed (47.4%; *n*=36). One respondent did not answer the question.

2. **Consider that any gaps in information provided arise from limited current knowledge about a disorder and its impacts, rather than from poor communication by doctors.**

There was a 40% response rate to this question, with 23.4% of the full sample (58% of those who responded [*n*=18]) thinking that doctors lacked clarity, while 16.9% of the full sample (42% of those who responded [*n*=13]) thought it was due to limited knowledge.

3. **Report sorrow about their child's condition and worry for their future.**

All but three parents/caregivers who responded reported some degree of sorrow. This ranged from 32.5% (*n*=25) who reported "extreme" sorrow, 41.6 (*n*=32) "considerable" sorrow and 13.0% (*n*=10) who reported "mild" sorrow. One respondent did not answer the question. Further, all respondents worried about the child's future, 79.2% (*n*=18) "a lot" and 16.9% (*n*=18) "moderately".

4. **Regard the condition as being at least moderately serious**.

This hypothesis was confirmed with 89% of parents (*n*=63) stating that they considered their child's condition to be at least moderately serious, ("moderately serious", 32% [*n*=20] and "very serious" 68% [*n*=43]). Three respondents did not answer the question and 14% [*n*=11] people considered it "not too serious" or not serious.

5. **Report significant deficits in their child's cognitive, social, emotional and physical function**

The results for this hypothesis are arranged separately for each of the above functions. Each table of quantitative results is followed by a table of representative comments. (As a consequence, the results for this hypothesis cover several pages.)

Cognitive

As shown in Table 2, more respondents reported that their children had frequent difficulty with following complex instructions and with problem-solving than with more basic tasks such as following simple instructions or remembering people's names.

As also shown in Table 2, a high proportion of respondents did not answer one or more of these questions. Comments indicate that some respondents have never seen their child attempt to exercise some of these skills, because of the nature of their condition.

Table 2

Effects of Condition on Child's Cognition

Cognitive Problems	Percentage of Respondents Endorsing					
	Very Often	Fairly Often	Sometimes	Almost Never	Never	Not Applicable/ didn't answer question
Following complex instructions	39.8	19.4	10.2	1.0	1.0	28.6
Reasoning & problem solving	34.7	20.4	14.3	3.1	1.0	26.5
Planning & decision making	34.7	18.4	14.3	4.1	0	26.5
Concentrating on task	33.7	19.4	15.3	6.1	0	25.5
Concentrating on reading	31.6	13.3	11.2	7.1	4.1	32.6
Keeping track of conversations	30.6	16.3	16.3	3.1	4.1	29.5
Writing	29.6	16.3	8.2	4.1	3.1	38.8
Reacting slowly	28.6	21.4	17.3	5.1	1.0	26.5
Remembering things	28.6	14.3	14.3	9.2	4.1	29.6
Attending to activity	28.6	25.5	17.3	2.0	0	26.5
Understanding instructions	23.5	21.4	16.3	7.1	2.0	29.6
Remembering where put things	22.4	11.2	21.4	13.3	2.0	29.6
Remembering what has been told	22.4	18.4	22.4	6.1	1.0	29.6
Finding correct words	22.4	14.3	18.4	9.2	2.0	33.7
Doing one thing at a time	21.4	20.4	16.3	8.2	3.1	30.6
Following simple instructions	18.4	17.3	26.5	6.1	2.0	29.6
Speaking	18.4	10.2	17.3	12.2	12.2	29.6
Understanding what has read	16.3	9.2	18.4	10.2	1.0	34.9
Remembering people's names	15.3	5.1	23.5	15.3	6.1	34.7
Forgetting something planned	14.3	5.1	16.3	14.3	4.1	45.9

Table 2A

Representative Comments on Cognitive Issues

Cognitive Problems
Delay
2-3 years behind peers.
About to book in for cognitive testing to assist with schooling in case there are better learning strategies we can use that will make learning at school easier.
Is only saying a few words but has total understanding of what is said around him and to him- does simple signing and pointing at word picture book.
My child is ASD with global developmental delay. He has delayed verbal skills and struggles to follow instructions if they are too fast or too long or use complex language.
Non-Verbal
I put not applicable on a lot of these questions as our child is nonverbal and can't read or write. My child can however, understand alot of what is being said, but cant follow instruction unless its one or two words, and needs to consistently be kept on track.
My son has ASD and ADHD. He is considered nonverbal but can say many words. He can spell and say any word he can spell. He doesn't really use spoken language. We have no idea how much he can read. He spends hours looking through chapter books, so maybe he can read or maybe he just likes the letter patterns.
With our son's ASD diagnosis, he also received a diagnosis of speech delay. While his speech is getting clearer, a lot of what he wants to talk about are about the things that interest him (escalators, game shows, numbers). When it comes to instructions, we have to keep those very short & very direct, & only 1 instruction at a time (eg: pick up your rubbish. Now put in the bin). His ECE center have also said that they struggle to get our son to focus or to follow instruction, esp if he is very focused on something he is enjoying. While, at times, this can be frustrating, we also know that this is how he is wired & we have to take it a bit slower than normal.
Concrete thinking
My child tends to see the world very literally and has trouble understanding things like sarcasm, teasing, and hyperboles. He needs time to process what has been said to him, and often asks me once we are home what someone was asking or telling him. I break concepts down into easy chunks for him, but many people in his life do not do this. He struggles to feel accepted by extended family and friends due to this.
He is highly distractable & is unable to do any schoolwork without constant re-direction from a teacher. He often does not register what people are saying to him. When overwhelmed he will become non-verbal & unable to communicate.
Our son is doing well with his cognitive function but his processing time takes longer than the average neurotypical child of the same age. He understands and comprehends well but depending on other physical symptoms such as sensory stimuli, anxiety, restlessness, illness etc these all impact on his ability to cognitively process things and successfully complete them within a environment that is suited to neurotypical children and adults. He copes extremely well in retrospect. Takes it all in but may not be able to process it all as expected depending on the environment and how he is feeling.
We have learnt to be very patient and go at [her] speed otherwise there are meltdowns.
Treatment
The child Psychologists we have seen have both minimised any issues we have raised and treated us as if we were being helicopter parents. Originally my son was diagnosed with APD but this has now been revoked with more comprehensive tests pointing to Autism.
There is no funding for beneficial or alternative therapies. Often this can provide comfort and slight change in our son's behavior but it comes at a cost, sadly low income families would not be able to afford it.
With family and school support my daughter’s life at school has improved. As a single mum I make sure I attend ALL her semester planning sessions so I know upfront what is ahead for her and can conduct a good conversation with her if there are questions (these are guaranteed from her).

Social, Emotional and Behavioural Problems

Ratings of social, emotional and behavioural problems associated with the condition that their children presented with are shown in Table 3, and the associated comments made are shown Table 3A. Issues concerning frustration and isolation were rated as the most frequent problems, with 53.2% of respondents reporting that their children felt frustrated very often, and a further 16.9%, fairly often.

Table 3

Ratings of Social, Emotional and Behavioural Problems

Social, Emotional & Behavioural Problems	Percentage of Respondents Endorsing					
	Very often	Fairly Often	Sometimes	Almost Never	Never	Not Applicable/ didn't answer
Felt frustrated	53.2	16.9	18.2	1.3	0	11.7
Limited social activities	49.4	28.6	7.8	1.3	1.3	13.0
Made it difficult to keep friends	48.1	15.6	18.2	2.6	1.3	14.3
Demanded lot of attention	41.6	24.7	16.9	2.6	1.3	13.0
Angered easily	40.3	19.5	16.9	10.4	1.3	11.7
Was socially inappropriate	39.0	24.7	19.5	2.6	2.6	11.7
Led to isolation from others	37.7	24.7	22.1	2.6	1.3	11.7
Affected social interactions	35.1	26.0	19.5	5.2	1.3	13.0
Limited social activities	31.2	26.0	15.6	11.7	3.9	11.7
Limited leisure activities	29.9	27.3	26.0	1.3	1.3	14.3
Worried a lot	28.6	23.4	18.2	7.8	1.3	21.0
Felt nobody understood him/her	28.6	23.4	16.9	5.2	1.3	24.7
Felt excited or interested	27.3	33.8	29.0	2.6	0	13.0
Felt pleased about achieving	20.8	26.0	32.5	7.8	0	18.2
Felt happy	19.5	29.9	35.1	3.9	1.0	11.7
Hit or attacked people	19.5	14.3	23.4	11.7	19.5	11.7
Swore in public	16.9	6.5	15.6	15.6	19.5	27.8
Been frightened of others	15.6	16.9	19.5	16.9	13.0	17.2
Was obedient	10.4	32.5	35.1	9.1	1.3	11.7
Felt valued	7.8	24.7	35.1	3.9	0	28.6
Wished he/she were dead	5.2	6.5	11.7	15.6	24.7	36.4
Felt no one cared	3.9	10.4	26.0	19.5	5.2	25.1

Again, the comments indicate that some respondents feel unable to assess their child's emotional experience with any degree of nuance, because of communication difficulties. A number of comments reflected a respondent's belief that a given concept – for example, wishing oneself dead - was beyond their child's capacity to consider.

Table 3A

Representative Comments on Social, Emotional and Behavioural Problems:

Social Problems
Limited Understanding
Our daughter has a limited understanding of social situations, she easily gets upset and frustrated if she feels out of control.
With all the skills and understanding he has of his situation social interaction is difficult.
He gets really frustrated when he can't keep up with his peers or doesn't understand what's happening socially. He will give up on things easily and call himself names (he hears this from other kids).
Friendships
Finds it hard to make friends.
It's hard because he doesn't really have any friends.
Need for Routine
Would rather stay at home if she had the choice. Will only go put on her own terms. When we get into a social situation it heightens her anxiety and the resulting panic attack/meltdown make social situations very difficult with swearing screaming and physical attacks all possible. Admittedly she is recognising when she is having trouble and coming to me to for help but is still having difficulty self regulating.
My son doesn't like to do anything out of routine - so he goes to school and comes home, then on weekends wants to stay home as well. We have tried joining him to after school activities and inviting friends over, however he struggles with the social interaction (Understanding what people are asking him to do mainly) and often ends up upset. Once he becomes discouraged it is incredibly difficult to re-engage him. At this stage, he is no longer involved in after school activities and does not have friends over to play.
Fatigue
It takes a lot of effort during social interactions and need to be spread out to recover.
He doesn't do after school activities because he is so tired from keeping it together all day. We often have to say no to anything after 3pm to avoid meltdowns even on the weekends. He had a public meltdown last week which was very frightening for our friends neurotypical daughter. He didn't hurt anyone but she was scared of the intense reaction. He also doesn't play games (like tag) with the other kids during breaks at school because he doesn't understand the rules.

Emotional Problems
Anxiety
Anxiety is the main issue with our son's emotional functioning. When he is anxious he can feel things are really tough and it's hard to see him so concerned about things especially his future and growing up.
My child does not understand many of these emotions and would not be able to verbalise them to you if he felt them anyway, I'm pretty sure he has anxiety but he doesn't know how to explain the feelings.
Our child seems to be a fairly happy child most of the time but can have some anxieties in certain situations.
Can have melt downs over small things eg a small cut on foot

Child can't explain feelings
Can only answer based on the emotions and behaviors displayed. Child does not have the comprehension to explain whether they feel valued or cared about.
It's very hard to answer the 'how they feel' questions when my child can't tell me how they feel.
It's hard to tell as, like I said before, with the speech delay, our son finds it hard to express himself. We do use NZSL to communicate basic words with him, but more often than not, we are the ones giving him the words to express how he is feeling in that moment. We also know that he LOVES praise & you can see it with the smile on his face or the cheeky grin he will flick you.
No idea on the more complex emotions. I don't think he knows about "dead" as a concept. I hope he feels loved. We try to show him, but he may not.
Need for praise
So much of her emotional wellbeing tells on my building her up. She finds it hard to recognize good things about herself.
The concept of feeling valued is beyond my daughter.
The feeling of value and caring are school based only. Not how he feels at home with me.
We constantly have to reassure our son he is doing well, and that we are proud of him. He asks frequently throughout the day, and is constantly needing validation to know his worth and that he is loved.

Behavioural Problems
Most of his aggression is directed and at his immediate family. He keeps it together at school and with others
Child is extreme - either super good, helpful and pleasant or having a meltdown, sweating, hitting and acting up
Swearing is a weird choice. I don't think he knows about swearing. He loves to say "fuckem". But when he is truly upset he will say things like "thanks Franklin". Which is his swear word but most people have no idea.
Swears all the time at us - physically threatens my husband, gets angry 😠 so fast and damaged door by kicking it.

Physical Problems

Ratings of physical problems associated with the condition that their children presented with are shown in Table 4, and the associated comments made are shown Table 4A. In this table, for the first question, "very often" indicates a limitation on a child's ability, whereas for all other questions in the table, "very often" indicates that the child is able to perform that activity in a manner similar to his/her peers. In other word, the first question is negatively worded, while the rest are positively framed.

High numbers of respondents said their children were never, or almost never able to independently go swimming (42.9%) or play other sports (45.5%). Given some of the written responses, the results for going to parties (53.2% "never", 15.6% "almost never") may reflect social rather than physical limitations.

Table 4

Ratings of Physical Problems

Physical Problems	Percentage of Respondents Endorsing					
	Very often	Fairly Often	Sometimes	Almost Never	Never	Not Applicable/ didn't answer
Needed more supervision than other children his/her age?	41.6	20.8	11.7	10.4	5.2	10.4
Played freely in the house like other children his/her age?	16.9	36.4	26.0	6.5	2.6	11.7
Played freely outside the house like other children his/her age?	11.7	18.2	31.2	10.4	15.6	13.0
Been able to do the physical activities his/her age peers do?	9.1	22.1	31.2	14.3	11.7	11.7
Gone swimming (i.e., swam independently)?	3.9	18.2	13.0	11.7	31.2	22.1
Participated in sports activities (other than swimming)?	3.9	10.4	22.1	18.2	27.3	18.2
Played with friends away from you or your home?	2.6	1.3	14.3	18.2	46.8	16.9
Stayed out overnight (with friends or family)?	1.3	5.2	9.1	11.7	54.5	18.2
Gone to parties without you or without supervision?	1.3	2.6	7.8	15.6	53.2	19.5

Table 4A

Representative Comments on Physical Problems:

Physical Problems
Child's motor skills/co-ordination etc
My child has difficulties with co-ordination, balance, and many sensory inputs such as certain clothing, the feeling of sweat, being out of breath etc. Due to this he actively avoids physical activity and needs a huge amount of emotional support and encouragement from myself or my husband just to go for a walk.
To take the kids to splash planet… would need to be in wetsuits because they can't regulate their temp very well and life jackets.
Difficulty of making it work for parents/caregivers
It's heart breaking how hard it is to get out. In the school holidays her cousins came to her and had a sleepover. She was so happy. They snuck up late and had a party. She did dancing lying down [in] her bed. It's such a rare event because it takes so much to make it happen.

Physically, our son is fit & can do everything any child can do. Probably more, considering he has tried to escape from kindy twice. As for time away from us, esp. overnight, we are struggling with his sleep at this stage, so not something we have considered.
My son needs constant supervision at all times anywhere he goes, there are only 2 people in his life who provide full time care for him and that is Mum and Dad.
Large groups that my kids will weave their way through and I'm left behind. Have to carry 20 kg youngest as he can't walk far with underdeveloped muscles.
Positive experiences
Involved in competitive gymnastics classes which has therapeutic benefits meeting sensory seeking needs.
Riding for Disabled was great...does that count as sport..I think so...
He is very capable and able. Especially in swimming. He is just still at an age where we supervise all our children swimming or in water. Very very confident in water and diving. Loves the beach and snorkeling.

Respondents were also asked to rate the overall impact of specific problems in social functioning *over the past four weeks*. As shown in Table 5, 48.1% of respondents reported that their child "very often" had difficulty keeping friends, while fewer than 4% said this was never, or almost never, a problem. This result, in combination with high results for limiting social activities and interactions, and isolating the child, highlights how central the problem of not meeting others' social expectations is for the children and by extension, for their families.

Table 5

Overall Impact of Condition for Child over Past Four Weeks

Problem	Percentage of Respondents Endorsing					
	Very Often	Fairly Often	Sometimes	Almost Never	Never	Not Applicable/ didn't answer
Difficulty keeping friends	48.1	15.6	18.2	2.6	1.3	3.9
Isolated from others	37.7	24.7	22.1	2.6	1.3	1.3
Affected social interactions at school	35.1	26.0	19.5	5.2	1.3	2.6
Limited child's social activities	31.2	26.0	15.6	11.7	3.9	10.4
Leisure activities	29.9	27.3	26.0	1.3	1.3	3.9
Frightened other people	15.6	16.9	19.5	16.9	13.0	18.2

Table 5A shows the comments made by respondents on the overall impact of specific problems above in social functioning over the past four weeks. There were fewer (25%, *n*=18) comments made in this section, with most recognising the difficulties of socialising and the limits that this placed on children's activities. There was comment on how little was available for the children to get involved with, and that what was available was expensive.

Table 5A

Representative Comments on Overall Impact of Condition for Child over Past Four Weeks:

Overall Impact
Child's options directly limited by condition
He doesn't do after school activities because he is so tired from keeping it together all day.
A lot of activities he would enjoy don't happen due to one aspect not sitting well with him - new place, strangers etc.
He will not understand instructions verbally.
Social cues are not his thing. He "babies" a lot of children his age because he is twice their size. Can be frustrating for kids trying to play with him.
He attends playgroup, picks up and drops off sister at kindy, goes to kindy gym and music. But he can't keep up with the others. He tries so hard though!
With sensory issues in place…social interactions are almost non-existent.
My child has difficulties with co-ordination, balance, and many sensory inputs such as certain clothing, the feeling of sweat, being out of breath etc. Due to this he actively avoids physical activity and needs a huge amount of emotional support and encouragement from myself or my husband just to go for a walk.
Child's options limited by external factors
There are very few activities for intellectually disabled children to do, and what there is, is very expensive.
Child's options limited by others
His peers at school know him and most of the time are accepting and inclusive, but not to the point he gets invited anywhere or to parties etc.
T is 10 years old & has only ever been invited to one birthday party & on one play date. Parents avoid him & will not have him over to play.
Positive experiences of physical activity
Riding for Disabled was great
Involved in competitive gymnastics classes which has therapeutic benefits meeting sensory seeking needs

6. **Report negative effects of raising a child with significant brain disorder/injury on family life, levels of conflict and apprehension, work life, social life, extra-family relationships, and finances, with more negativity in those who report more extreme deficits in their child's functioning**

While Table 6 below shows "apprehension about what is happening" to be the most common effect reported *a lot*, when those reporting *a lot* and *moderate* negative effect are considered together, 89% of respondents rated apprehension highest, followed by less enjoyment of leisure activities at 84%, impaired relationships at 81%; economic problems at 78% and apprehension and worry at 74%.

Table 6A shows some of the comments made by respondents on the overall negative impact on family quality of life. In total 43 (56%) respondents commented on these aspects.

Table 6

Percentage of Respondents reporting Negative Effects on Family Life

Effects	Percentage of Respondents Endorsing				
	A lot	Moderate	A little	No	Missing
Apprehension about what is happening	58.4	35.1	2.6	--	3.9
Less enjoyment of leisure activities	55.8	26.0	11.7	2.6	--
Apprehension and worry	42.9	31.2	13.0	9.1	3.9
Changes to employment	46.8	18.2	13.0	7.8	14.3[1]
Tension and/or conflict among family members	42.6	31.2	13.0	9.1	3.9
Economic problems	41.6	36.4	11.7	6.5	3.9
Impaired relationships outside immediate family	37.7	44.2	11.7	2.6	3.9

1. Not applicable as not working outside the home

Table 6A

Representative Comments on Negative Effects on Family Life

Pressure on family relationships
After 1 year of uncontrolled seizure, constant hospitalisation, my husband left unable or unwilling to keep going. For the past 18 yrs. I have been a solo parent and although it has been extremely difficult I have also had many highs and have a beautiful young man who is the light of my life. Yes things are up and down but that's just our life. I can't change his health or injury with great support from family and friends we have made the most of things.

Our family is falling apart. My husband has developed addiction problems because he hasn't faced the trauma and grief from raising our daughter. I now have parenting and protection orders and am raising 4 children, 1 severely disabled solo. Despite going through abuse and all of this, we do not qualify for any additional support. My daughter requires two person transfers yet we are not funded for them. I have to employ manage and train all her carers yet I have not been trained how to do this.
One of the greatest difficulties we have is in the sibling relationship. We have non-identical twin boys, one of whom had Autism spectrum disorder and a intellectual disability. There can be tension in their relationship due to disagreements. Even just little jokes can leads to meltdown in my child with autism. His brother ends up feeling anxious and guilty. It can be hard for my son to see that his brother is being kind and gentle with him, or trying to help him.
Isolation
We don't go out as much as we used to due to our son's sense of being overwhelmed in certain situations. We can prep & remind & have everything we need to go out, but some days it really is too hard. If we absolutely have to go out, we worry about if we will have a meltdown, will he run off from us, will the environment be too stressful & overwhelming. We literally have to say no to things some times because the fear & the what if's are too much to deal with.
It makes it hard to go on family outings as he can get overwhelmed or try to run away.
I think the hardest thing is lack of community understanding. I wish people would be quicker to lend a hand rather than judge. For the longest time I isolated us because of public comments when we were out. I don't do that anymore. I stand up for him more now in public but I wish I didn't have to because its tiring on top of everything else.
Change to Employment
I eventually had to give up my career to care adequately for her so all aspects of my life changed. You certainly find out who your friends are when one has an autistic 2 year old in tow.
The biggest barrier has been financial, losing a full time wage means you can't better your living situation without considerable support.
Our child has nonverbal ASD. I (mum) cant work as there is no after school care or holiday programmes available.
Worry about Future
I am worried for his future and what will happen when my husband and I aren't around, should he need lifelong care.
I cant seem to shake the mum guilt that i did something to cause these issues. And I constantly feel guilty I can't help him more. And worry ALL the time about his future!!
The stress on our family is immense and sadly my husband hasn't coped. I'm really worried about our future. What if I get hurt? Who will lift my daughter.
Lack of Support
It is the waiting for the doctors to make up their mind if my son has autism 2 year wait since his name was put on the list He also has a range of other issues but to them its in the grey area so he doesnt get funding for being at school even though he needs a teacher aid.
My whole life has changed emotionally, socially and financially. It is a daily battle for support services and it is very isolating and tiring.
Waiting for professional help, intervention and support to arrive was so slow and very minimal especially at a young age for a child on the spectrum.

7. Report lower impact on some of these quality of life features if their child is being funded under ACC

It was not possible to make this comparison as there were so very few children who had sustained brain injury through accident. Many people did not answer the question.

8. **Report higher levels of negative impact if their child's disorder has caused sudden deterioration or loss of function, as opposed to having been chronic from birth (for example, an otherwise healthy child experiencing anoxia from a swimming accident, rather than as a birth injury).**

It was also not possible to test this hypothesis owing to most children having autism.

9. **Occasionally identify positive effects that have come from the experience of living with a child with serious brain injury/disorder, possibly in terms of perspective, valuing small successes, or building stronger relationships within the family.**

This hypothesis was assessed with a single question, i.e., *has your child's disorder or the experience of dealing with the disorder produced any positive results for your family?* Overall, 85.1% of respondents noted some positive results for the family from having a child with a serious brain injury/disorder, with 13% finding that it brought "a lot" of positive effects, 31.2% endorsing a "moderate" degree of positive effect, a 37.7% "a little" positive effect for the family. Still 14.3% of respondents noted no positive effect at all.

The comments made regarding the positive effects of living with a child with severe neuropathology are shown in Table 7A.

Table 7A

Representative Comments on the Positive Effects of Living with a child with Serious Brain Injury/Disorder

Perspective on Life
It changes our perspective on what is priority in our life.
He's taught me so much about what matters in life and how to he kind to myself and others. I have grown into a better version of myself having to learn to parent a small person who doesn't fit into the worlds mold.
Patience
We have learned to be patient and how to remain calm when everything goes bad.
As parents we have learned more patience and understanding. His siblings are learning to be kind and inclusive of neurodiverse people.
Learnt patience and other parenting techniques that are less common.
Tolerance, understanding, I've learnt a lot from my child.
Raising a child on the spectrum has rebuilt and reshaped who I am as a person. I have learned qualities that many people either forget to practice or simply take for granted, qualities such as patience, kindness, peace, empathy, acceptance, balance (mind, body, soul) - activism, advocacy, honesty.

Strength
It has taught me to be stronger for my son and to fight for what he deserves in life.
We have had to be proactive in learning about how to parent creatively in our situation which ultimately has benefitted the rest of the family.
We have become a tight supportive family due to the "battles" we have forght for fairness and support in education, and in the health system
Family closer
Understanding each other, triggers, and being able to find ways that allow everyone in the family to be catered to. Less conflict.
We find a lot of joy in small things that other families take for granted. I cried happy tears the first time he pedaled a trycicle and now to our surprise he is reading and enjoying books.
Has made both of our children very aware of compassion & understanding. They are both very self aware and know their emotions and how to express them safely and openly
We know who our real friends are
He has also brought me into a very cool community of parents and families who are experiencing life in a similar way.
Has made as closer as a parental unit to come together to help our son as much as we can. Also majorly grown my relationship with my parents who are always there for a chat and to take Ryan off our hands for a break
Chain reaction, one diagnosis of child led to fathers diagnosis, and later brothers. Awareness hs been huge.
It has helped with my husband who I always thought was on the spectrum and now he acknowledges he is like our son. Helped immensely in dealing with some of the negative behaviors he has. (On the negative it explains why my husband is not flexible in his own ideas and behavior too)

10. **Report negative emotions, such as sadness and frustration, after completing the survey**.

Again, this hypothesis was assessed through a single question i.e., *has completing the survey made you feel any particular emotions*? Many respondents (63% *n*=49) reported feeling emotional after completing the survey, with *n*=43 (59%) making specific comments. Of these respondents *n*=17 (40%) began their comment with the word *sad/sadness.*

This question came at the end of the survey with most making strong comments about the effect that not only the survey, but the overall effect of having a child particularly with autism has on their family. The comments made regarding the effect on respondents of completing the survey are shown in Table 8A below.

Table 8A

Representative Comments on the Emotional Impact of Completing the Survey

Sadness, Depression & Despair
Always feels a bit sad when one compares kids to neurotypical kids, there is a grief that never leaves, even if you are proactive and fully accept your kids for who they are.

I feel incredibly sad for my son who struggles socially and is very lonely and isolated from his peers
Just upset at the severity of our situation at this stage
Made me realize how isolated I am. Feel quite sad that help is not easy to find
Sad at times that he cannot be fully accepted by society because he is so amazing but staunch in my love and acceptance of him.
Sad that other children and even parents aren't kinder. I wish schools and other adults did better at teaching their child to include and be patient with children like mine. I wish sports activities were also more inclusive because they don't want children like mine participating. He experiences rejection on a daily basis and he knows.
Sad. Sad that he can't have friendships like the rest of us. I should add at this stage that he will seek out his favourite people at school to play with if he wants to, but generally he seems to be happy in his own world playing his own solitary game...solitary to us' but in his mind he is playing with his friends from his favourite shows and that is real to him and it seems to satisfy him and make him very happy.
Depressed with reality
Anxiousness over his future and our coping with it all
I would say i feel melancholy. I am so proud of my son & what he can do & has achieved, but I also know how much hard work he is, how tired I can be at the end of the day, how frustrated I can get trying to understand his needs. Like any parent with a child with ASD, I worry about his future & how the wider world will accept his uniqueness. And how he will handle the challenges he will face. And lately, I have been craving having a free flowing conversation with my son, knowing that it might happen one day - or might not. It still pings when you hear others having that "How was your day?" "It was great Mum" conversation & i don't get that ... I might not. The what if's & how's can be very hard to deal with, even on the strongest of days.
Sadness and worry that he will never be accepted by his peers as "normal" Frightened he won't be able to live a "normal" life/job/career/partner/relationships Extremely anxious about what happens when his father & I can no longer care for him Happy that studies like this will help ease parents struggling and anxieties/worries in the future!
Lack of Resources & Understanding
Despondent. We try so hard to advocate for disability rights but it’s like banging our head on a brick wall. Sad. Our family is falling apart. We’ve only ever been given just enough support to scrape by day to day. It’s not about income it’s about having someone experienced, on the ground, able to takeover so we can have time to be, knowing our daughter is in safe hands having fun. Meeting the minimum needs is breaking families. Imagine if we were well supported then our family wouldn’t be spending taxpayer dollars on the family court process, shine, winz, etc. And the emotional toll it takes to advocate for those minimum needs is huge, we only got that because I spent 12 months advocating.
Angry at complete incompetence of govt and lack of support
We have tried so hard for our daughter, from an education system that had no clue to a mental health system that is overwhelmed to breaking point. She's such a wonderful person and it's heartbreaking that this is what she gets. She's entitled to more.
Proud that we have survived....so far!! .I feel like it's the two of us against the world.. My whole life changed at 50...@a time when I had my own health challenge of cancer. There is simply not enough support for families tho I ran a support group for families locally. .. but basically it's bloody hard...a survey like this just reinforced how hard it is...tho it was very well designed and easy to use..sometimes it's important to face how hard it is but also acknowledge how far we have come. So thankyou

Chapter Seven: Discussion

When initially planning this thesis, the intention was to develop a survey on quality of life that parents/caregivers of children with epilepsy could complete, which would be useful for the Wellington School of Medicine's project on epilepsy. That project moved on rapidly however, allowing insufficient time to develop and test a new survey. The epilepsy project leaders chose an existing measure, and our goal for this piece of research was revised to include the parents or caregivers of children with severe neurological conditions.

While the study attempted to reach parents/caregivers of children with any serious brain disorder or injury, far more responses were received from parents/caregivers of children with ASD than from parents/caregivers whose children had other injuries or disorders, put together. This may have been because more parents/caregivers of children with ASD join one of the support organisations approached to take part in the research, or there may be some other characteristic of these parents/caregivers which makes them more likely to respond to surveys. While extremely grateful for their willingness to participate, it was unfortunate that there were not more responses from parents/caregivers of children with other conditions.

This outcome meant that some between-group comparisons which had been planned were not possible, and of course, also meant that the results represent a sampling of the experience of only a sub-category of the group of New Zealanders whose children have serious brain injury/disorders.

The descriptions and comments made within the survey by parents/caregivers were of an unexpected depth and detail. Respondents spent a generous length of time on the survey (mean=32 minutes). Less easily measurable was the openness and vulnerability of many replies. This wealth of information would ideally have been analysed qualitatively using a

technique such as interpretative phenomenological analysis, but this was not possible within the scope of the current research study and will occur at a later date.

Implications of results

Slightly more than half the respondents felt they had received clear information about their child's condition and prognosis. This is a worryingly low level, in relation to a topic of such importance for both caregiver and child, and in light of Lee et al.'s 2009 finding that lack of support from medical professionals contributed to lower HRQoL. It falls far short of Old et al.'s 2011 finding that 91% of New Zealanders strongly agreed they expected doctors to be helpful sources of health education and advice (though of course, a measure of expectation is not equivalent to a measure of actual experience). While it is understandable that a parent/caregiver would receive insufficient information in cases where medical professionals have been unable to identify a diagnosis, this is the case for few of the respondents to our survey. It is concerning that parents/caregivers managing a child's condition as widespread as ASD should feel inadequately informed. The fact that slightly more respondents connected lack of clarity with doctors' communication than with global paucity of knowledge suggests that there is a place for continuing communications training for medical staff, as well as for ongoing research into the conditions affecting these children.

The State Services Commission's annual "Kiwis Count" report (2019) did show lower levels of satisfaction with medical professionals among disabled than among able-bodied respondents, so the outcome here may reflect that parents/caregivers of disabled children are similarly less satisfied with the service they and their children receive.

A large majority of respondents reported sorrow over their child's condition and saw it as a serious concern, and all had spent time worrying about the child's future. Like the families studied by Hickey et al. (2018), some respondents spoke of the "trauma" that had affected their families, rather than the child alone. All four elements Jordan and Linden

(2013) found in mothers of children with brain injuries – grief, exhaustion, anxiety and guilt - were specifically mentioned by respondents.

Some of the comments indicated that the worries were both immediate and long-term. One mother asked what would happen to her daughter if she, the mother, injured herself lifting the child single-handed. Another wondered what life-long care would be provided to her child when she and her husband died, which is in line with international research showing this to be a common concern (Marsack-Topolewski, & Graves, 2020), and also with a New Zealand study of parents of disabled adults (Thakkar, 2018).

A large majority of respondents viewed their child's condition as moderately or very serious, supporting hypothesis 3. Some parents/caregivers of children with ASD, who view the condition as not serious, or not very serious, passed comments indicating that ASD is a difference rather than a disorder or medical condition, in a manner similar to Armstrong (2010). Given that they also reported problems which seemed significant, it may be that they were making the point that it is the system which is a problem rather than the ASD, (cf. "Autistic Reader", 2016).

Respondents reported that their children were behind their peers in all the fields asked about: cognitive, social, emotional, behavioural and physical. The most frequently endorsed problems were the social, emotional and behavioural challenges the children experienced: 53.2% of respondents said their child "felt frustrated" very often; 54.5% reported their child had never stayed out overnight with family or friencds; and 68.8% said their child had never, or almost never, gone to a party unaccompanied by a parent/caregiver. In the cognitive domain, by contrast, the most highly reported item was that the child very often "had difficulty following complex instructions" (39.8% of respondents endorsing). The commentary provided underlined that most respondents were more concerned about the social limitations on their child that on his or her cognitive challenges. This may reflect a

sense that control over working on cognitive challenges lies within the family, but control over social inclusion does not.

Over 90% of respondents reported that their child's condition had had negative impacts on: family life, on levels of conflict and apprehension, work life, social life, extra-family relationships and finances. This fits with international findings by Bompori et al., (2014), Ozgur et al., (2018), and others.

The most highly endorsed impact for families was apprehension about what is happening currently, with 93.5% reporting that this affected them "a lot" or "moderately". Issues with relationships outside the immediate family had affected 81.9% "a lot" or "moderately", and 81.8% found their enjoyment of, or access to, leisure activities were reduced "a lot" or "moderately". Financial problems had impacted all but 10.4%.

As so few respondents were caring for children with conditions caused by injury and receiving ACC entitlements, it was not possible to assess whether funding from ACC has an impact on family QoL.

Similarly, there was insufficient data to assess whether family QoL suffers more when a child regresses than when a child has always been disabled.

In spite of the negative outcomes of having a child with a serious brain disorder/injury, 85% of parents/caregivers reported positive effects. These fell into similar areas to those found by Myers et al., (2009) including increased patience and compassion, greater understanding of others, closer family ties, appreciating the small things, and stronger parenting skills.

Respondents were moved by the experience of completing the survey. The most commonly mentioned emotion was sadness. This fits with findings in Lindblad et al. (2007) and Hickey et al. (2018).

The cause of the sadness may have been specific to focusing on the situation of their own child, or perhaps on reflection the whole experience of living with ASD is overwhelmingly sad for many people. Some of the comments provided by respondents suggest each of these possibilities:

> "The stress of accessing support at home and in the education system. The worry about whether I am doing the right things for him and my other typical child."
>
> "The frustration of not always knowing what he wants, or why he's having a meltdown, or why he is so hyped up."
>
> "Realising my son is getting further and further behind his peers."
>
> "Sadness and worry that he will never be accepted by his peers as "normal". Frightened he won't be able to live a "normal" life/job/career/partner/relationships."
>
> "My favourite mantra is 'I would not change my child for the world, but I will fight to change the world for him'. Society is becoming more aware but we still have a long way to go with acceptance and making sure the things are available to celebrate neurodivirsity in all its forms."

The survey and limitations

The survey itself performed well in some areas but could have been modified further. In particular, the sheer number of skills parents were asked to assess their children on was probably excessive for a survey seeking to identify trends rather than specific skill areas to be improved. For example there could have been five questions on physical functioning rather than nine, though this would have affected the psychometric properties of the underlying measures and made our survey less comparable to others using the same measures. Given that so many respondents felt sad after completing the survey, it is possible that the sheer number of questions unnecessarily exacerbated their unhappiness.

Word choice presented some challenges. While we included fluency in English as a criterion for participation, we wanted the survey to be clear to any reader.

The most challenging issue was how to describe the conditions affecting the children. We wanted to hear from New Zealanders raising children who had neurological effects which made their lives more difficult, and which were likely to persist. In many cases, this means children with disorders and/or injuries. We realised, however, that there is a range of views on how ASD, for example is described. While we chose "brain disorder/injury" for the survey, in the interests of clarity, more than one respondent did raise the point that ASD may be viewed as a difference rather than a disorder. In retrospect, it would have been better to use "brain disorder/injury/difference"and assign it an acronym. Similarly, one question referred to a child's "suffering" an injury or disorder, which struck at least one respondent as a confronting wording – a better choice would have been "affected by".

The study was limited by the paucity of responses from parents whose children were affected by conditions other than ASD.

Future research

Future research in this area needs both greater depth and width. Families raising children with other significant disabilities must be reached, and when common needs have been identified, detailed work will be needed to identify and implement precise, practical solutions which can improve the QoL of affected families.

Hindsight

In conducting this research, I have learned the difficulty of predicting who will respond to a survey, and how they will respond. If the list of organisations I contacted had not included Autism NZ, the responses received would have been too few to carry any

weight, and I might well have concluded that the survey itself was flawed in some way which prevented its eliciting useful responses.

I have been impressed and moved by the respondents' comments. Their eagerness to share their experience, and their willingness to lay bare their private pain speak to the paucity of opportunities this group of parents/caregivers have had to be heard. Several addressed this issue directly, even thanking us for the opportunity to share their experiences. One mother spent five hours with the survey open, and wrote extensive comments. I picture her leaving it repeatedly to answer the needs of her child and others, and returning over and over to paint a picture of her family life.

The abiding lesson of this research, for me, is that there are many families in New Zealand who lack the support needed to raise their children as they would wish, to make the most of their child's capacities and to enjoy their family life. These families' voices need to be heard, and heeded, much more widely.

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Appendix 1

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

School of Psychology

Information Page

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Survey on the experience of raising a child with a significant brain injury or disorder

Participant Information Sheet

My name is Julia Donovan. I am a Master's student at Massey University, and I am conducting a survey which may be of interest to you. I work in the community sector, with volunteers, and am interested in the complex challenges faced by New Zealanders who must shoulder greater caregiving responsibility than most of us do.

I am being supervised in my research by Dr Janet Leathem, who is both a professor in the psychology department at Massey University, and a practising clinical psychologist. Dr Leathem has extensive experience in researching neuropsychological issues in New Zealand, and decades of practical experience working with children and adults who have experienced brain injury/disorder.

You are invited to take part in research that aims to understand more about the experience of people in New Zealand raising a child with a serious brain injury or disorder. A serious brain injury or disorder is one which is likely to have long-term or permanent effects which significantly affect a child's functioning in at least one of the following areas: cognitive, emotional, behavioural, social or physical. The injury or disorder may be genetic, or may have resulted from an accident or illness, or as a side-effect of medical treatment. This is because we are interested in the shared experience of caring for a child who faces significant intellectual challenges, rather than in the specific causes of those challenges.

In particular, the survey examines how raising a child with a serious brain injury or disorder affects quality of life. Understanding any such effects is essential to ensuring that the best supports are made available to New Zealanders in this situation.

New Zealand residents who are proficient in English, and who are raising a child affected by a serious brain injury or disorder are invited to complete an online survey which will take

approximately 25 minutes, or perhaps as long as 45 minutes if a participant chooses to provide extended responses (this is optional). The first part concerns family relationships, work, social activities, relationships outside the immediate family, finances and emotional impacts. It also asks for the participant's assessment of the child's health and well-being. The second part is an optional section where participants can write about their experiences.

If you would like to participate, please click on the Survey button below to proceed to the survey. It will be available for 6 weeks between 11 October and 22 November 2019.

Your participation is completely voluntary. If you decide to participate, you can:

- be assured that your name or any identifying data will not be used, and anything you write will be anonymised before analysis;
- ask any questions about the survey by contacting Dr Leathem or Julia Donovan, whose contact information is provided below;
- skip any questions you do not wish to answer, or leave the survey without completing it;
- be given a summary of the project findings when it is concluded.

Thank you for reading this information sheet and considering participation in this interview. Please contact Julia Donovan or Janet Leathem if you have any additional queries.

Contact information

If you have any questions or queries regarding this project, please don't hesitate to contact the following:

Researcher
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This project has been reviewed and approved by the Massey University Human Ethics Committee: Application NOR 19/34

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor Craig Johnson, Director (Research Ethics), telephone 06 356 9099, extn 85271, email humanethics@massey.ac.nz.

Consent

Respondent Consent

Thank you for participating in this survey.
You have the right to decline to answer any particular question, or to decide not to continue at any point.

I have read and understood the information sheet for this study and consent to collection of my responses.
(Please click on the 'Yes' choice if you wish to proceed.)

- ○ Yes
- ○ No

Brain injury

Our questions may not cover every issue that has been important for you, your child, and your family. Comment boxes are placed at the end of sections for you to add further thoughts about your experience. Please feel free to use them, or skip them, as you prefer.

Does your child (or a child for whom you provide care) have a serious brain injury or disorder?

- ○ Yes
- ○ No
- ○ Uncertain

If uncertain, please explain.

Please indicate your relationship to the affected child:

- ○ Father
- ○ Mother
- ○ _____ Other (please specify)

Which ethnic group do you belong to?
(If your answer includes more than one ethnic group, please indicate which one you consider to be your primary ethnicity).

- ○ New Zealand European/ Pākehā
- ○ New Zealand Māori
- ○ Pacific Islander
- ○ Asian
- ○ _____ Other

At what point did you become aware that your child had a serious brain injury/disorder?

- ○ At or before birth
- ○ By 3 months of age
- ○ By 1 year of age
- ○ By five years of age
- ○ Between 5 and 10 years of age
- ○ Over 10 years of age

Were the effects of the injury/disorder always present, or did they occur as a result of a childhood accident or illness?

- ○ Always present
- ○ Result of childhood injury or illness
- ○ Not sure

Does what your doctors have told you about the nature and future of this brain injury/disorder seem sufficiently clear?

- ○ Yes
- ○ No

Does the lack of clarity about the nature and future of your child's brain injury/disorder result from ...
(please select as many as apply)

- ☐ Poor explanations or limited clarity on the part of the doctors
- ☐ The medical world having limited current knowledge of the injury/disorder
- ☐ Something else

If something else, please explain.

Family Effects

In this section of the survey, please consider the entire time since your child was diagnosed.

Has the knowledge that your child is suffering from this injury/disorder caused you sorrow?

- ○ Extreme
- ○ Considerable
- ○ Moderate
- ○ Mild
- ○ No

Does the injury/disorder your child is suffering from seem to you something?

- Very serious
- Moderately serious
- Not too serious
- Not serious

Please select the choice which applies to you.

	A lot	Moderately	A little	Not at all
Does the injury/disorder your child is suffering from make you worry about his/her future?				
Has your family life changed for the worse?				
Is there more tension and/or conflict among family members?				

	A lot	Moderately	A little	Not at all
Are you more apprehensive (that is, do you worry more) about what is happening?				
If you work outside the home, or are self-employed, has your child's injury/disorder caused changes for the worse in your work?				

Has your child's injury/disorder worsened your non-working activities (pastimes, hobbies, vacations, etc.)?

- A lot
- Moderately
- A little
- Not at all
- Not applicable

Please select the choice which applies to you.

	A lot	Moderately	A little	Not at all

	A lot	Moderately	A little	Not at all
Has your child's injury/disorder worsened extrafamily relationships (friends, social groups, etc.)?	○	○	○	○
Has your child's injury/disorder caused economic problems?	○	○	○	○

	A lot	Moderately	A little	Not at all
Has your child's injury/disorder, or the experience of dealing with the injury/disorder, produced any positive results for your family?	○	○	○	○

Please explain or describe any of these positive results associated with your family.

If you would like to make any further comment on the effect of your child's injury/disorder on your life, please do so here:

Child's health and wellbeing

This section asks about your child's health and well-being. Please answer each question by clicking the appropriate button. Certain questions may look alike but each one is different. Some questions may ask about problems your child does not have. Please try to answer each question as it is important for us to know when your child does not have these problems. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can.

For this section of the survey, please think about the LAST FOUR WEEKS only.

Cognitive Functioning

Your child's COGNITIVE FUNCTIONING

The following questions ask about some problems children have with concentrating, remembering, and speaking.

Compared to other children of his/her own age, how often during the past 4 weeks has your child ...

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
had difficulty attending to an activity?	O	O	O	O	O	O
had difficulty reasoning or solving problems?	O	O	O	O	O	O
had difficulty making plans or decisions?	O	O	O	O	O	O
had difficulty keeping track of conversations?	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
had trouble concentrating on a task?	O	O	O	O	O	O
had difficulty concentrating on reading?	O	O	O	O	O	O
had difficulty doing one thing at a time?	O	O	O	O	O	O

Compared to other children of his/her own age, how often during the past 4 weeks has your child ...

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
reacted slowly to things being said and done?	O	O	O	O	O	O
found it hard remembering things?	O	O	O	O	O	O
had trouble remembering names of people?	O	O	O	O	O	O
had trouble remembering where he/she put things?	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
had trouble remembering things people told him/her?	O	O	O	O	O	O
had trouble remembering things he/she read hours or days before?	O	O	O	O	O	O
planned to do something then forgot?	O	O	O	O	O	O

Compared to other children of his/her own age, how often during the past 4 weeks has your child ...

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
had trouble finding the correct words?	O	O	O	O	O	O
had trouble understanding or following what others were saying?	O	O	O	O	O	O
had trouble understanding directions?	O	O	O	O	O	O
had difficulty following simple instructions?	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
had difficulty following complex instructions?	O	O	O	O	O	O
had trouble understanding what he/she read?	O	O	O	O	O	O
had trouble writing?	O	O	O	O	O	O
had trouble talking?	O	O	O	O	O	O

If you would like to make any further comment about your child's cognitive functioning, please do so here:

Emotional Functioning

Your child's EMOTIONAL FUNCTIONING
Below is a list that describes how your child might feel in general.

Compared to other children of his/her own age, how often during the past 4 weeks has your child ...

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
felt down or depressed?	O	O	O	O	O	O
felt happy?	O	O	O	O	O	O
wished he/she was dead?	O	O	O	O	O	O
felt frustrated?	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
worried a lot?	O	O	O	O	O	O
felt confident?	O	O	O	O	O	O
felt excited or interested in something?	O	O	O	O	O	O
felt pleased about achieving something?	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
felt nobody understood him/her?	O	O	O	O	O	O
felt valued?	O	O	O	O	O	O
felt no one cared?	O	O	O	O	O	O

If you would like to make any further comment about your child's emotional functioning, please do so here:

Child's Behaviour

Your child's BEHAVIOUR.
Below are statements that describe some children's behavior. Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

Compared to other children his/her own age, how often during the past 4 weeks does each of the following statements describe your child?

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
He/she was socially inappropriate (said or did something out of place in a social situation).	O	O	O	O	O	O
He/she angered easily.	O	O	O	O	O	O
He/she hit or attacked people.	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
He/she swore in public.	O	O	O	O	O	O
He/she was obedient.	O	O	O	O	O	O
He/she demanded a lot of attention.	O	O	O	O	O	O

If you would like to make any further comment about your child's behaviour, please do so here:

Social Functioning

Your child's SOCIAL FUNCTIONING
Below are questions about social interactions and activities. Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

During the past 4 weeks, how often has your child's injury/disorder ...

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
limited his/her social activities (visiting friends, close relatives, or neighbours)?	O	O	O	O	O	O
affected his/her social interactions at school or work?	O	O	O	O	O	O
limited his/her leisure activities (hobbies or interests)?	O	O	O	O	O	O

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
isolated him/her from others?	O	O	O	O	O	O
made it difficult for him/her to keep friends?	O	O	O	O	O	O
frightened other people?	O	O	O	O	O	O

During the past 4 weeks, how limited are your child's social activities (compared with others his/her age) because of his/her injury/disorder or related problems?

- O Limited a lot
- O Limited somewhat
- O Limited a little
- O Limited rarely
- O Not limited

If you would like to make any further comment about your child's social functioning, please do so here:

Physical Functioning

Your child's PHYSICAL FUNCTIONING
The following questions ask about physical activities your child might do.

In his/her daily activities during the past 4 weeks, how often has your child ...

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
needed more supervision than other children his/her age?	○	○	○	○	○	○
played freely in the house like other children his/her age?	○	○	○	○	○	○
played freely outside the house like other children his/her age?	○	○	○	○	○	○
gone swimming (i.e., swam independently)?	○	○	○	○	○	○
participated in sports activities (other than swimming)?	○	○	○	○	○	○

	Very often	Fairly often	Sometimes	Almost never	Never	Not applicable
stayed out overnight (with friends or family)?	○	○	○	○	○	○
played with friends away from you or your home?	○	○	○	○	○	○
gone to parties without you or without supervision?	○	○	○	○	○	○
been able to do the physical activities other children his/her age do?	○	○	○	○	○	○

If you would like to make any further comment about your child's physical functioning, please do so here:

Support

Has completing this survey made you feel any particular emotions?

- ○ Yes
- ○ No

If so, please describe them and add any comments you feel are relevant.

If the survey has caused you any distress, please consider seeking support, either from friends and family, or from your GP, your child's healthcare provider, or a relevant support group.
A list of support groups, with contact details, will appear at the end of this survey.

Tell Story

If you would like to tell the story of your child's injury/disorder, and the way it has impacted on your life, please continue to the next section.
Feel free to omit any identifying details. If you include names or other details, they will be anonymised before data is analysed.

Do you want to complete this part of the survey?

- ○ Yes
- ○ No

Written Story

What was the cause of your child's condition? (e.g. epilepsy, birth injury)

Does your child receive ACC support?

- ○ Yes
- ○ No

If so, what form does that support take?

If not, do you feel he/she should receive ACC support?

What have been the biggest challenges of caring for your child?

What kind of support have you had – from family, support groups, the medical establishment, government?

What kind of support helps the most?

Do you find people understand your child's condition easily?

Do you find people understand how your life is affected by your child's condition?

Is there anything else you wish to add, to help us understand how your child's condition has affected your life and your family's life?

End

Thank you for participating in this research.

After you click on the 'Submit' button below, you will be transferred to a separate survey in which you can enter your contact details if you wish to receive a summary of the results when it is completed.

Powered by Qualtrics

Appendix 2

Sample email to support organisations asked to distribute the survey

Kia ora

I'm Julia Donovan, a Master's student at Massey University, and I am conducting a survey which may be of interest to you. I work in the community sector, with volunteers, and am interested in the complex challenges faced by New Zealanders who must shoulder greater caregiving responsibility than most of us do. Parents of children with serious brain injury/disorders fall into this category.

I am being supervised in my research by Dr Janet Leathem, who is both a professor in the psychology department at Massey University, and a practising clinical psychologist. Dr Leathem has extensive experience in researching neuropsychological issues in New Zealand, and in supervising students' research. She also has decades of practical experience working with children and adults who have experienced brain injury or disorders.

There is little research into the experience of New Zealand families raising a child with a serious brain injury/disorder – whether from an accident, an illness, or a congenital condition.

This survey aims to measure how raising a child with such an injury affects the parent's or caregiver's quality of life. I am keen to understand which areas of life are most affected, so that it will be clearer which forms of support are most valuable.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 19/34. If you have any concerns about the conduct of this research, please contact Professor Craig Johnson, Director (Research Ethics), telephone 06 356 9099, extn 85271, email humanethics@massey.ac.nz.

I am seeking respondents who are raising a child with a serious brain injury/disorder (which means one which is likely to have long-term or permanent effects which significantly affect a child's cognitive, emotional, behavioural, social or physical functioning). Respondents need to be New Zealand citizens or permanent residents, be fluent in English, and willing to spend 25-45 minutes to complete this survey. I would like to find as many respondents as possible, but I am aiming for a minimum of 80.

The questions in the first part of the survey concern family relationships, work, social activities, relationships outside the immediate family, finances and emotional impacts. It also asks for the respondent's assessment of the child's health and well-being. The second part is

an optional section where respondents can write about their experiences in response to open-ended questions.

The survey will be online until 22 November at the following link:

Brain injury/disorder survey

It can also be accessed by copying and pasting the following address into a browser:

https://massey.au1.qualtrics.com/jfe/form/SV_5jb4ZaUpjzzAve5

Yours faithfully

Julia Donovan
021 722 445