The unmet needs of siblings of children with whaikaha/disabilities in Aotearoa/New Zealand

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Abstract

Siblings of children with whaikaha/disability live a life of constant disruption and challenge, due to their siblings needs. International research indicates that there is a small but significant group of siblings experiencing psychological distress; in Aotearoa/New Zealand, there is very little mental health support available for these siblings. This research aims to identify the unmet needs siblings of children with autism spectrum disorder (ASD), Down syndrome (DS) and cerebral palsy (CP) in Aotearoa/New Zealand. By identifying these needs, we can then inform future development of support services that are targeted towards improving the health and wellbeing of these siblings.

This survey is informed by an insider perspective and replicates previous research which used a mixed method online survey design, with a modified version of the Sibling Cancer Needs Instrument and a qualitative exploratory question. A modified version of the Zarit Burden Interview was also included in the current study. Ninety-seven participants took part in the survey across three disabilities (ASD $n = 55$, DS $n = 39$, CP $n = 11$). ASD siblings had the highest percentage of unmet needs (69.9%) followed by DS (41.9%) and lastly CP (42.9%). When comparing these disabilities, it was found that there was a significant difference between ASD and DS, between males and females and between one to two siblings and more than three siblings. The thematic analysis in the current study identified ‘taha hinengaro’ (mental, emotional health) as the area where siblings need the greatest level of support. It was also found that ASD siblings were the only siblings to report being physically and emotionally harmed by their sibling and caregiving was primarily mentioned by female siblings. The domain with the highest number of unmet needs for siblings of children with whaikaha/disabilities was ‘support from friends and other young people’. Our results support previous studies and indicates that both siblings of children with cancer and serious chronic health conditions and siblings of children with disabilities could be supported together. Given that the needs of siblings have been identified along with how these needs can be met, further focus and research is needed on the impact of providing support to siblings.

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Glossary

Term	Explanation
Hinengaro	Psychological (Durie, 2001)
Hōkai nukurangi	To achieve what is important to you, cerebral palsy (CP) (Opai, 2022, May 6)
Pūira kehe	Condition of the odd number chromosome, Down syndrome (DS) (Te Pou, 2020)
Taha	Side/part (Durie, 2001)
Takiwatanga	In his or her own time and space, autism spectrum disorder (ASD) (Tupou et al., 2021)
Tinana	Physical (Durie, 2001)
Whaikaha	Disabled, to have strength and ability, be otherly abled and enabled (Te Pou, 2020)
Wairua	Spiritual (Durie, 2001)
Whānau	Family (Durie, 2001)
Whāngai	Foster child, adopted child (Keane, 2017)

Chapter One: Introduction

> "I just feel awful for my brother, he's the one having to go through that", and I never really reflected on the fact of how the diagnosis might have affected me, because I was like "I'm fine, I'm neurotypical, it's not a thing to affect me." Sibling of a child with a disability. (Hanvey et al., 2022, p. 6)

Prior to presenting the formal literature review to this thesis, I will position myself and how I have chosen to look at the needs of siblings of children with disabilities. I will provide background for this research and situate it in the Aotearoa/New Zealand context by interweaving my own story of being a sibling of a child with a disability in combination with the academic literature.

My main motivation for choosing this topic comes from my own experience of growing up with a sibling. An estimated more than 80% of people under the age of 18 grow up with at least one sibling (McHale et al., 2012). However, my younger sibling has a disability. Through my own experience I noticed a lack of support and understanding for myself as a sibling and my family. According to Murray (2018) in New Zealand the majority of families receive no funding or support towards caring for a child with a disability; they found that out of 95,000 children with disabilities only 8,700 receive funding. This has an impact on siblings in terms of the amount of care they receive as the parents' time is taken up with caring for the child with a disability. For other families in this study, if there was access to support this was largely specific to the child with a disability and there was little consideration for the wellbeing of the wider family that the child lives in and interacts with (Murray, 2018).

Being in the position of growing up in a family with a child with a disability, I experienced first-hand the impact of this on my own wellbeing. My family (like many others) was centred around the child with a disability and their needs. Research has found this necessary division of attention impacts the family environment, which contributes to reduced capacity for tending to the needs of other siblings (Black et al., 2020; Turns et al., 2016). This can at times be a very lonely and isolating experience for siblings. It has also been found that some siblings are at greater risk of depression and anxiety and may struggle to adjust to changes in life (O'Neill & Murray, 2016). However, along with studies demonstrating these negative impacts, research has also shown that having a sibling with a disability can have a positive impact on children and their outcomes (Black et al., 2021). For example, siblings have been found to be more empathic, caring, patient and tolerant than their peers (Arnold et al., 2012; Barr & McLeod, 2010; Dew et al., 2008; Giallo et al., 2012). Thus, these experiences mould siblings into the people they are today.

Through my own experience I realised that if I had the opportunity, I would find a way to make a contribution to the area of sibling experience so that siblings can have their voices heard and be supported in the future. In examining the current literature on siblings of children with disabilities, I have read countless articles detailing both positive and negative experiences of these children and the outcomes they have faced as a result. This research reflected my own experience of growing up with a sibling with a disability. The literature mainly focuses on the impact and consequences of having a sibling with a disability but fails to look at what siblings actually need; instead, studies assume what is needed from negative consequences that some people experience. Research that focuses on the sibling perspective as to what they need is very limited.

In directing my thesis towards siblings' experiences of having a brother or sister with a disability and their needs, I wanted to not only contribute to an area where there is a lack of

research but challenge the assumption that siblings are a passive member of the family and unaffected by disability in the family. The focus in the literature is primarily on the parents (typically the mother) and the child with a disability and what support they require, leaving the sibling largely invisible. However, the sibling relationship is the longest lasting family-based relationship a person will have during their lifetime, outlasting the parent relationship and starting before the relationship with one's partner (Arnold et al., 2012; Shojaee et al., 2018). By the time people reach 70 years of age, 75% of people will still have at least one sibling (Settersten Jr, 2007). Consequently, it is no surprise that due to the long-term nature of the sibling relationship, it is likely that these siblings will play a significant role in each other's lives, for better or worse.

My aim throughout this thesis is to understand the needs of siblings of children with disabilities in Aotearoa/New Zealand. This is so that one day a practical support system can be created that meets the needs of these potentially vulnerable siblings on their journey through life. In Aotearoa/New Zealand there are very limited support services available for siblings of children with disabilities; an overview of these services is discussed below (see the section on Regional and National support services in Aotearoa/New Zealand). Therefore, this research is needed to help guide the development and implementation of services that are appropriate for siblings needs. The following sections will look at theories relevant to siblings and disability. Disability will be defined from within the Aotearoa/New Zealand cultural context, including the interface between disability and the New Zealand Health system. This will be followed by a description of burden and unmet needs, including the motivation for the current research. This chapter will finish with an overview of what support services are available to siblings of children with disabilities.

Family Systems Theory

Siblings are a significant part of the family system. Systems theory is a useful theory to understand in relation to having sibling with a disability, as systems are the basis of all social interactions. The systems theory framework is important for exploring the impact disability has on the family environment. Generally, in families that have a child with a disability, family life revolves around that individual and their needs; they are the centre of the system. Roles, priorities and routines in the family system surround this child and these change throughout the child's life course (Farrell & Krahn, 2014). Everyone must constantly adjust to changing needs and shifting circumstances, which can be stressful for the whole family unit. The family system regularly has to restabilise and find equilibrium due to the constant disruption through managing a disability.

According to Meadan et al. (2009) the family system is comprised of four subsystems including the marital, parental, sibling and extended family relationships. These smaller subsystems are all part of the larger family system. When an issue occurs in one relationship in the system, this can spill over and affect the other subsystems in the family (Turns et al., 2016). In families with a disabled child, parents often experience what is called 'burden' in the literature (Oskam, 2020; Pavlopoulou & Dimitriou, 2020; Zarit et al., 1985; Zarit et al., 1980) and stress due to the caregiving of the child with a disability requires. This can affect the parental relationship they have with their other children who do not have a disability - which can also impact the relationship that nondisabled siblings have with their brother or sister with a disability (Roper et al., 2014).

Siblings can have a powerful influence on each other (McHale et al., 2012) both directly and indirectly in the family system. Siblings are an important part of the family unit and are imbedded in the system, having as much of an influence on the system as anyone else in the family (Dyke et al., 2009). It is not only the family system around the disabled child

that is affected but the other wider systems in the community that the sibling interacts with can also be impacted. Hence, there have been many calls from the literature (and from therapists) to include siblings in research and therapy as they are an integral part of the family unit (Hallion et al., 2018).

Health, Disability and Culture in Aotearoa/New Zealand

The experiences of siblings of children with disabilities are set within a cultural context. This includes differences in access and quality of support as well as expectations on siblings regarding providing caregiving. The country a sibling lives in can have a powerful influence on how the disability impacts their daily lives. Therefore, it cannot be assumed that international research is representative of the Aotearoa/New Zealand experience of being a sibling, and there are only a few studies looking at siblings of children with disabilities in Aotearoa/New Zealand. But before delving further into the literature it is important to first situate health and disability in the Aotearoa/New Zealand context.

In Aotearoa/New Zealand, the Treaty of Waitangi/Te Tiriti o Waitangi is the founding bicultural document, which constituted an agreement between two peoples, settlers and Māori - the indigenous people of Aotearoa/New Zealand (Levy & Waitoki, 2015). Te Tiriti promised equality between Māori and non-Māori and has three main principles: partnership, protection and participation. Therefore, in order to uphold the principles of Te Tiriti, it is important to include how Māori conceptualise health. This is because how health and wellbeing is conceptualised comes from within a sociocultural context (Wilson et al., 2021). Te Whare Tapa Whā is a holistic model of health that comes from within a Māori world view which includes four aspects of health akin to the walls of a house (Durie, 2001). The four aspects are taha wairua (spiritual), taha whānau (family), taha hinengaro (psychological) and taha tinana (physical) (Durie, 2001). All are needed for maintaining optimal health; if one

aspect is lacking, the whole house is weakened and may fall down. Health is also viewed as a collective responsibility (Levy & Waitoki, 2015).

The New Zealand health system is very medicalised, complicated and differs significantly from Te Whare Tapa Whā in that it only focuses on two aspects - taha tinana (physical) and taha hinengaro (psychological). This health system is primarily funded through tax and run by the government, which means New Zealanders can access care without medical insurance (Ministry of Health, 2011). However, this system is very complex and made up of several different organisations as illustrated in Figure 1.

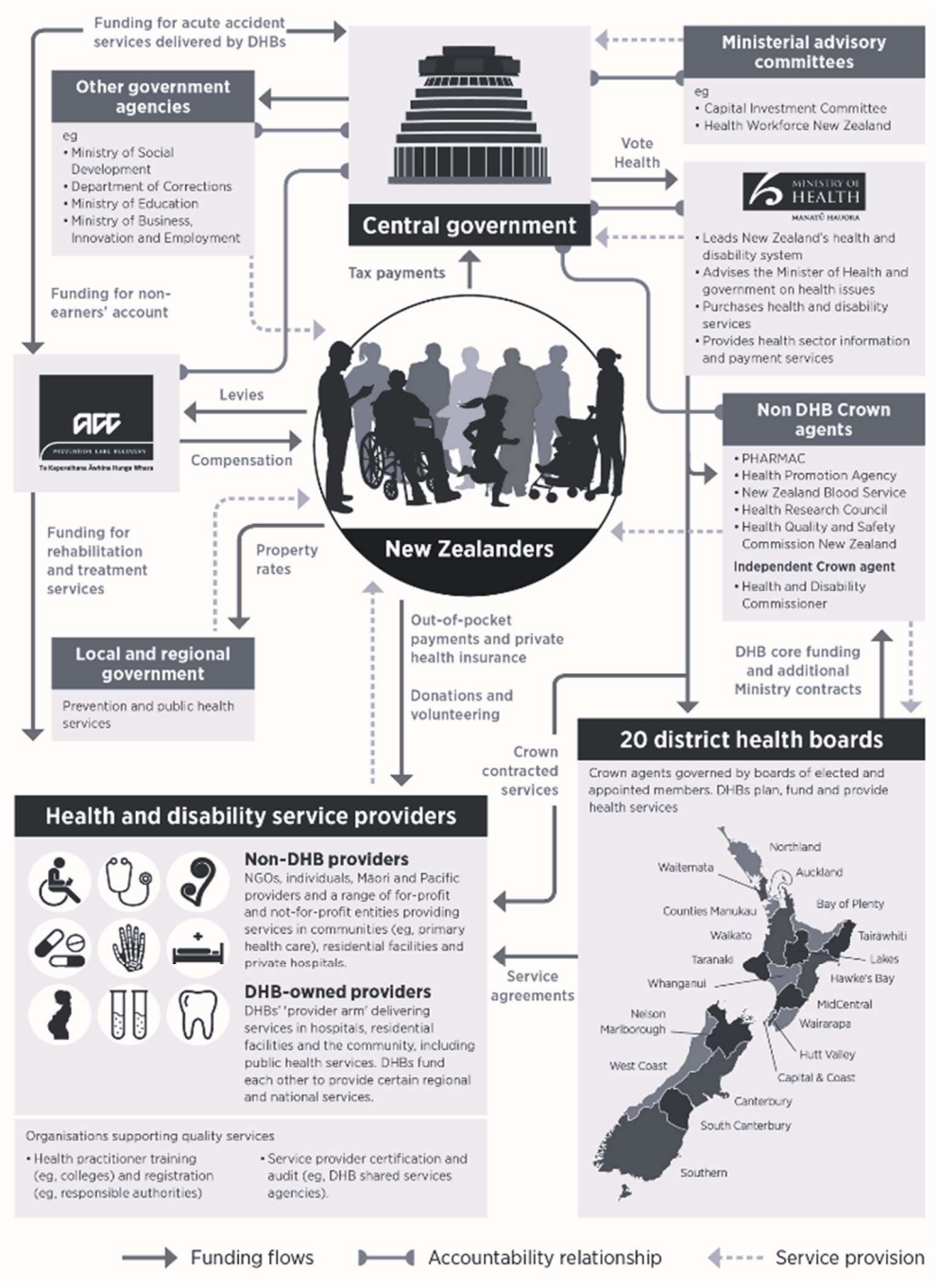
In addition to health, the New Zealand health system also covers disability; because there are often comorbidities between disabilities and other health conditions, the line between what is a medical issue and what is a disability can be blurred. Nevertheless, it is through this system that families can access support and funding for a child with a disability. However, only a small number of families with a child with a disability receive funding to go towards care (8,700 out of 95,00); this means that there is a significant shortfall in caregiving that has to be taken up by many families (Murray, 2018).

In New Zealand, it is estimated that 11% of children aged under 15 have a disability (Statistics New Zealand, 2014). The most common causes of disability in children are first, conditions that existed at birth (49%) and second, conditions caused by illness and disease (Statistics New Zealand, 2014). A disability is defined as a significant limiting, long lasting condition that causes physical and/or psychological impairment, and results in a person being unable (or limited in their ability) to carry out daily activities (Statistics New Zealand, 2014). This includes cancer, chronic illness, mental illness and other conditions that take more than six months to resolve (Statistics New Zealand, 2014). This is a very broad definition of disability; therefore, the next section will further narrow down the definition of disability in

the Aotearoa/New Zealand context. How disability is perceived has strong links with culture, in that not all countries define disability in the same way.

Figure 1

Overview of the New Zealand Health and Disability System



(Minister of Health, 2016, p. 38)

Defining Disability

In Aotearoa/New Zealand the predominant definition of disabled people is “those who have long-term physical, mental, intellectual or sensory impairments which (in interaction with various barriers) may hinder their full and effective participation in society on an equal basis with others”; this comes from the United Nations Disability Convention (United Nations, n.d.). New Zealand's disability strategy 2016-2026 uses this definition which is based on the social theory of disability (Minister for Disability Issues, 2016). This definition is broad and encompasses a range of conditions and situations. However, this thesis will specifically focus on developmental and physical disabilities such as autism spectrum disorder, Down syndrome and cerebral palsy, which will be discussed later in the thesis.

The definition of disability comes from within a theoretical context. This context dictates how disability is viewed by the family and wider community, which in turn contributes to the impact the disability has on the family system as well as the sibling. Therefore, it is important to look at how disability is theorised; two of the most prominent are the medical model of disability and the social model of disability (Retief & Letšosa, 2018). The medical model views people as being made up of specific parts much like a car or piece of machinery and consequently a disability can be fixed like you would a car. This centres on the idea that you ‘cure’ a disability by giving a medication, prosthetic or performing surgery etc. The disability comes from within the person, and they are the ones that need assistance (Retief & Letšosa, 2018). Alternatively, the social theory of disability is centred on the idea that the environment influences whether someone experiences disability. The central idea is that society is not built to accommodate people with disabilities so therefore it is society disabling the person and their family (Retief & Letšosa, 2018). Regardless of the model, the impact and experience of disability extends to those that associate with the person who has a disability; hence the impact on the life of siblings is also recognised.

The move towards the social model of disability has only occurred relatively recently in Aotearoa/New Zealand and resulted in one of the biggest changes in disability that New Zealanders have seen. This was the move from institutional based care to home and community care with the closing of the last institution, the Kimberly Centre, Levin in 2006 (Stewart & Mirfin-Veitch, 2008). This was a huge step forward in recognising that people with disabilities deserve to be part of society and be included in the community. However, this did not come without drawbacks including placing significant demands on some families to care for their relative with a disability or to make arrangements for their care (Stewart & Mirfin-Veitch, 2008). These changes consequently have impacts both positive and negative for families now and into the future. The family is responsible for the person with a disability for life which inevitably may impact siblings in a variety of ways across the life span.

Thus, being a sibling of a child with a disability can be a profoundly challenging experience, one that both positively and negatively impacts the sibling. There have been numerous calls from the literature as well as a statement from the Royal Australian and New Zealand College of Psychiatrists stating that siblings need support including planning for the future ("Addressing the needs of siblings of children with disability or chronic illness," 2012; Hanvey et al., 2022; Naylor & Prescott, 2004; Paul et al., 2021).

Burden

Due to the move to community-based care, burden has become an important concept to consider when it comes to looking at people who surround the person with a disability. Burden can be thought of in two ways - both in a subjective and objective sense. Subjective is about a sense or feeling about something, feeling the strain, and feeling psychologically weighted down by something, generally pointing to negative perceptions. Alternatively,

objective reflects the activities and situations being the cause of the negative experience rather than how one perceives the event.

Liu et al. (2020) concluded after an extensive search of the literature that caregiver burden can be described as the perceived multifaceted strain of caring for a relative or loved one over a long period of time; combining both the subjective and objective view of burden. Multifaceted strain includes a number of physical and psychological consequences such as insomnia, change in appetite and irritability (Liu et al., 2020).

Turan Gurhopur (2017) discusses burden as something that impacts not only the family member primarily doing the caregiving but the whole family. The concept of family burden acknowledges that all family members are impacted by the disability and the caregiving that sometimes must be done. This is based on a family systems perspective with the notion that if burden affects one part of the system another part of the system will be impacted too. The whole family takes on the burden of disability due to the adjustments other parts of the system have to make in response to the burden placed on one member.

Research is leaning away from relying on diagnosis to determine how high needs a child with a disability is; instead, perceived burden is thought to be a better indicator of this. Studies in this area indicate that when a disability reaches a certain point of high need in terms of caregiving and impact on family life the type of disability a child has becomes less relevant (Breslau et al., 1982). More recent studies looking at factors that impact the quality of life in families with a disabled child found that higher disability severity, severity of medical needs and severity of behavioural needs are associated with lower levels of life satisfaction and higher levels of stress for parents (Jenaro et al., 2020; Mian et al., 2004). Thus, perceived burden is an important factor to investigate alongside a specific diagnosis.

Burden Measure for Siblings

The ZBI-22 is one such measure that has been developed and used for the purpose of measuring perceived burden. The ZBI was originally devised in the 1980's, after observing the difficulties that family members faced in caring for someone with Alzheimer's (Zarit et al., 1985). It was also discovered that there was no way to measure the impact that caregiving has on the family members looking after their relatives. Zarit et al. (1980) felt it was important to look at factors that contribute to burden such as the behaviour of the person being cared for, the level of impairment they have and how much formal and informal support the caregiver receives.

The creation of the measure was informed by Zarit's clinical experience and literature of the time; covering areas that caregivers most frequently brought up as impacting them (Zarit et al., 1980). The initial purpose proposed for the interview was to identify sources of burden that caregivers experience (Zarit et al., 1980). This was because research at the time concluded that people with dementia and/or chronic illnesses who were cared for in the community experienced many benefits to their quality of life, however, this neglected the significant burden placed on relatives and others doing the caregiving (Zarit et al., 1980).

Since the development of the measure - the original Zarit Burden Interview (ZBI) - the ZBI-22 version has been regularly used to measure the burden of caring for someone who has a disability and/or medical conditions. It is currently the most frequently used measure of caregiver burden and often used with parents of children with disabilities (Liu et al., 2020). This measure has also been used in Aotearoa/New Zealand where it was used for selecting participants for a study looking at the parents of children with disabilities (Oskam, 2020). The measure was used so that the only parents who subjectively viewed their child as high needs as a result of their disability were included in the study (Oskam, 2020).

Although the burden on parents and primary caregivers is well researched, there is not yet a body of literature on the burden siblings perceive that they and their family experience, meaning there is a lack of a suitable measure for this population.

Needs

The current body of research has investigated the negative consequences that some siblings of children with disabilities experience - but has not investigated what needs are not being met that potentially lead to these negative outcomes. Instead needs have primarily been assumed for siblings rather than asking siblings what they felt they needed. In a related area looking at siblings of children with cancer, researchers found a lack of consideration for the needs of siblings as dictated by the siblings themselves; as a result, they developed the Sibling Cancer Needs Instrument (Patterson et al., 2011).

Needs Based Measure for Siblings

The Sibling Cancer Needs Instrument (SCNI) was developed by Canteen in Australia: a charity that supports young people impacted by cancer. This measure was created to identify the unmet psychosocial needs of young people who have a sibling with cancer (Patterson et al., 2011). This is so that interventions and support can be developed to meet the needs that siblings of children with cancer have, as well as evaluate the current support services that are available (Patterson et al., 2014).

The topic of unmet needs was chosen by Canteen Australia because it was found in the literature that siblings of children with cancer are negatively impacted by a range of negative emotional and psychological issues. For siblings of children with cancer there was a lack of knowledge in the research on how to effectively support siblings to care for their own psychosocial needs (Patterson et al., 2014). They also found that siblings often do not have

the chance to talk about how they are impacted and lacked support (Patterson et al., 2014). Therefore, the researchers identified that there was a gap in the literature for an instrument that allows siblings to express their needs and for these to be quickly and easily identifiable in order to develop services and interventions that meet their specific requirements (Patterson et al., 2014).

This instrument was developed with a small focus group made up of siblings of young people with cancer as well as phone interviews with these people and along with Canteen staff that work with young people impacted by cancer (Patterson et al., 2011). This generated several domains of need for which representative items were developed (Patterson et al., 2011). The final resulting instrument covers seven domains of need including: 1) information about my sibling's cancer; 2) 'time out 'and recreation; 3) practical assistance; 4) dealing with feelings; 5) support from my friends and other young people; 6) understanding from my family; and 7) relationship with my sibling with cancer.

Autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand

Autism spectrum disorder, Down syndrome and cerebral palsy are typically classed as high need disabilities placing a significant amount of the burden on the family including the sibling. Therefore, these disabilities will be covered below with regards to their known specific impacts on siblings. In this current research, these will act as a proxy for the numerous other disabilities that children experience in Aotearoa/New Zealand. The next section will look at three common disabilities and the associated needs of siblings in childhood. These disabilities will be discussed briefly with specific focus on the impact on siblings.

Recently a glossary of terms has been developed for the health and disability community in Te Reo the indigenous language of Māori (Te Pou, 2020); therefore each

disability will have its name in both English and Te Reo. For example, disabled/whaikaha means to have strength and ability, be otherly abled and enabled; this word has been created by the Māori disabled community (Te Pou, 2020).

Autism Spectrum Disorder in Aotearoa/New Zealand

Autism spectrum disorder /Takiwatanga, in his or her own time and space;(Bowden et al., 2020), is commonly referred to as a neurobiological difference. It is estimated that there are 10,000 people with autism spectrum disorder (ASD) in New Zealand based on international prevalence figures of about 1 in 102 people (Bowden et al., 2020). 68% of people with ASD also have coexisting conditions such as depression, anxiety, and intellectual disability (Bowden et al., 2020). It has also been concluded that ASD is more commonly identified in New Zealand European children compared with Māori and Pasifika children (Bowden et al., 2020).

ASD/Takiwatanga is considered to be an invisible disorder as it comes with no physical abnormalities. In Aotearoa/New Zealand the mean age of diagnosis is 6.6 years (SD = 5.8 years), although on average, parents first notice their child may be on the autism spectrum at 3.2 years (SD = 3.0 years) (Eggleston et al., 2019); some receive a later diagnosis due to issues not being more apparent until the demands of adulthood occur. ASD occurs on a spectrum, and consequently is a very heterogeneous disorder. People diagnosed with the same disorder may experience a diverse range of difficulties. These difficulties occur in three main areas: language skills, social behaviour, and in cognitive and thinking skills. There is no specific known cause of ASD; although, it is known that genetics can play a part (Ozonoff et al., 2015), as well as a number of pre and post-natal environmental factors (Bowden et al., 2020). As such, family members (including the sibling) are at risk of having this disorder themselves or a related disorder (Koukouriki et al., 2021).

Various forms of therapy may form part of the treatment and support process. There is no specific therapy for children with ASD/Takiwatanga; therefore, the type of therapy a child receives is based on the child's needs (Katarzyna & Fred, 2020), availability and what the family can afford. Therapy is primarily with the parent and child (Katarzyna & Fred, 2020); occasionally the sibling may come along to a family therapy session. This means that the sibling may feel abandoned or jealous as they are not receiving as much care and attention as the child with ASD is (Watson et al., 2021).

From the literature it can be concluded that ASD/Takiwatanga has a powerful effect on siblings. Bontinck et al. (2018) looked at siblings of children with ASD and the sibling relationship. They found that for sibling pairs where a child has ASD there are more negative relationship factors than for sibling pairs where ASD is not present (Bontinck et al., 2018). Koukouriki et al. (2021) likewise found that siblings of children with ASD had higher depressive symptoms compared to siblings who do not have a sibling with a whaikaha/disability. Rixon et al. (2021) found that siblings of children with ASD have more internalising and externalising problems than siblings of other children.

Lamsal and Ungar (2021) and Meadan et al. (2009) looked at siblings of children with neuro developmental disorders and received mixed results as to whether the quality of life of siblings is affected or not. Similarly, Macks and Reeve (2007) conclude that having a sibling with ASD/Takiwatanga can enhance psychological and emotional development. However, they also point out that if siblings have a number of demographic risk factors, this effect can instead be negative (Macks & Reeve, 2007). These studies indicate that what impacts siblings is made up of complex interactions of different factors. They also indicate that whaikaha/disability does not necessarily equal disadvantage for everyone.

Cerebral palsy in Aotearoa/New Zealand

Cerebral palsy (CP)/Hōkai Nukurangi, to achieve what is important to you (Opai, 2022, May 6). In Aotearoa/New Zealand it is estimated that a baby is born with CP every 3 days and currently there are more than 10,000 people living with this disorder. While there are no exact figures (because data is not being collected on this at present), the Cerebral Palsy Society New Zealand has a register that they hope in time will be able to produce accurate data (Cerebral Palsy Society of New Zealand, 2021).

CP/Hōkai Nukurangi is the most common cause of physical disability for children in Aotearoa/New Zealand and worldwide (Dew et al., 2008). It is permanent and lifelong and caused by a one-time brain damage event either before or shortly after birth. However, diagnosis takes time; only 16% of children are diagnosed before 5 months old and 59% diagnosed after 12 months old in Aotearoa/New Zealand (Williams et al., 2021). CP affects people to different degrees; for example, one limb may be impacted, or it can be the whole body. But generally, movement, muscle control, posture, muscle coordination, reflex and balance are affected (Butko et al., 2022). There is no cure for this whaikaha/disability; instead, therapy, treatment, intervention and assistance devices are focused on managing the condition in order to have a good quality of life (Honan et al., 2022).

The research on siblings of those with physical disabilities such as spina bifida and cerebral palsy have discovered three main concerns held by siblings; medical emergencies, reactions of people outside family and friends, and worries about now or the future (Pit-Ten Cate & Loots, 2000). These are stressful situations and siblings of these children are exposed to more of these circumstances than the general population. However, the literature points to some contrasting findings; for example, Dew et al. (2008) reviewed the literature on the psychosocial impact of having a sibling with a physical disability and found that it did not

have a negative impact on the sibling. Thus, the research indicates that there is ambiguity as to whether siblings of child with CP are impacted negatively or not.

Down syndrome in Aotearoa/New Zealand

Down syndrome (DS)/Pūira Kehe, condition of the odd number chromosome (Te Pou, 2020) is a chromosomal abnormality that occurs when there is an extra copy of chromosome 21. Internationally it is estimated that 1.3 in every 1000 babies born will have DS or Trisomy 21 (Mulvey & Wallace, 2000). de Graaf et al. (2022) estimated that between 2016 and 2020 there were 41 babies born per year (1 in 1450) with DS in Aotearoa/New Zealand. During this same period the prevalence rate has dropped by 71% and has been dropping since 2011 due to the ability to detect DS prenatally and select a termination (de Graaf et al., 2022).

DS/Pūira Kehe is usually diagnosed before or at birth and is a lifelong condition. Children with DS are known to be at risk of a range of medical and mental health conditions such as autism spectrum disorder, intellectual disability, depression, pneumonia, and leukaemia (Jeter & Turns, 2022). As such DS makes up 15% of the intellectual disability population and is one of the most common causes of genetic impairment. Abnormalities in facial features are a key characteristic of DS including small nose, small eyes and large forehead (Jeter & Turns, 2022). There is no cure for DS; instead, treatment is focused on health conditions associated with the condition and assisting people to live as normal a life is possible. With medical advances people with DS are now able to live into their 50s which is a significant improvement on previous years (Choi & Riper, 2013; Shivers & McGregor, 2019). But this has an impact on siblings of children with DS, as people with DS are likely to outlive their parents and therefore siblings may have to take over the responsibility of caregiving (Choi & Riper, 2013; Shivers & McGregor, 2019).

Singh (2014) wrote a Master's thesis in Aotearoa/New Zealand about younger siblings of children with DS/Pūira Kehe. The focus was on understanding the experience of having an older sibling with DS, including the rewards and challenges of this and how they cope with it. The relationship the younger sibling of a child with DS had with their sibling was found to be positive and they enjoyed a good close relationship (Singh, 2014). It is important to note that this study had only a small number of participants so more research is needed to understand the experiences of younger siblings. A literature review of 23 studies including six from Australia concluded that there are both positive and negative consequences of being a sibling of a child with DS (Choi & Riper, 2013). For some siblings having a brother or sister with DS improved their lives and made them more patient and resilient people.

Regional and national support services in Aotearoa/New Zealand

The research indicates that there are significant impacts on the entire family, including the disabled child's sibling where there is high need. However, there are very limited support services for siblings of children with disabilities and currently Aotearoa/New Zealand does not offer needs-based support services to these children nationwide. This section outlines the current support services that offer assistance to siblings.

1. Under 'Parent to Parent' there is 'SibSupport NZ' which aims to support siblings in their unique family situation by providing three support groups (Parent to Parent New Zealand, 2023). 'SibShop' - an opportunity to spend the day doing fun activities, an opportunity to meet other siblings and make friends. 'SibCamp' - a weekend away full of activities for just siblings and an opportunity for siblings to network, for ages 8 to 18. Finally, 'Second generation' - which focuses on adult siblings. In addition to

this they have online resources including videos of children describing what it is like to grow up with a sibling with a disability in Aotearoa/New Zealand. There are booklet resources for siblings that are appropriate for each age group, ranging from birth through to adulthood. A booklet titled 'My sibling has a disability' is also available, which goes through a number of concerns a sibling of a child with a disability may have (Parent to Parent New Zealand, 2020).

2. Young carers New Zealand is part of Carers New Zealand and have a Facebook page that regularly advertises opportunities for young carers to connect with one another (Young Carers New Zealand, n.d.). Carers New Zealand also has a brochure for young people called 'Are you a young carer?' that includes options for support and ways to support your own wellbeing (Carers New Zealand, n.d.). This is important as many siblings of children with disabilities can be classed as young carers as well.
3. There is also generic mental health support for children and young people in Aotearoa/New Zealand form organisations such as Youthline (Youthline, n.d.), and What's up (Barnardos, n.d.). These organisations provide free counselling by phone, text or online that can easily be accessed by children and young people themselves.

All these services are valuable; however, there is only one service that caters for children of siblings with a disability. The number of events they hold are extremely limited and only available in Aotearoa/New Zealand's largest city, Auckland. The Parent to Parent program offers support to all siblings of children with any disability which is very inclusive; however, this may be problematic as not all siblings are impacted in the same way. There is no service currently set up that is specifically for siblings of children with whaikaha/disability that can respond to their needs. For example, something as simple as being able to talk to someone who understands or has experienced something similar is not an option for them.

When comparing siblings of children with chronic illnesses and siblings of children with whaikaha/disabilities in Aotearoa/New Zealand, there appears to be more resources and research on siblings of children with cancer and chronic illness compared to siblings of children with disabilities. For example, there is The Child Cancer Foundation (Child Cancer Foundation, n.d.), Canteen (Canteen Aotearoa, 2023), True Colours (True Colours Childrens Health Trust, n.d.), plus psychological services available in the Manawatu Area through the Massey Cancer Psychology Service and the Massey Health Conditions Psychology Service where the family and whānau are also supported (Massey University, 2023). For the disability sector there is no such comparable service or support specific to siblings and families of children with whaikaha/disabilities.

This overview of support services available to siblings of children with a disability highlights that this is an area that is significantly under serviced. The research points to significant impacts of disabilities on siblings and high needs, and supports the need for targeted services that provide support of the needs of siblings of children with a disability that is available regardless of where the family resides.

Chapter Two: Literature Review

This chapter will review the existing literature on siblings of children with whaikaha/disabilities and describe the key variables and findings that impact these siblings and their ability to cope.

The Impact of Childhood Whaikaha/Disability on Siblings

The dominant approach in the research has focused on the negative effect that having a sibling with a disability can have (Lalavani & Polvere, 2013). This has come from when interest in siblings first started and the observations and assumptions from that time. According to Cuskelly (1999), interest in siblings of children with disabilities started in the 1970's; it was concluded at this time that siblings were at risk of psychological problems from observations that psychiatrists had made. Later it was argued that disability may benefit siblings and impact them positively, a shift Findler et al. (2009) states has only occurred recently. Therefore, it is now concluded that childhood disability impacts siblings concurrently in both negative and positive ways. Researchers have not managed to collectively establish whether siblings of disabled children are more adversely affected than siblings of other children. Many different constructs such as quality of life, psychological issues, adjustment, coping, behaviour issues, school achievement, social functioning, and sibling relationships have been examined. The conclusion reached from this body of work is that there is a small but significant group of children who are at risk of a number of psychological difficulties which means that these siblings have needs that are not being met currently.

Gathering information on the difficulties that siblings of children with disabilities face has predominantly been with the mother of the child. Using the mothers as the primary informant in a large number of studies was viewed as problematic and that siblings need to be talked to directly (Dew et al., 2008), as there are discrepancies in parent reports compared to sibling reports. Likewise Senner and Fish (2010) found that there was an insignificant correlation between the parent and child report on the sibling need and involvement profile. Therefore, it is important that siblings articulate what they struggle with themselves and what they need to maintain their wellbeing, so that services can cater to the needs they have.

Arnold et al. (2012) is one of the few studies that specifically looked at the needs of siblings. They developed and used their own survey called the Supporting Siblings Survey which was completed by 139 adult siblings of people with developmental disabilities. This survey focused on support needs and found that siblings wanted more disability related information and to be included, as siblings did not feel they were being heard and wished to get support from other siblings, plus support for themselves (Arnold et al., 2012). This highlights that the experience of having a sibling with a disability is often a very individualised personal experience for each person.

Unfortunately, in the sibling whaikaha/disability space there is lack of sibling specific instruments to measure what their needs are (Dyke et al., 2009). The Sibling Daily Uplifts and Hassles Scale (Giallo & Gavidia-Payne, 2006) is one of the limited number of scales used to understand the impact of having a sibling with a disability. However, it does not produce information on the specific needs of this group. This is problematic as needs information is important for designing and providing services to meet the needs of this unique population.

A literature review by Dew et al. (2008) analysed twenty one studies on siblings of people with lifelong disabilities. All but two studies used standardised tests to collect data,

more than fourteen different tests were used for parents and more than twenty two for siblings (Dew et al., 2008). Likewise a later review by Marquis et al. (2019) looked at forty six articles on siblings of children with intellectual/developmental disabilities written between 1970 and 2017. They found similar issues, in that there were many different tests used and many different definitions used when it comes to measuring how siblings are coping. The review included quantitative and qualitative research and used a narrative approach so a wide range of topics that came up in the research could be covered (Marquis et al., 2019). Another literature review used thematic analysis for similar reasons; it was used to analyse and combine different types of studies together and identify the main themes and concepts (Watson et al., 2021). Thus, another complication in establishing the impact of disability on siblings is the various different methodologies being used.

In summary, before providing formal support to siblings, it is important to first do an assessment on needs which gives information on what people perceive they need help with and how current services are meeting their needs. Quality of life and patient satisfaction surveys are related constructs but do not link to what people desire or focus on a solution.

Psychological impact

The literature has primarily focused on the psychological impact of having a sibling with a disability, particularly the negative consequences. According to Giallo et al. (2012), 20 to 30% of siblings of children with disabilities are at risk of mental health difficulties or in the clinical range for being diagnosed with a mental health condition in Australia. It has been found that siblings tend to internalise concerns as to not worry their parents (Giallo et al., 2012; Rixon et al., 2021) which can lead to psychological issues such as depression (Koukouriki et al., 2021; O'Neill & Murray, 2016) and anxiety (O'Neill & Murray, 2016). Hence, lower levels of wellbeing for siblings of children with disabilities compared to other

children have been found (Emerson & Giallo, 2014). Hanvey et al. (2022) has concluded this is due to siblings having high levels of unmet emotional needs which impacts on their wellbeing. It is clear that some siblings struggle to cope with having a sibling with a disability and this has a negative psychological impact on them.

One of the main themes from the research is sibling worry; many children are concerned about the future and what it holds for them and their sibling with a disability (Watson et al., 2021). This worry has also been found to be at a higher level compared to brothers and sisters of other children (Sommantico et al., 2020). It has also been found that Aotearoa/New Zealand siblings have similar concerns (McDonald et al., 2009). In addition to worry, siblings also experience guilt due to being the sibling that does not have a disability and seeing their sibling struggling due to their disability and the challenges they face (Hanvey et al., 2022). This worry and guilt that siblings experience suggests that there may be needs that are not being met.

In addition to the internalising of psychological issues there can also be externalising behaviour exhibited by the siblings of children who are disabled (Rixon et al., 2021). An Australian study on 52 siblings of children with disabilities identified behaviour issues at higher rates than for other siblings (Giallo et al., 2012). This can look like some siblings becoming angry and lashing out at others and being non-compliant, often because they feel lonely and annoyed in a world where there sibling gets all the attention (Giallo et al., 2012). This can be an indication that their emotional needs are not being met.

A particular group of siblings of children with disabilities have repeatedly been found to be at much higher risk of negative psychological impacts compared to siblings of children with other disabilities. These are the children who have a sibling with ASD. Siblings of children with disabilities report considerably more stress than siblings of children without disabilities and this is particularly the case for siblings of children with Autism (Pilowsky et

al., 2004; Shivers et al., 2019). Koukouriki et al. (2021) found the level of depression is also much higher in siblings of children with Autism than of typically developing siblings.

It is clear that siblings have an effect on the psychological outcome of other siblings (Black et al., 2020) particularly when one has a disability. However, a recent literature reviews have found that it is not primarily the disability itself that has an impact but the broader consequences of the disability that has the greatest impact on the mental health of siblings (Marquis et al., 2019; Neely-Barnes & Graff, 2011). Marquis et al. (2019) included 46 articles in their literature review and found the factors that affect the health of siblings, include income, single parent, parent education, ethnicity, sex, age, birth order, sibling caregiving, worry, disability type and severity, comorbidities, disabled child's behaviour, burden, family functioning, social isolation and stigma (Marquis et al., 2019). The next sections will focus on family functioning, sibling caregiving, school and social impact, culture, parental treatment, gender, age and developmental stage, sibling relationship, disability type and burden.

Family functioning

The research suggests that siblings are affected by the family environment in which they grow up in (Turns et al., 2016). When there is a disability in the family, life can often revolve around the child with a disability. There is also unequal sharing of parental resources such as time and energy; this is because most of the resources are used on the disabled child, therefore there is less available for the other siblings (Black et al., 2020). This is an example of spillover (Black et al., 2020). According to Black et al. (2020) spillover occurs when things that happen in one relationship affect other relationships (both good and bad), even if they are not connected.

Having a child with a disability constantly challenges family dynamics (Chase & McGill, 2019), due to the child's constantly changing needs. For some this means family life is interrupted by intensive daily routines, appointments, behaviour issues, sickness, and stressed parents. This has led several studies to conclude that siblings live a life of constant disruption (Barr & McLeod, 2010; Black et al., 2020; Donnan, 2020). However, for many siblings, disability and disruption is the norm (Burke, 2010; Stalker & Connors, 2004); they may not know any different and the needs of the child with a disability often comes first. However, this challenging dynamic can leave siblings feeling invisible and their needs not recognised by others (Hanvey et al., 2022).

The family is primarily responsible for the day-to-day care of the child with a disability and mothers tend to take on much of this care (Pavlopoulou & Dimitriou, 2020). This has a negative impact on mothers who along with siblings may also experience a number of psychological and emotional difficulties associated with having a child with a disability including, trauma, guilt, anger (Brown, 2013), anxiety and distress (Koukouriki et al., 2021) due to the care and attention that child requires (Giallo et al., 2012). This undoubtably has a spillover effect into the relationship a mother has with their other children in the family. These children may sense the difficulties their parent is having and respond to this by isolating themselves and not causing issues in order to help the family function (Barr & McLeod, 2010) - thus, sacrificing getting their own needs met for the good of the family (Barr & McLeod, 2010).

Within the family dynamic, siblings of children with disabilities may be very independent and look after themselves, developing the skills to do this much earlier than other children. Aotearoa/New Zealand research found some of these children grew up quickly, became mature, independent and did not need assistance from their parents (McDonald et al., 2009). They may have done this out of necessity because their parents were

often busy with their sibling but also to take the pressure off their parents (McDonald et al., 2009). It is important to remember that siblings still need care and support from their parents even though they may be capable beyond their years (Vella Gera et al., 2020). Lack of perceived social support from whānau/family is known to contribute to depression in siblings of children with whaikaha/disability (Koukouriki et al., 2021).

There can also be on-going grief as the child with disability moves through to young adulthood without achieving developmental milestones like other children (Brown, 2013). Also, known as 'chronic sorrow', this is sometimes experienced by parents of children with disability or chronic illness once they realise their child may not be able to have the life they envisioned, leading to feelings of disappointment, loss and a longing for a child that never was (Coughlin & Sethares, 2017). For parents, chronic sorrow is well documented and defined; however, for siblings of children with disabilities this concept is yet to be defined or researched, despite it being reasonable to expect that some siblings likely experience chronic sorrow too. Siblings may realise at different times throughout their lives, that the sibling experiences they hoped to have, and the experiences they witnessed others having may perhaps never be. Both parents and offspring may have to process ongoing grief to do with the child with a disability.

Another influential factor in family functioning is family size; families who have a child with a disability tend to be larger than other families according to a recent literature review (Marquis et al., 2019). This has been found to both positively and negatively affect siblings as well as family functioning. A positive of more children is that there are more people to help share the burden of taking care of someone with a disability and siblings can look after and support one another. On the other hand, the impact may be negative as there is less parental time and money to go around because this needs to be spread over several siblings in addition to the child with a disability.

Along with families being larger, many families with disabled children have also been found to be in a low socioeconomic situation (Cuskelly, 1999; Donnan, 2020; Emerson & Giallo, 2014; Giallo et al., 2012; Neely-Barnes & Graff, 2011). This is thought to be because parents are required to spend time caring for their child with a disability rather than earning money through paid work (Emerson & Giallo, 2014); therefore low income families may do more caregiving (Marquis et al., 2019). In Aotearoa/New Zealand it has been estimated that families with a child with a disability are more likely to be single parent households and experience financial hardship more often than families with children who do not have a disability (Murray, 2018). This puts siblings at further risk (Macks & Reeve, 2007), contributes to siblings having negative experiences (Dyke et al., 2009) and results in a lower sense of wellbeing (Emerson & Giallo, 2014). Research has also found that being in a low socioeconomic situation has a greater impact on siblings than the disability itself (Dyke et al., 2009).

It is widely considered that families of children with disabilities have a higher incidence of divorce than families of children without disabilities. It has been estimated that the rate of divorce of couples with a child with a disability is between 70% and 90% compared to non-disabled at 50% (Sobsey, 2004). An internet search of the grey literature including blog posts, forums, documentaries and online articles on the divorce of parents of children with disabilities report that divorce rates are higher compared to couples whose children do not have a disability. Professionals who work with families of children with disabilities also believe there is a higher rate of divorce in parents of children with disability, despite there being little empirical evidence to suggest this (Namkung et al., 2015). These professionals may have come to this conclusion due to predominantly seeing the families that are in distress. Society also has a strong perception that having a child with a disability has a

significant negative effect on the parents due to the physical and emotional demands of caring (Sobsey, 2004).

However, recent studies - including a large longitudinal study with 7000 participants - concluded that the divorce rate of families with a child with a disability is no higher than that of families without a child with a disability (Namkung et al., 2015). Divorce is not an uncommon experience for many children; it alters the family unit and is well known to have a negative impact on some children. However, little is known about how divorce impacts children with disabilities and the siblings of these children, although, it is reasonable to expect that potentially siblings are impacted uniquely in a way that is different when compared to siblings of children without disabilities. For example, siblings' roles in the family system may change as they may have to fill the caring gap left by a parent, caring for the child with a disability and receiving less care themselves. Siblings may also find themselves being the main constant in the disabled child's life; for example, moving between parents together and being in the same school together. While divorce is typically stressful for all families, for families of children with disabilities divorce is significantly more challenging due to already existing stresses from having a child with a disability (Namkung et al., 2015).

A further significant issue with regards to family functioning is highlighted in a recent literature review, which found that a number of studies reported that children with disabilities are more likely to be maltreated, abused and neglected (Marquis et al., 2019). In addition it has been theorised that abuse involving the mother while pregnant can occur and this may lead to having a child with a disability or the child could have been abused soon after birth (Sobsey, 2004). Sobsey (2004) theorised that the abuse of a disabled child may not be because of the disability but rather a continuation of previous maltreatment and abuse. From this we can assume that some siblings are likely to also be impacted negatively too.

However, there have not been any studies that look at whether siblings of children who have disabilities have been abused too or impacted by seeing their sibling abused (Marquis et al., 2019).

Having a child with a disability can have the potential to disable the whole family. This is called ‘disability by association’ (Burke, 2010), where people who are in a close relationship with someone with a disability are seen as different and stigmatised (Nieweglowski & Sheehan, 2017). This ranges from experiences such as places not being accessible (e.g., not wheelchair accessible) or accommodating (e.g., too loud for someone with Autism), to stigma from others who do not understand or are not respectful (staring, social exclusion) (Burke, 2010). This can lead families to struggle to go out as a family and enjoy social experiences together, isolating the family. Alternatively, the family can go out without the child with a disability but finding suitable affordable respite care can be a challenge for many families. Families with children with disabilities in Aotearoa/New Zealand often face a number of barriers to accessing assistance such as knowing what is available, how much it costs, what you are entitled to and whether it is suitable for your circumstances (McDonald et al., 2009). Siblings may experience disability by association in terms of being excluded or stigmatised in social situations due their sibling’s disability (Scavarda, 2023).

In summary, the challenges associated with children with disabilities can have a profound impact on family life, affecting everyone in the family system. Siblings play a key role in the overall functioning of the family both in childhood and into the future which is frequently missed when a substantial amount of focus of the research is on the mother. The brothers and sisters of children with disabilities tend to take on more responsibilities and duties than what is usually expected for a child of their age and developmental stage (Watson

et al., 2021). Siblings are often required to provide care and help out a lot in their families in order for the family to be able to function.

Sibling caregiving

Part of siblings helping in the family unit is through participating in caring for their sibling with a disability. Although young carers are not the focus of this thesis, caregiving is an inevitable part of life for many siblings. Siblings take on caring roles within the family to both meet their own needs and that of the family. Assisting parents with caregiving means that the sibling can spend time with their parents and get attention from them as proportionally more time has to be spent on caring for the disabled child rather than the other children. Also, as mentioned previously, accessing support for caregiving is challenging and the amount of funding a family has for caregiving varies substantially; therefore, family members, (including siblings) often step in to do the caregiving to make up for the shortfall in funding.

Thus, while parents usually do most of the caregiving for the child with a disability, a number of siblings also undertake caring roles. Children with disabilities require a lifetime of support most of which is provided by the whānau/family. As siblings get older some take on more caregiving roles for their siblings and some take over the caregiving responsibility once their parents are no longer able to do it (Kruithof et al., 2021). Consequently, a number of studies have found that most siblings worry about the future and say they require more information on their siblings' condition including what they are diagnosed with, what future care they may need (Kruithof et al., 2021; Pit-Ten Cate & Loots, 2000; Siblings Australia, 2018).

In Aotearoa/New Zealand a Master's thesis titled "Who cares about us?" looked at the hidden population of young caregivers (Donnan, 2020). "Young carers" are children who

care for their family members, including siblings. This thesis is the closest piece of Aotearoa/New Zealand research found in relation to the present study, that looks at the experience of siblings of children with disabilities. These children are often referred to as the "invisible carers" (Chase & McGill, 2019) because society sees siblings as just siblings and not the other roles they undertake. Often people are aware of adults caring for people with illness and disability but are not aware that children do this work too, and sometimes are forced to do so (Donnan, 2020). Caregiving can be a profoundly isolating experience (Donnan, 2020); people do not see the care these children provide, and teens often do not realise that they are a carer themselves. Therefore, Young Carers New Zealand released a pamphlet titled "Are you a Young Carer?" (Young Carers New Zealand, 2022) to acknowledge this and help them identify themselves. It is important to note that some siblings genuinely want to help with their sibling who has a disability, be part of the experience and share the load (Chase & McGill, 2019). For these children, caring is the norm and doing this also gives bonding time with their sibling.

Research on young carers and their families in Aotearoa/New Zealand found that many chose to care and many feel a strong sense of obligation and duty to care and support (McDonald et al., 2009). Siblings helping with caregiving also allows their parents to take a break (Watson et al., 2021). Siblings that find themselves in the position where they no longer want to help with their disabled family member, keep going as not to disrupt the family and put pressure on their parents (McDonald et al., 2009). Also, for some siblings they will be expected to take over caregiving from their parents when they are no longer able to which can be a source of worry and stress (Lee et al., 2019). However, for some siblings, caring relationships can be reciprocal for example siblings that are physically disabled can still help their siblings with things like home work, emotional support and a listening ear (McDonald et al., 2009).

School and social impact

School is a central part of the childhood experience including social and academic development, and the formation of relationships with both peers and teachers. School is also a place with many challenges for siblings to navigate. Children with disabilities benefit from having siblings as they can assist their sibling with a disability to access the world from a peer perspective (Franklin et al., 2018). Siblings can educate other children about disability and stand up to other children at school when their siblings are being picked on or stared at (Watson et al., 2021). Also, some spend time with their sibling at break time, so they are included as part of the social scene and have someone to hang out with.

But this does come with negative impacts for some siblings as they face stigma due to their relationship with their sibling (Paul et al., 2021) and being different (Sommantico et al., 2020). This includes getting teased and bullied. It is not only peers at school that impacted siblings negatively, but also a lack of understanding from teachers around their home situation and how that was impacting them at school (McDonald et al., 2009). For example, getting a full night's sleep and getting homework done is challenging for some, impacting their performance at school.

On the other hand it has been found that having a sibling in special education for their disability resulted in good achievement for the sibling without a disability (Gottfried & McGene, 2013); this is an example of positive spill over. Some Aotearoa/New Zealand siblings viewed school as a break from the demands of home life (McDonald et al., 2009) and a chance to separate themselves from the disability, particularly when the siblings are at separate schools. However, when at the same school, siblings are sometimes called on to assist their sibling with a disability which may impact the sibling's ability to be independent.

Siblings may also be subjected stigma by association with others saying hurtful things and teasing them because of their family member's disability (Barr & McLeod, 2010). This creates an extension of the diagnosis to the sibling just because they are associated with the child who has a disability (Franklin et al., 2018). Awkward reactions of strangers can cause siblings distress and make them annoyed (Pit-Ten Cate & Loots, 2000; Stalker & Connors, 2004). Siblings found people do not understand, stare and are rude and thus they may experience unhelpful attitudes of people in the community (Pavlopoulou & Dimitriou, 2020). A number of studies have shown that siblings face stigma in relation to having a sibling with a disability which can lead to less interaction with peers, distress and being bullied (Marquis et al., 2019). Some siblings do not feel able to tell others about their sibling being disabled because they fear being stigmatised which can lead to relationship issues, as siblings may not feel they are able to be completely truthful about their whānau/family (Sommantico et al., 2020).

Some siblings feel socially isolated due to their experiences of living with a sibling with a disability, due to being different from peers, who do not share the same experiences and therefore do not understand. Siblings may also avoid after school activities and feel unable to do them due to their sibling's needs, leading to social isolation (Barr & McLeod, 2010). They also have less opportunities to participate in extracurricular activities and social events because their sibling has a disability (Marquis et al., 2019). When siblings are interacting socially they often feel invisible (Hanvey et al., 2022); people ask how their sibling is doing but do not take interest in the person standing in front of them.

Autism has been found to be particularly problematic in the social lives of some children. Some children with Autism display socially unexpected behaviour which can embarrass siblings or make them fear the reactions of others (Pavlopoulou & Dimitriou, 2020) due to their lack of acceptance. Therefore to avoid this, siblings tend to go to a friend's

house instead of having a friend over because of their sibling's behaviour and concerns their friend might not be accepting (Vella Gera et al., 2020). On the other hand, earlier research by Pit-Ten Cate and Loots (2000) found the opposite - that siblings did not have any problems with friends because of their sibling's disability. However, this study did focus exclusively on physical disability. To sum up it appears from the research that the behaviour related to a disability has more impact on social relationships than presence of disability itself. Therefore, it is important to investigate the social requirements of siblings, between differing disabilities.

Despite the many negative impacts, most siblings are well adjusted (Pilowsky et al., 2004) and do not suffer negative school and social impacts; nonetheless, it is clear that some children are significantly impacted in social areas. Parents are not present in a number of social situations where siblings are, for example at school. Therefore, asking parents about how their child without a disability is doing socially is potentially problematic as they are not there to know. This further bolsters the argument of the importance of asking siblings themselves what they support they need in this space to be able to succeed.

Positive impact

So far, much of the research has focused on the negative impact of having a sibling with a disability; however, there has also been research that demonstrates a more neutral impact and even some benefits of having a sibling with a disability. While the literature points to many challenges and difficulties for siblings there are also opportunities for siblings to grow.

Stress related psychological growth is one of the most significant positives to come out of the experience of growing up with a sibling with a disability (Findler et al., 2009; Hua Sim & Frydenberg, 2015). Research has found siblings can develop several positive attributes from managing a sometimes-difficult situation. Siblings have been found to be empathetic,

understanding, have more self-control, greater acceptance of difference, and mature earlier than their peers (Arnold et al., 2012; Barr & McLeod, 2010; Giallo et al., 2012). Research points to siblings appreciating the good things in life and appreciating what they have rather than what they do not; this is part of gratitude and can lead to positive emotions (Dew et al., 2008). Similarly, research points to siblings being aware of the prejudice people hold against others (Dew et al., 2008) and being more tolerant of peoples' differences (Barr & McLeod, 2010; Dew et al., 2008). Siblings have been argued to be self-aware and have insight into their own views of the world (Hua Sim & Frydenberg, 2015).

These positive impacts were even found in siblings of children with ASD who have been reported to be the most negatively impacted. From reviewing the literature, Watson et al. (2021) found positives such as increases in empathy, coping, understanding and siblings were proud that they could help their sibling. These siblings also see the strengths that their sibling have, and really value their siblings' contributions to their own life, their family and wider society (Carter et al., 2020; Paul et al., 2021). Siblings thus may see their brother or sister as just as important and unique as anyone else. So, it is no surprise that siblings have a passion for advocacy (Pavlopoulou & Dimitriou, 2020) and fighting for the rights of others.

Despite the number of difficulties and challenges siblings face, most are optimistic about their lives and their ability to succeed in the future (Chase & McGill, 2019). Siblings reported that the impact of having a sibling with a disability was generally positive and they developed proactive strategies for coping with associated challenges, including learning to compromise and strategize to cope and overcome struggles (Watson et al., 2021). However, according to Dew et al. (2008), this should be viewed with caution as most people who volunteer to take part in research are more likely to report positive views than those that do not. Overall, it appears siblings gain skills and report positive-things about being a sibling of a child with a disability, but they also report associated problems and negative impacts (Dew

et al., 2008; Pit-Ten Cate & Loots, 2000). The positive impact of having a sibling with a disability has potential benefits for everyone, as research suggests that siblings tend to pursue careers in helping professions and also engage in volunteer work (Milevsky & Singer, 2022); consequently, it is important to address the unmet needs of siblings, so the negative impacts do not overshadow the positive impacts.

Variables that affect sibling adjustment and coping

This raises the question as to why some siblings struggle to cope and have negative consequences when their sibling has a disability, while others experience no impact or experience growth and positive outcomes. This has not been widely explored internationally and even less so in Aotearoa/New Zealand. Understanding what affects siblings' abilities to cope and adjust to having a child in the family with a disability is difficult due to the number of factors that can impact the sibling. This section will identify some key variables that affect siblings' ability to cope.

Cultural context

There are differences internationally between countries in terms of how health systems work, what services and support are provided and how accessible these are. These differences have an impact on the experience of growing up with a sibling with a disability. In the international literature it has been found that culture has an impact on how siblings are impacted by disability (Marquis et al., 2019). Research in the United States of America found that Latino siblings had many more problems than other siblings including relationships with parents, internalising, and emotional issues (Lee et al., 2019). Caregiving roles have been found to be important in Latino families (Lee et al., 2019), much like in Māori families who

are also more likely to undertake caregiving responsibilities (Oskam, 2020). However, it has also been found that there are cross-cultural similarities in concerns that siblings experience, from children from areas such as Latin America, Africa and Asia-Pacific (Paul et al., 2021).

Most of the research to date on siblings of children with disabilities has primarily been from a western perspective, comprising of studies mostly from Europe and the United States of America (Lam et al., 2021). A review by Marquis et al. (2019) looked at 46 articles on siblings of children with intellectual/developmental disabilities written between 1970 and 2017 and found most came from the United States of America, the United Kingdom and a few from Australia. Similarly, another literature review that looked specifically at the siblings of children with ASD found that most of the literature to date has come from Europe (Watson et al., 2021). This means that this research may not be representative of Aotearoa/New Zealand siblings.

Aotearoa/New Zealand is bicultural and therefore has both western and non-western models of health used concurrently in our health system, including both medical and holistic models of health and wellbeing. Te Whare Tapa Wha is the most common holistic model of health used in Aotearoa/New Zealand and comes from Te Ao Māori (the Māori world view) (Durie, 2001). Within this world view is the concept of whānau (family) which is very broad and inclusive; relatives and friends can be part of the whānau too. A number of Māori children grow up as whāngai which involves being raised by whānau members who are not your biological parents as well as living in multigenerational households with extended whānau. Whāngai, cousins and siblings are all equally close, so all will be included in this research (Keane, 2017), to reflect the broader concept of whānau and different types of households. This is also in line with Te tiriti o Waitangi (Treaty of Waitangi) Aotearoa/New Zealand's founding document.

Tupou et al. (2021) have done a scoping review looking at 13 articles relating to Māori and Autism. They found that Māori are a diverse population and found Māori have differing perspectives on what Autism is and whether it should be labelled or not (Tupou et al., 2021). Differences and disabilities have been described by Māori as something that is a normal part of life, to be embraced and nurtured, which has both strengths and challenges (Tupou et al., 2021). In contrast Māori also describe disability as a consequence or punishment for a wrong doing committed by a family member in the past (Tupou et al., 2021). However, what they do have in common though is a holistic, interdependence connection and a strong emphasis on the influence of wider whānau and the interconnection between the person with a disability and their whānau.

It is also important that any intervention or support service is appropriate and responsive to diverse cultural needs. Lee et al. (2021) examined eight articles on the impact of cultural identity on siblings of children with disabilities and concluded that interventions need to be culturally responsive.

Parental differential treatment

Siblings felt that their needs were not seen due to the focus always being on their brother or sister with a disability (Hanvey et al., 2022). Research suggests that parents try to treat all their children equally but, do not always succeed in their attempts to do so (Pit-Ten Cate & Loots, 2000). Siblings found that their parents parented them differently to their disabled sibling and had different rules and expectations (Watson et al., 2021). Siblings also find that most of the attention from their parents is directed to the child with a disability (Watson et al., 2021). Parents are aware of not being able to provide as much care for their

non disabled children due to the amount of time they must spend on the child with a disability and may feel guilty for this.

This differential treatment also leads to some siblings feeling pressure to be responsible for many household duties. They also sometimes help with taking care of their siblings due to the lack of availability of others to do this (Watson et al., 2021). At the extreme end of this is the parentification of some siblings; instead of being able to enjoy the innocence and lack of responsibility of childhood, some of these children are required to support their parents when perhaps they should have been receiving support themselves (Murrin et al., 2021). Siblings need to feel like they are also a priority in their parents' life (Vella Gera et al., 2020) and without this, siblings sometimes feel jealous of the attention their sibling is getting (Dervishaliaj & Murati, 2014).

Gender

Gender has been found to be a variable that has a significant impact on siblings. Hamama and Gaber (2021) found gender differences in relation to a number of variables such as negative affect, flexible coping strategies and family cohesion. Female siblings have often been found to more frequently take on some level of caring role for their disabled sibling compared to their male counter parts (Marquis et al., 2019). It is also more expected of the female sibling to take on a caregiving role which is not expected of the male siblings (Marquis et al., 2019). Females have also been found to be more caring towards their sibling with a disability and more prosocial (Giallo et al., 2012). Generally, it is the oldest female sibling that does most of the caregiving (Donnan, 2020; Kandel & Merrick, 2003). In Aotearoa/New Zealand it has been found that siblings (regardless of sex) help out and support their sibling with a disability (McDonald et al., 2009). Due to more expectations being put on female siblings, this may mean differences exist in needs between genders.

Gender has also been found to be a moderating factor in the behaviour of siblings of children with disabilities. Older sisters showed more positive behaviour towards their ASD sibling compared to their counterparts (Bontinck et al., 2018). It has also been found that male siblings tend to have more conflict in relationships with their sibling who has Autism (Guidotti et al., 2021; Marquis et al., 2019).

Age and developmental stage

The sibling relationship may start as being reciprocal in the younger years but eventually the sibling may have to have some level of responsibility for the person with a disability. Depending on the disability, at some point younger siblings will developmentally overtake their older sibling who has a disability, which can result in that child then taking over the older sibling role. At this point some children will also assist in the caregiving of their sibling with a disability. As siblings get older they are often expected to be more involved in caregiving (Jacobs & MacMahon, 2016). As the child with a disability moves through different developmental stages their needs change (Giallo et al., 2012).

The ‘inheritance factor’ is another consideration for siblings (Burke, 2004), particularly as they age and develop. Several studies have found that siblings tend to worry about what the future may hold for both themselves and their sibling, what the plan might be around their care, what roles will be expected to undertake, and who will make the decisions around care if this is needed (Donnan, 2020; Gibbons & Gibbons, 2016; Jacobs & MacMahon, 2016; Pit-Ten Cate & Loots, 2000; Rossetti et al., 2018; Sommantico et al., 2020). This thinking about the future often starts happening in the adolescent years (Jacobs & MacMahon, 2016), which is a stressful time for any young person due to changes in the brain without adding in the complexities of having a sibling with a disability (Franklin et al., 2018).

Young adult siblings are often aware that disability could have an impact on their life into the future and they could inherit caregiving and decision-making responsibilities for their sibling.

The inheritance factor also pertains to an increased chance of having the disability yourself, a related disability, or having children with the disability. Siblings therefore may start to feel concerned about potential genetic issues in the teen years as this is the time developmentally when children start thinking about the future. Autism spectrum disorder has a significant genetic inheritance contribution to it. Up to 50 percent of cases of ASD are inherited due to genetic mutations (Zhao et al., 2007), although it is important to remember that a number of genes are involved in ASD. Siblings are also at risk of impairment in social skills but not at a level to be diagnosed with ASD (Sadock et al., 2014).

Down syndrome is a genetic condition as well, although is not generally hereditary. 95% of cases of Down syndrome occur by chance (Coppedè, 2016). The other 5% are hereditary and most caused by translocation where an extra copy of chromosome 21 is attached to another chromosome (Coppedè, 2016). Therefore, some siblings may be carriers of the translocation which increases their chance of having a child with Down syndrome themselves.

Cerebral palsy is also generally considered not be a heritable condition. However there are heritable pregnancy and birth conditions that increase the chance of having a child with cerebral palsy such as preeclampsia, preterm birth, breech position, foetal growth restriction and placental abruption (Schaefer, 2008). To sum up, genetic inheritance could be a concern for some adolescent siblings and a potential source of worry for siblings around their future.

Sibling relationship

There are a number of impacts on the sibling relationship when a child has a disability; often the relationship is impacted negatively. For example lack of closeness and emotional intimacy in the relationship has been found (Dew et al., 2008). Earlier research found that compared to other sibling pairs there is less competition, less prosocial behaviour, less intimacy and less nurturance (Kaminsky & Dewey, 2001). Relationships where one child has ASD have been found to have higher levels of conflict compared to other disabilities (Rixon et al., 2021). On the other hand, in other studies high levels of closeness have been found in sibling relationships with children who have intellectual and developmental disabilities (Sommantico et al., 2020). Therefore, it is apparent that not all sibling relationships are impacted in the same way by disability.

The size of family also impacts on relationships between siblings. Kaminsky and Dewey (2002) found that large family size helps facilitate healthy adjustment in siblings of children with ASD. It also means potential spreading of the burden between siblings, more hands to help out round the house (Dyke et al., 2009), as well as siblings being able support each other as often their parents are busy with their sibling with a whaikaha/disability.

There is much controversy surrounding the impact birth order has on siblings. In a literature review on the siblings of children with disabilities it was not clear whether birth order has an impact. It has been reported that if the disabled sibling is older than the siblings there is a disadvantage; when the disabled child is younger than the siblings there is an advantage. But other studies have found that birth order does not make any difference to siblings (Marquis et al., 2019). Black and colleagues found that in families of three children when the third born is disabled, the disability has a greater impact on the second born compared to the first born (Black et al., 2021). Parents perceived that their children were not

negatively by having a sibling with Down syndrome if the child was later in the birth order; they even thought it was beneficial (Black et al., 2020).

Disability type variable

Within the sibling literature there have been studies that look at the impact of disability severity and type. The findings show there are many similarities in the impact on siblings from different disabilities, but it is also clear that there are differences in how a disability affects a sibling. The similarities in the sibling experience show that there is value in looking at several disabilities to establish whether sibling needs can be met together instead of for each specific disability.

Throughout this literature review it has been highlighted that not all disabilities impact siblings equally. Autism has consistently been found to have the greatest negative impact on siblings compared to other disabilities such as Down syndrome and cerebral palsy. So much so that there is enough research on the siblings of children with ASD to be able to have a literature review that exclusively focuses on this, which is not the case for other disabilities (Watson et al., 2021). A study conducted by O'Neill and Murray (2016) found the siblings of children with Autism had elevated rates of anxiety and depression compared to siblings of children with Down syndrome. ASD also has challenging behaviour associated with it and this can have an impact on siblings (Carter et al., 2020). In addition, parents of children with ASD have been found to be more stressed than other parents, which has a greater negative impact on siblings compared to other disabilities (Meadan et al., 2009). This indicates that a categorical approach to studying the impact on siblings may be necessary due to potential differences in unmet needs of siblings of different disabilities.

Burden

Children of siblings with multiple disabilities can have more issues with emotional distress than a single disability alone (Marquis et al., 2019). This is because having more disabilities to manage and cope with causes a higher level of burden for families. Some studies found that higher levels of caregiver burden on parents predicted more externalising behaviours in siblings (Marquis et al., 2019). The level of burden has an impact on the amount of care siblings of children with whaikaha/disability receive from their parents as well as the amount of caregiving siblings do themselves. It is not known whether burden does have an impact as a study looking at the related concept of severity found no impact (Marquis et al., 2019). It is important to remember the experiences of siblings of children with disabilities are very individualised due to variation included under each a disability diagnostic label. Therefore, burden will also be included alongside the disability diagnosis.

Study Rationale and Aims

The first two chapters of this study have reviewed the literature and described the potentially negative impact of whaikaha/disability on a portion of siblings. The variables that affect siblings' ability to cope have been summarised and the gap in existing support services available in Aotearoa/New Zealand for siblings of children with disabilities has been described. The international research on the multiple effects (positive and negative) on siblings of growing up with a child with a disability is compelling as well as very mixed in terms of results. Many of the studies have vastly different methodologies which make it difficult to compare. However, research points to there being a number of siblings who are struggling with psychological issues, including depression, anxiety and stress symptoms.

A significant amount of the existing literature on siblings of children with disabilities relies on the outside view. Sibling experiences are reported on from the view of parents, teachers and professionals rather from the siblings' perspective. This reliance on observational reports can be problematic as a number of studies have shown that often a child's self-report and a parent's report on the sibling of a child with a whaikaha/disability do not match. Parents both overestimate and underestimate the impact on siblings. For example, Burke (2004) found that if the parent is struggling, they often assume that their child is also struggling with the same thing. This suggests that at times, the parents' report reflects how the parent sees things rather than the sibling. Parents also usually report more concerns than their children and if children report more concerns than their parents, they are usually young and male (Guite et al., 2004). Therefore, the present study focused on the perspective of siblings through their direct report to avoid the potentially distorted views from proxy perspectives. This is because they are the ones experiencing siblinghood and disability; if a support system is going to fill their needs and be appropriate, siblings' voices need to be heard and incorporated into any recommendations and design of services (Naylor & Prescott, 2004; Pavlopoulou & Dimitriou, 2020).

The interventions that have been developed internationally have relied on inferring what siblings need, based on their levels of anxiety or depression for example. Therefore, before developing a needs-based service it is important to do research that identifies the unmet needs of siblings of children with disabilities, across all levels of distress and issues. An aim of this study is that the results will contribute to the development of a needs based psychological service which will help support siblings' health and wellbeing.

The literature is unclear on whether a non-categorical or categorical approach is most appropriate for investigating childhood disability. The categorical approach involves comparing different specific disabilities e.g. ASD, DS and CP; this allows the ability to

compare the impact of specific disabilities that meet certain diagnostic criteria. On the other hand, using a non-categorical approach to disability and including all disabilities under one category, is problematic due to the range of conditions included under the banner of disability (see 1.2.1 Defining Disability). Some studies include chronic health conditions in disability as well. Combining the two means there is a lack of comparison between siblings of children with disabilities and siblings of children with chronic illnesses. As both have several commonalities putting them together makes some sense. But separating them and comparing them may make more sense as there are also some key differences.

Consequently, this study will investigate the unmet needs of the most common childhood whaikaha/disabilities in Aotearoa/New Zealand: autism spectrum disorder, Down syndrome and cerebral palsy. As resources are not infinite in Aotearoa/New Zealand, it is our ethical responsibility to cover a broad range of disabilities that affect the most siblings so that addressing the needs of siblings can benefit a maximum amount of this vulnerable sibling population. This information will be valuable for determining whether services established in this area will be able to be developed using a non-categorical approach.

Likewise, the literature is also unclear on whether chronic health conditions and disability should be investigated as separate categories; therefore, this study will compare previous findings around the unmet needs of sibling of children with cancer and serious chronic health conditions with the current study and siblings of children with disabilities in Aotearoa/New Zealand. Both disability and health conditions are looked after under the government healthcare system in Aotearoa/New Zealand.

This research was also narrowed down to three specific disabilities so a meaningful comparison could be made with siblings of children with cancer and serious chronic illness in Aotearoa/New Zealand as a recent thesis on this topic used the same instrument that is in this study (Armstrong, 2019). This is important for determining the most appropriate way forward

for support services to meet the needs of both populations of siblings in Aotearoa/New Zealand.

The literature is unclear whether burden has an impact on the psychological health and wellbeing of siblings. But what is known is that disability is extremely heterogenous and exists on a continuum; consequently, the impact of specific disabilities is not consistent. Therefore, burden will also be examined as two people can have the same disability, but it can impact the family in different ways and to a greater or lesser extent. As a diagnostic label is not always the best way of measuring impact on the family, an additional aim is to establish whether burden has an impact on sibling needs.

The influence of culture and health system on the impact of disability on siblings means that there is uncertainty about the representativeness of international literature for the Aotearoa/New Zealand population. Aotearoa/New Zealand is a bicultural nation where western and holistic models of health (such as Te Whare Tapa Wha) are used alongside each other. Aotearoa/New Zealand also has a vast number of ethnicities with many New Zealanders identifying as more than one ethnicity. There has been limited research regarding the impact of culture on siblings of children with disabilities; therefore, the general relationship of culture will be looked at, to be inclusive and in line with the Treaty of Waitangi (see section on culture).

Research aims:

- Identify whether siblings of children with disabilities including autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand have unmet needs, and if so, identify what these needs are.
- Identify the similarities and differences in the unmet needs of children with disabilities compared to existing research on siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand. This will involve

comparing the mean percentage of unmet needs of siblings of children with disabilities in Aotearoa/New Zealand with siblings of children with cancer, cystic fibrosis and diabetes in Aotearoa/New Zealand.

- Identify whether there are any differences in unmet needs between male and female, non-binary and other gendered siblings in Aotearoa/New Zealand and what these needs are.
- Identify whether there are any differences between siblings that are older than their disabled sibling or younger than their disabled sibling and if so, what are these.
- Identify whether the number of siblings in a family has an impact on the unmet needs of siblings of children with disabilities in Aotearoa/New Zealand.
- Identify whether the level of burden has an effect on the unmet needs of siblings of children with disabilities in Aotearoa/New Zealand.
- Identify whether there are any reported differences between the unmet needs of Māori and other ethnic groups of siblings of children with disabilities in Aotearoa/New Zealand and if so, what these needs are.

Chapter Three: Methodology

This chapter will describe the Methodology the current research utilises; the survey that was used; how participants were recruited; the criteria siblings had to meet to participate; how data was collected and stored; the analysis process; and important ethical considerations.

Research methodology

The positivist realist approach is based on the concept that there is an objective reality that is separate from the mind which can be observed and measured (Haigh et al., 2019). This approach also takes into account that reality is based on people's experiences both past and present as well as their interactions in society (Gilpin, 2006). Hence, it emphasises that to understand one's experience and perspective it is important to collect information such as gender, ethnicity, culture, age, socioeconomic status, as the understanding of a topic is dependent on the context in which the phenomenon occurs (Gilpin, 2006).

This research was also done from a reflexive stance, where making sense of the research topic, survey and subsequent data was from the perspective of being a sibling of a child with whaikaha/disability myself; making sense from an insider perspective (Iaquinto, 2016). Here my knowledge from living the experience of having a sibling with whaikaha/disability myself was combined with the literature, and the data from the current study was made sense of from this perspective. Thus bringing together both personal and academic experience (Fox & Wayland, 2020) to inform and interpretate the current study. The reflexive stance also aligns with the inclusive 'nothing about us without us' research approach which was developed in the disability sector (Jackson & Moorley, 2022) and has now spread to other stigmatised and minority groups.

Quantitative and Qualitative Research

The current study uses both quantitative and qualitative methods of collecting data to answer the research questions and explore relevant concepts. According to Guidotti et al. (2021), to understand the sibling experience in the most detail and depth it is important to gather both quantitative and qualitative data at the same time. The primary methodology for this study is quantitative with one qualitative question at the end.

Quantitative research is valued for its ability to answer specific research questions and test hypotheses, produce results that are objective, consistently reliable and able to be generalised (Greenhalgh et al., 2020). This is done by measuring and testing phenomena and collecting this data in a structured way. This is useful for looking at a phenomenon across a population because it produces statistical data which is important for generalising results and making inferences about the population, which assist in the determination of the needs of a population (Greenhalgh et al., 2020).

On the other hand, qualitative research is valued for its ability to discover ideas and interpret these in-depth and with a high degree of detail on a particular phenomenon (Greenhalgh et al., 2020). This is done in an unstructured way and allows participants to freely articulate what they think. This produces broad details focused data that requires interpretation to be able to come to a conclusion; this also produces an extensive amount of information on a particular phenomenon (Greenhalgh et al., 2020). Thus, the final question in the current survey is important for: discovering ideas and hearing different perspectives; gaining the unique perspective of siblings; and exploring what they feel will address their needs instead of assuming based solely on quantitative data.

Descriptive Research

Descriptive research is a type of observational study and as such is nonexperimental; there are no specific treatments given and instead things are allowed to happen naturally as they would outside of the lab environment (Greenhalgh et al., 2020). This type of research is particularly useful in situations where it would be unethical to subject people to certain conditions or impractical to do so. As is the case with the current study as it is not ethical nor practical to place a child with a disability into a family and then see what needs arise for the sibling in the family. Therefore, the current study uses a descriptive research approach which is used to describe a phenomenon that is already occurring, using a method that involves questionnaires and surveys.

Survey research

The online approach to survey research has become common place and is currently the most popular form of survey research. This is due to a number of factors such as the ability to distribute widely, maintain privacy and an automated data collection process (Greenhalgh et al., 2020). This makes this method particularly advantageous when it comes to researching hard to reach populations as well as populations that are invisible and have been excluded from the literature (McInroy, 2016). It is also useful for populations that are geographically isolated (McInroy, 2016). Further, from a safety point of view this method is also advantageous as participants are able to remain anonymous and do the survey in a location of their choice using a device of their choice. This gives access to populations that are currently understudied due to the social stigma of participating in research on sensitive topics (McInroy, 2016). The population in Aotearoa/New Zealand is small, predominantly rural and spread out, particularly in Te Wai Pounamu, the South Island. Not to mention the sibling disability population is not a population that has received much attention, and as such

is mostly invisible (Naylor & Prescott, 2004). Therefore, it is of great importance that a survey such as this is available in an online format.

The online survey in this study is also cross sectional and studies the sibling disability population at a single point in time. It measures a number of variables and characteristics at the same time in order to discover the commonalities in the population (McInroy, 2016).

Research questions

The current study aims to identify the unmet needs of siblings of children with disabilities in Aotearoa/New Zealand. Autism spectrum disorder (ASD), Down syndrome (DS) and cerebral palsy (CP) were chosen for inclusion in this research as their onset occurs in infancy, is persistent over time and lifelong. These three disabilities have the highest prevalence in childhood and vary in terms of the domains the child is most affected in. ASD has primally a behavioural impact, CP mainly impacts the physical and DS is more global in its impact.

As well as comparing and identifying the unmet needs of siblings with different disabilities the level of burden siblings subjectively experience was also a factor considered, due to the heterogeneous nature of disability and the inability of a diagnostic label to indicate how children are affected by disability.

The questions being asked in this research were:

- Do siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand have unmet needs and if so, what are they?
- What are the similarities and differences in unmet needs between siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand?

- Are there differences in the unmet needs of female siblings, male siblings and other gendered siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand?
- Are there differences in the unmet needs of siblings of high burden children, medium burden and low burden children with autism spectrum disorder, Down syndrome and cerebral palsy?
- Are there differences in the unmet needs of siblings who are older than the child with autism spectrum disorder, Down syndrome and cerebral palsy and siblings who are younger than the child with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand?
- Are there differences in the unmet needs of siblings of differing ethnicities of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand?
- Are there differences in the unmet needs of siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand and siblings of children with cancer, cystic fibrosis and diabetes in Aotearoa/New Zealand?
- Explore the relationship between sibling needs and siblings' subjective level of burden on them and their family/whānau.
- Explore the relationship between disability diagnosis and level of burden siblings subjectively experience.

Method

Participants

Criteria

To determine if participants were eligible for the current study – the Sibling Disability Needs Survey – participants were asked a series of demographic questions to ensure they met the criteria: be age 18 years or over; have a sibling or someone who was like a sibling (cousin, whāngai) who is diagnosed with autism spectrum disorder, Down syndrome or cerebral palsy; and that they grew up living with their sibling/whānau member in Aotearoa/New Zealand.

The minimum age of eighteen years old was chosen because it allows siblings the autonomy to participate in research without requiring the consent of their parents and protects younger more vulnerable children from harm as they may not fully understand the consent process. The minimum age of eighteen is also so that siblings are able to reflect on their experience through the passage of time and mentally process their experiences. Older siblings are less entrenched to the family system and have a bit more psychological distance due to their age. Having the requirement of growing up with a child with a disability is in reference to the long-term nature of disability and ensuring siblings have lived with the child who has a disability throughout many changes occurring during the life course. This is also because this research is aimed at investigating the unmet needs of siblings who have spent a significant period of their lives living with their disabled sibling.

Recruitment

The snowball method was the primary method used to recruit participants. I utilised my personal networks to distribute information about the research and recruit participants. Social media was also a significant method of distributing the link for the survey. A number of organisations who work with families of children with disabilities assisted with distribution of the information about the research and the link to the survey, including Autism New Zealand, Cerebral palsy Society New Zealand, New Zealand Down syndrome Association, Altogether Autism, Parent to Parent, and Young carers New Zealand. Interested potential participants were mainly recruited though social media and email. They were asked to click on a link and follow this to the information sheet which had further information explaining what the research was about and written informed consent.

The advertisements included a link to the survey which started with an information sheet (see Appendix A). In this sheet was information about the current research, the purpose and importance of it. The criteria, research procedure, how data will be managed, what the possible risks of participation might be, how to access support, participants rights and contact details for more information about the study were included in the information sheet. After the information sheet was a page on consent which required participants to select yes confirming their consent and then the survey began.

Measures

There were two measures adapted for use in the current study: the Zarit Burden Interview (ZBI) and the Sibling Cancer Needs Instrument (SCNI). The adaptions allowed them to be used in the online environment and for an Aotearoa/New Zealand sample. These measures were also adapted so they are appropriate for siblings of those with disabilities.

Zarit Burden Interview (ZBI)

Permission was granted by the author Zarit, through Mapi Research Trust who oversee the distribution of the ZBI-22 (Zarit et al., 1985) to adapt the measure for use on the sibling population in Aotearoa/New Zealand in an online format.

This measure was chosen and edited for siblings as they have not previously been looked at regarding how much burden they perceive them and their family/whānau have experienced. From an extensive review of the literature, it was determined that it was important to measure burden due to the inability of disability diagnostic labels to indicate the level of severity of a disability. Inclusion of burden allowed for the exploration of the relationship between disability, burden, and needs as looking at disability and needs only may not give the full picture of how siblings are impacted.

This measure originally had 29 items and was used for looking at caregiving burden for those looking after someone with dementia (Zarit et al., 1980). Later it was reduced to 22 items which is frequently used for studies throughout the world and in many different languages (Hagell et al., 2017), including Aotearoa/New Zealand (Oskam, 2020). This made it the most appropriate burden measure to adapt for siblings of children with disabilities in Aotearoa/New Zealand.

This measure includes a 5 point Likert scale for each of the 22 items: 0 never, 1 rarely, 2 sometimes, 3 quite frequently, 4 always (Zarit et al., 1985). Total scores for this measure have been interpreted in different ways depending on the measures use, it is generally taken that scores above 21 indicate burden (Hagell et al., 2017) and scores over 41 indicate high burden (Oskam, 2020). Therefore, it follows that scores were interpreted as 0-20 little or no burden, 21-40 mild to moderate burden, 41-60 moderate to severe burden, 61-88 severe burden. The range is from 0 to 88. For this study the score has been interpreted to

represent the level of burden that the sibling and their family/whānau had experienced and was calculated by taking the sum of all items.

It has been found that ZBI performs very similarly to the Family Burden Interview Scale in terms of psychometric properties, including convergent validity and internal consistency (Yu et al., 2020). This measure has been validated across countries and languages with different populations of caregivers (parents, children, partners) (Yu et al., 2020). Therefore, it was concluded that this measure is likely to be suitable for use in the current study.

Adaption of the ZBI to the Sibling Burden Interview (SBI)

The ZBI has been adapted to the SBI and involved the following modifications which have been made to better reflect and capture the sibling perspective:

1. Replacement of the word 'relative' with the words 'sibling/whānau member'. Example question 4 reads "Do you feel embarrassed over your sibling/whānau member's behaviour?".
2. Replacement of the word 'family' with the words 'family/whānau'.
3. Question 3 has been changed from 'Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?' to 'Do you feel stressed between the needs your sibling/whānau member has and trying to meet the other responsibilities you have?'. This is so that it better reflects the sibling experience rather than the parent or primary caregiver.
4. Question 8 has been changed from 'Do you feel your relative is dependent on you?' to 'Do you feel your sibling/whānau member is dependent on your family/whānau?'

5. Question 12 has been changed from ‘Do you feel that your social life has suffered because you are caring for your relative?’ to ‘Do you feel that your social life has suffered because of your sibling/whānau member?’
6. Question 14 ‘Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?’ to ‘Do you feel that your sibling/whānau member seems to expect you to take care of him/her more than they should?’
7. Question 15 has been changed from ‘Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?’ to ‘Do you feel that your family/whānau do not have enough money to take care of your sibling/whānau member in addition to the rest of your expenses?’
8. Question 16 has been changed from ‘Do you feel that you will be unable to take care of your relative much longer?’ to ‘Do you feel that your family/whānau will be unable to take care of your sibling/whānau member much longer?’
9. Replacement of the word ‘illness’ with ‘whaikaha/disability’ as this survey has been altered for people who have siblings with whaikaha/disability. For example, Question 17 now reads ‘Do you feel you have lost control of your life due to your sibling/whānau member’s whaikaha/disability?’
10. Question 18 changed from ‘Do you wish you could leave the care of your relative to someone else?’ To ‘Do you wish your family/whānau could leave the care of your sibling/whānau member to someone else?’
11. Question 19 ‘Do you feel uncertain about what to do about your relative?’ To ‘Do you feel uncertain about what your family/whānau should do about your sibling/whānau member’s care?’

12. Question 21 ‘Do you feel you could do a better job in caring for your relative?’ To ‘Do you feel that your family/whānau could do a better job in caring for your sibling/whānau member?’
13. Several questions have been worded to ask siblings how they feel their family is burdened rather than only themselves to reflect the notion that whaikaha/disability impacts the whole family system. Question 22 ‘Overall, how burdened do you feel in caring for your relative?’ To ‘Overall, how burdened do you feel your family/whānau is in caring for your sibling/whānau member?’

Sibling Cancer Needs Instrument (SCNI)

Permission was granted by Canteen Australia to adapt the SCNI (Patterson et al., 2014) for use in the current study. The SCNI was modified for use in an online survey format as well as in the Aotearoa/New Zealand context. This instrument has also been adapted for whaikaha/disability (the focus of this research) and a group of siblings that share several similarities with cancer and health conditions.

The SCNI was originally developed in Australia to look at the unmet psychosocial needs of young people who have a sibling with cancer so they could develop interventions and support to meet the need that siblings have as well as evaluate the current support services that were available (Patterson et al., 2014). Later the SCNI was modified to be able to look at the unmet needs of young people who have a parent with cancer, this is called the Offspring Cancer Needs Instrument (Patterson et al., 2017). In Aotearoa/New Zealand the SCNI has recently been successfully modified to look at chronic health conditions as well as cancer via an online survey (Armstrong, 2019). This shows that the SCNI is applicable to the

Aotearoa/New Zealand population and suggests that the instrument may also be valid for the whaikaha/disability population which is closely related to chronic health conditions.

For the current study, the original instrument was modified to reflect the culture of Aotearoa/New Zealand as well as the whaikaha/disability context. The resulting instrument was then referred to as the Sibling Whaikaha/Disability Needs Instrument (SDNI).

The above measure was also be used so that a comparison can be drawn between siblings of children with chronic illnesses and siblings of children with whaikaha/disabilities in Aotearoa/New Zealand. A recent master's thesis in Aotearoa/New Zealand used this instrument to look at siblings of children with cancer, type 1 diabetes and cystic fibrosis (Armstrong, 2019).

Psychometric properties of the SCNI

Canteen Australia developed the SCNI for siblings aged 12 to 24 years old who have a sibling with cancer. The measure currently has 45 items and was reduced from 73 items using Rasch analysis (Patterson et al., 2014). The 45 item SCNI has 45 items across 7 domains including information about my sibling's cancer, 'time out' and recreation, practical assistance, support from friends and other young people, dealing with feelings, understanding from my family and my relationship with my sibling who has cancer. Under each of the seven domain headings was the phase 'I currently need', followed by the questions relate to that domain. Each question was answered on a 4-point Likert scale: 1 no need, 2 low need, 3 moderate need and 4 strong need.

In being consistent with other research using the SCNI, for the purposes of data analysis the results were spilt into two groups: 1 no need and 2 low need represented needs met; 3 moderate need and 4 strong need were categorised as unmet needs (Armstrong, 2019; Patterson et al., 2017). The proportion of unmet needs was calculated by taking the number of

unmet needs and dividing it by the total number of responses; this was expressed as a percentage.

A modified version of the SCNI was used in Aotearoa/New Zealand on siblings of children with cancer and chronic illnesses (Armstrong, 2019). This measure had a Cronbach's alpha of 0.97 indicating of high level of internal consistency for this population (Armstrong, 2019). Therefore, it is highly likely that this measure is also appropriate for the sibling whaikaha/disability population in Aotearoa/New Zealand. Construct validity was established for this measure as well using the Varimax criterion, this indicated that the items congregated together in the same way that the original SCNI did (Armstrong, 2019).

Adaption of the SCNI to the Sibling Whaikaha/Disability Needs Instrument (SDNI)

The adaption of the SCNI to the SDNI involved the following modifications:

1. Replacement of the word 'sibling' with the words 'sibling/whānau member'
2. Replacement of the words 'I currently need' to 'I needed' to reflect siblings answering the survey in retrospective based on what they felt they needed growing up with a sibling with whaikaha/disability.
3. Replacement of the word 'cancer' with the words 'whaikaha/disability' as this measure is now being used in the whaikaha/disability context.
4. Question 2, replacement of the word 'condition' with the word 'whaikaha/disability' as this is more appropriate.
5. Question 3, 'To be able to get information about my sibling's type of cancer and its treatment in a way that I can understand' rewritten, 'To get information about the type of whaikaha/disability and assistance and/or treatment my sibling/whānau member needs in a way that I can understand'; these changes make the question appropriate for disability as well as for siblings looking back at their childhood.

6. Question 4, the word ‘treatment’ changed to the words ‘treatment/therapy’ as whaikaha/disability commonly has therapy as well as treatment.
7. Question 5, the words ‘cancer and treatment’ to the word ‘whaikaha/disability’ as this makes better sense for the sibling whaikaha/disability population.
8. Replacement of the words ‘health care professionals’ to ‘health care and whaikaha/disability professionals’; this takes into account the whaikaha/disability perspective.
9. Question 10, ‘To feel like a 'normal' young person, which it seems I’ve lost as a result of my sibling’s cancer’ to ‘To feel like a 'normal' young person, which it seems has been affected by my sibling/whānau member’s whaikaha/disability’. Lost implies that the siblings had something before to lose; this does not make sense for siblings of children with a whaikaha/disability as there is not often a distinguishable time before whaikaha/disability due to the age of siblings.
10. Question 16, the last word ‘anymore’ deleted because it does not make sense for whaikaha/disability as there is not always a time before whaikaha/disability.

Aotearoa Sibling Whaikaha/Disability Needs Survey

The final survey consisted of demographic questions, followed by the Sibling Burden Interview and Sibling Whaikaha/Disability Needs Instrument. Several demographic questions were bilingual to ensure the survey is inclusive towards Māori.

The following demographic questions were included:

- Did you grow up with a sibling with a Whaikaha/disability? (options: yes, no)

- What is your gender? (options: Male/Tāne, Female/Wahine, Gender Diverse/Irahuhua, prefer not to disclose) Options for gender are in line with the Stats NZ statistical standards that were updated in 2021. This follows the empirical evidence that shows gender exists on a spectrum and is non binary (Cameron & Stinson, 2019). This question was included as research has shown that gender has an impact on children's experience of being a sibling of a child with a whaikaha/disability.
- What is your ethnicity? (options: Māori, Pākeha/NZ European, Pacifica, other) Options for ethnicity have been chosen as they are the same as for the New Zealand Census 2018. Participants can select more than one ethnicity, as this acknowledges that many New Zealanders come from diverse ethnic backgrounds. This question has been included as research has shown that culture and ethnicity have an impact on siblings' experiences of have a brother or sister with a whaikaha/disability. Therefore, it is important to be able to know something about the diversity of siblings being studied.
- What whaikaha/disability has your sibling/whānau member been diagnosed with? (options: Autism spectrum disorder/Asperger's Disorder, Down syndrome and Cerebral palsy). Both Autism spectrum disorder and Asperger's Disorder written in as some siblings may have been diagnosed under the old Diagnostic Statistics Manual DSM4 which listed these as separate disorders.
- What is your current age?
- How many parents were in your primary household? (options: 1, 2 or more than 2)
- What age is your sibling compared to you? (options: older, younger, same)
- How many siblings do you have?

- What region did you and your sibling who has a whaikaha/disability grow up in? (options: Te Tai Tokerau – Northland; Tāmaki makau rau – Auckland; Waikato, Te Moana a Toi – Bay of Plenty; Te Tai Rāwhiti – Gisborne; Te Matau a Māui – Hawkes Bay; Taranaki, Manawatū/Whanganui, Te Whanga nui a Tara – Wellington; Te Tai o Aorere – Tasman; Whakatū – Nelson; Te Tauihu o te waka – Marlborough; Te Tai Poutini – West Coast; Waitaha – Canterbury; Otākou – Otago; and Murihuku – Southland).

After completing the demographic questions participants were presented the first of two measures, the SBI which has 22 questions. This section of the survey measured the subjective burden that siblings and their family/whānau experience due to having a child with a whaikaha/disability. The SBI included the adaptions mentioned previously with the 5-point Likert scale that was used in the ZBI-22.

Following the SBI was the SDNI a 45-item measure adapted from the SCNI. As mentioned previously this measure included the seven same domains as the SCNI, adapted to include whaikaha/disability related language, as well as the same 4-point Likert scale. This section measured the number and type of unmet needs siblings had when they were growing up with a sibling who has a whaikaha/disability.

Finally, these measures were followed by the final question in the survey which was an open-ended qualitative question.

On completion of the survey participants selected the submit button and their responses were electronically collected by Qualtrics software. This online survey software was chosen as it is a well-known software used by many universities for the purpose of research and collecting data due to its ease of use and ability to be used in a range of devices

and easily shared on social media (the primary method of recruiting); but most importantly it is known for being a highly secure platform (Qualtrics, 2022).

Data Analysis

The statistics packages used to examine the data exported from Qualtrics was RStudio (name changed to Posit October 2022) which is a free, open-source statistical package using the programming language R and SPSS (Statistical Package for the Social Sciences) which is a paid statistical analysis software. Mean percentages of unmet needs for males and females were compared using an independent groups t-test; likewise a comparison was made between one and two parent households. A comparison of the three disabilities was presented. A comparison of the four levels of burden was presented. The relationship between disability type and burden was explored with descriptive statistics and appropriate graphs. This was done for each domain and item in the survey and each disability condition. Mean number of needs of siblings was reported along with the standard deviation and range. In addition, a comparison was made between the unmet needs of siblings of children with Autism spectrum disorder, Down syndrome and Cerebral palsy in Aotearoa/New Zealand and siblings of children with cancer, diabetes and cystic fibrosis in Aotearoa/New Zealand.

The qualitative method of thematic analysis was applied for the final question to uncover the themes of how siblings think their needs could be met. Reflexive thematic analysis – using the researchers own experiences and knowledge to interpret the data - was used for the interpretation of the qualitative data (Braun & Clarke, 2019). This involved using my own pre-existing experience of having a sibling with whaikaha/disability in conjunction with knowledge gathered from the literature review to interpret the written responses from participants. The thematic analysis was done in accordance with Braun and Clarke (2006) six

stages of thematic analysis which involved ‘familiarising myself with the data’ followed by ‘generating codes’ then ‘searching for themes’, ‘reviewing themes’ then ‘defining and naming themes’ and finally ‘producing a report’.

Ethical considerations

Full ethical approval was obtained from the Massey University Human Ethics Committee prior to recruiting participants to complete the survey.

It was considered that there is a possible risk of harm to participants due to the close nature of the sibling relationship and asking participants to reflect on a potentially traumatic period of their lives. Therefore, to ensure the safety of participants, the consent page of the survey stated that participants should seek advice from a health professional before completing the survey if they were receiving hospital-based care for a mental health condition. Although it was considered unlikely this online survey would cause harm to participants, it was still important to minimise the potential harm and psychological discomfort this survey could cause. The following steps were taken to mitigate any risk of harm to participants.

- When the survey was submitted by the responder, a thank you page was displayed that included the details of available support services should participants need them.
- Participants were also informed at the start of the survey that they have the freedom to miss out specific questions or stop doing the survey at any time.
- The data collected from the study was completely anonymous and included no identifying information with the responses. The data collected was only used for the purpose of research. All data was collected using Qualtrics using

Massey University's School of Psychology (Te Kura Hinengaro Tangata) licence for this software. Data was initially stored on Qualtrics cloud-based system that was password protected; later data files were downloaded to a local computer also protected by password for data analysis.

- A predominantly quantitative approach limited the impact of my own biases in relation to growing up with a sibling with a whaikaha/disability myself. This approach is objective which means mitigating the potential for my personal views to impact the results.
- The survey and results were reviewed by my supervisor (a senior clinical psychologist and Associate Professor) to enhance the trustworthiness of the findings. There was also commitment to following the principles of good qualitative research as outlined by Yardley (2000). The qualitative data was checked against previous findings of siblings of children with disabilities to ensure was generally typical of siblings. The qualitative findings were also compared with the quantitative data which also contributed to ensuring the interpretation was unbiased. Doing this research from the perspective of being a sibling of a child with a whaikaha/disability myself has been important for making sure the measures make sense for siblings as well as being beneficial for the interpretation of the qualitative question. It is also an advantage from a recruitment point of view as siblings maybe have been more likely to participate when they knew the person conducting the research 'gets it' and understands their point of view.

Cultural considerations

As part of the ethical considerations for this research cultural considerations were included too. This is because here in Aotearoa/New Zealand though the principles of Te Tiriti o Waitangi/Treaty of Waitangi (participation, protection and partnership), research must be conducted in a way that is consistent with these. To ensure this took place cultural consultation was sought as part of the process of ensuring the research is ethical with regards to Māori who are likely to participate in the research. A number of words in the survey were written in both Te Reo and English (see appendix for details), as using inclusive language is important for inclusion and participation of different ethnicities. The information sheet also included details such as defining a sibling as someone who is like a sibling, and includes brothers, sisters, cousins and whāngai; this is because what is considered a sibling is much broader in Te Ao Māori (the Māori world). The information sheet also incorporated the concept of Whakawhānaungatanga, the process of establishing relationships and connecting. At the start of the information sheet, I explained my connection to the research kaupapa/topic and where I come from as part of introducing myself.

My personal relationship with the topic was important for forming a relationship of understanding with the participants of my study; it was important to inform my participants that I have a sibling with a disability. This assured participants that the answers they provide will be examined and reported by someone who understands first-hand the experience of being a sibling with a disability. The measures used were altered to align with the perspective of having a sibling with a disability who grew up in the Aotearoa/New Zealand context. Sharing my story was important for connecting, showing understanding and helped participants to feel at ease in participating in the research. I took great care to ensure my research was appropriate for siblings within bicultural Aotearoa/New Zealand. It is also

hoped that the participants will benefit from the study in knowing that their experiences of disability are legitimate and understood.

This research predominantly used a mainstream approach, as different ethnicities including Māori participated in the research but were not the focus of the research. The ethnicity data was not of primary importance to the research itself but is valuable as a baseline and to ensure the sample is representative of the Aotearoa/New Zealand population. This was important as this research aimed to identify the unmet needs of siblings with the view this information will be used to better support the health and wellbeing of siblings of children with disabilities in Aotearoa/New Zealand in the future. This also allows other researchers to further build on this research and investigate differences in greater depth.

Participants had the autonomy to consult whoever they choose to in respect to the research and seek whānau support. Participants could likewise choose to not share their participation in research with anyone. People could follow protocols that were important to them with regards to participating. Participants were informed of the risks of participation to both themselves and others.

It was not anticipated that the research would impact Māori more negatively than other ethnic groups. Childhood disability is more common in Māori 15% compared to New Zealand European 9%, (Statistics New Zealand, 2014); however this is not the case for the disabilities being included in this study. Slightly more New Zealand European children are diagnosed with ASD compared to Māori, rates of children with Down syndrome are similar for both ethnic groups, these both have a primarily genetic etiology (Craig et al., 2013). Since there is no prevalence rate data for Cerebral palsy, hospital admission data for children with Cerebral palsy is looked at and New Zealand European children were found to have slightly higher rates of this condition (Craig et al., 2013). Therefore, these three disabilities were chosen as they have similar prevalence rates across ethnicities.

Chapter Four: Results

Chapter overview

This chapter describes the results of the current study. The aims of this study were to identify the unmet needs of siblings of children with Autism spectrum disorder, Down syndrome and Cerebral palsy in a Aotearoa/New Zealand Sample. Comparisons have been made between family burden and unmet needs, whaikaha/disabilities, Māori and non-Māori, whaikaha/disability and cancer and serious chronic health conditions, age groups, older vs younger siblings, genders, number of caregivers, and number of siblings. Both RStudio software (V2023.06.1+524) and the statistical package for the social sciences software (SPSS V28) was used to analyse the results.

Throughout this chapter the seven domains included in the Sibling Disability Needs Survey will be referred to by their abbreviation as outlined in Table 1.

Table 1

Abbreviated Domain Names of the Sibling Disability Needs Instrument

Domain	Number of items	Abbreviation	Need:
Information about my sibling/whānau member's whaikaha/disability	8	INFORMATION	For information about their siblings whaikaha/disability and associated treatment in a easily understandable and age appropriate way.
"Time out" and recreation	6	TIME OUT	To have a break or time out away from the disability and be able to do sport or social activities
Practical assistance	3	ASSISTANCE	For support with daily living including household chores, education, work and connection with relevant support services

Dealing with feelings	8	FEELINGS	To be able to express their feelings about their siblings disability and how it has impacted them and their needs for help with their feelings.
Support from friends and other young people	8	FRIENDS	To feel supported and understood by their friends regarding their experience of whaikaha/disability and to be able to spend time with other siblings experiencing the same thing.
Understanding from my family	5	FAMILY	To feel supported and acknowledged by their family and be able to tell them about their experience with disability
My relationship with my sibling who has a whaikaha/disability.	7	SIBLING	For help with their relationship with their disabled sibling and issues arising in this relationship

Quantitative Results

Sample overview

Data screening

The data was checked for missing values prior to being analysed. Where there were more than half the answers missing for a domain that domain was not included for that participant. When a domain was missing less than half the responses, the mean was taken from the answers that were given. Domain means were used as the total for each domain. As a result, the sample size will vary between domains and will depend on the type of analysis carried out.

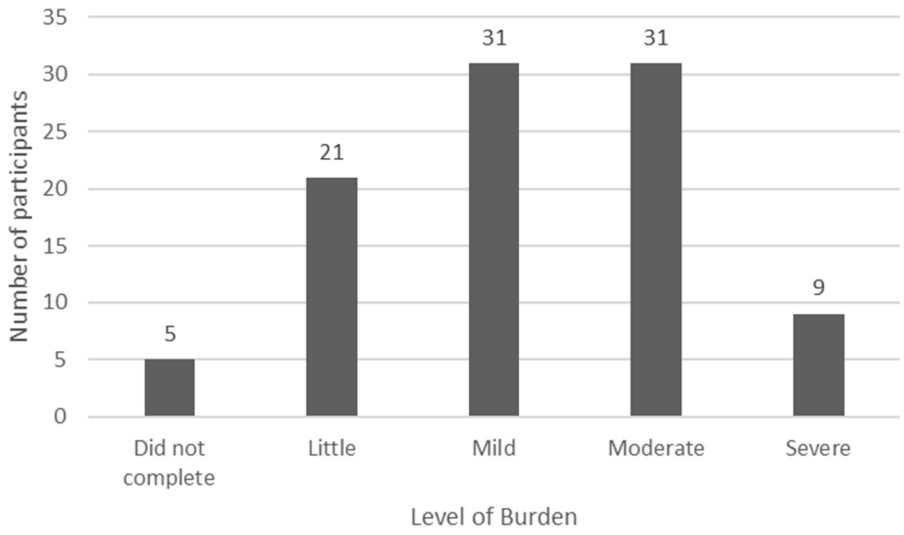
Sample characteristics

Of the 141 respondents the final sample included 97 participants, with a mean age of 25.45 years (SD = 6.213) and mode 18 years. This sample included 77 females, 18 males, and 4 gender diverse. The ethnic breakdown is as follows: 86 identified as New Zealand European, 20 Māori, 2 Samoan, 1 Cook Islands Māori, 1 Tongan, 2 Chinese, 2 Indian, 1 English, 1 Fijian, 1 Irish, 1 Japanese, 1 Pakeha and 1 who preferred not to say. In this sample there were 55 siblings of children with autism spectrum disorder (ASD), 39 siblings of children with Down syndrome (DS), and 11 siblings of children with cerebral palsy (CP).

The profile of the participants in terms of burden is shown in Figure 2.

Figure 2

Distribution of Participants Across Burden Levels



A subset of 81 of the final sample included participants that answered more than half the questions in each domain. The mean age for this group is 25.25 (SD = 6.141). This sample included 37 siblings of children with ASD, 30 siblings of children with DS, 6 siblings of children with CP, and 8 siblings of children with ASD plus either DS or CP. This data subset was used for the analysis of the domains and will be referred to as the domain sample.

A subsequent subset of the final sample included 69 participants who answered all questions in the Sibling disability needs instrument. There were 32 siblings of children with ASD, 25 siblings of children with DS, 6 siblings of children with CP and 6 siblings of children with ASD plus either DS or CP. This data set will be used for the comparing unmet needs with burden and unmet needs with age as well as the numbers and proportions of unmet needs.

The largest sample possible was used for each analysis.

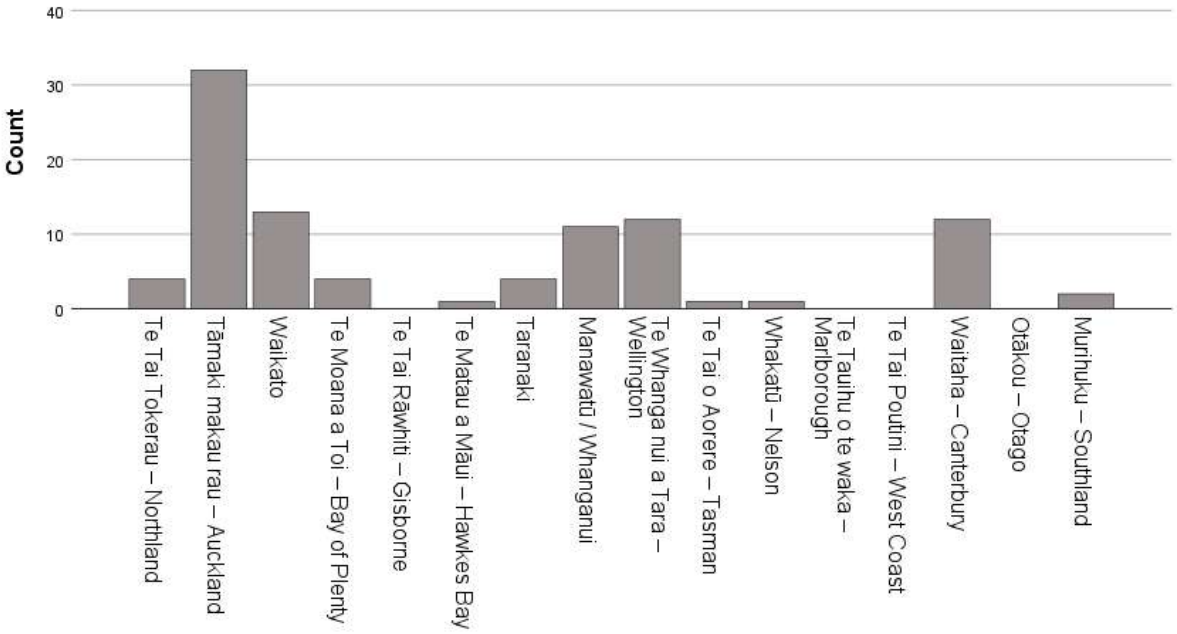
Regional response

The majority of regions were represented in this study (see

Figure 3). Thirty three percent of respondents lived in Tamaki Makaurau/Auckland (*n* = 32), this is roughly proportional of the Aukland population compared to the rest of the country. The region with the next highest number of participants is Waikato (*n* = 13), followed by Te Whanga nui a Tara/Wellington (*n* = 12), and Waitaha/Canterbury (*n* = 12), then Manawatū/Whanganui (*n* = 11). Te Tai Rāwhitit/Gisborne, Te Tauihu o te waka/Marlborough, Te Tai Poutini/West Coast and Otākou/Otago had no participants.

Figure 3

Number of Responses from Each Region



Disability Diagnosis

The disability with the highest number of respondents was ASD (*n* = 55) followed by DS (*n* = 39) and lastly CP (*n* = 11). Included in this was a small group of siblings who were siblings of children with two disabilities - either ASD and DS, or ASD and CP.

Psychometric properties of the Sibling Needs Survey

Face and content validity

The sibling disability needs survey used the same items as the SCNI; these were edited so they made sense to siblings looking back on their childhood growing up with a sibling with a whaikaha/disability. The language used in the SCNI was also edited to reflect biculturalism in Aotearoa/New Zealand. Face and content validity were already established for the SCNI in a study where siblings and staff from the cancer community were consulted and qualitative data was collected (Patterson et al., 2014; Patterson et al., 2011). Further an edited version of the SCNI that has already been used on siblings of children with cancer, cystic fibrosis and diabetes in Aotearoa/New Zealand which found that all items were endorsed by at least one participant (Armstrong, 2019). In the current study all items were endorsed by at least one respondent which indicates that the items are relevant for identifying the needs of siblings of children with disabilities in Aotearoa/New Zealand.

Construct validity

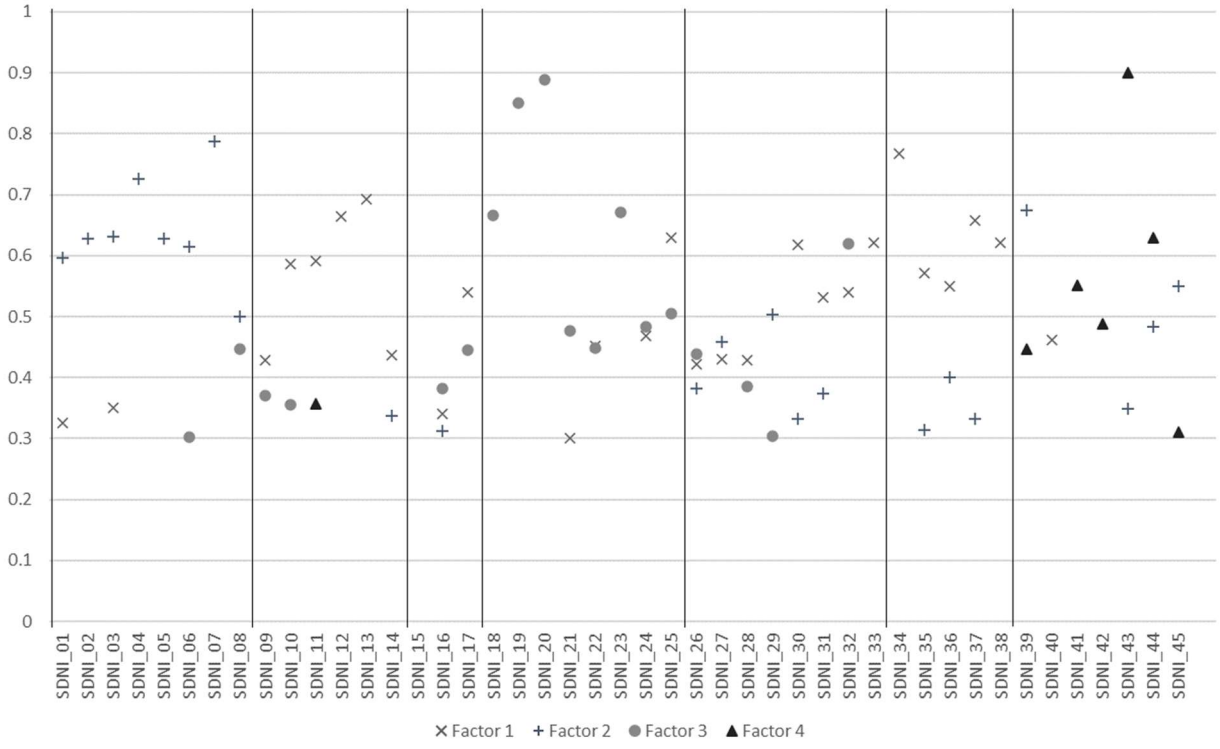
A parallel analysis was performed on the current data using RStudio software and the varimax criterion; this indicated that the number of factors that the data can support is four, the original SCNI also supports four factors (Patterson et al., 2014).

Figure **4** shows the factor loading for each item of the SDNI and is divided into domains. Only factor loads of more than 0.3 were plotted on the graph so that the relationship between the items and factors was able to be distinguished. Doing this meant that item 15, in the ASSISTANCE domain did not have any factor loading. Factor 1 had the highest loading for all items in the INFORMATION domain. Factor 2 had the highest loading for all items in the TIME OUT and FAMILY domains. Factor 3 was highest for nearly all items in the

FRIENDS domain. Factor 4 was mostly only in the SIBLING domain. All domains show so their items are loaded across the domain in a similar way apart from ASSISTANCE and FEELINGS where the factor loadings do not show a pattern. This shows that the links intended by the developers of the SCNI may not reflect the way siblings of children with whaikaha/disability in Aotearoa/New Zealand report the items. This suggests that some items and domains may have lower construct validity.

Figure 4

Exploratory Factor Analysis of Sibling Disability Needs Instrument with Factors, Items Grouped by Domain



Internal consistency

Cronbach's Alpha was calculated for each domain and sample as a whole. Internal consistency was found to be excellent for the SDNI (α = 0.963). Further, all domains had excellent internal consistency; INFORMATION (α = 0.892), TIME OUT (α = 0.853), FRIENDS (α = 0.904), FEELINGS (α = 0.885), FAMILY (α = 0.892), and SIBLING (α = 0.840), except ASSISTANCE (α = 0.699), which had an acceptable level of consistency.

Unmet needs in an Aotearoa/New Zealand population

For the analysis of the numbers and proportions of unmet needs for the individual items in the SDNI the sample that completed every question was analysed (*n* = 69). This groups mean number of unmet needs was 25.47 (SD = 13.35, range 0-45) and the most commonly reported number of needs was 41. 94.2% of respondents endorsed at least one unmet need, 84.1% of respondents endorsed ten or more unmet needs, and 50% of participants indicated they had 28 or more unmet needs. The mean percentage of unmet needs was 59.6%.

For the analysis of unmet needs for each domain, the number of participants that provided enough responses to provide a valid score for any domain were included. The domains with the highest proportion of unmet needs were FRIENDS (66.3%) followed by FAMILY (64.3%) and TIME OUT (62.1%). The domain with the lowest proportion of unmet needs was INFORMATION (43.0%) (see Table 2). Table 2 shows the mean proportion of unmet needs for each domain.

Table 2

Mean Proportion of Unmet Needs for Each Domain

Domain	Items	*n*	Mean	SD
FRIENDS	8	86	0.663	0.476

FAMILY	5	84	0.643	0.482
TIME OUT	6	87	0.621	0.488
FEELINGS	8	84	0.560	0.499
SIBLING	7	83	0.494	0.503
ASSISTANCE	3	86	0.488	0.502
INFORMATION	8	86	0.430	0.498

For the analysis of the mean percentage of unmet needs for each individual item the sample included participants who provided a valid answer for any item, who also provided a valid answer for any of the domains on the SDNI. The most commonly endorsed item by participants was item 24 ‘To have had someone close to discuss my feelings about my sibling/whānau member’s whaikaha/disability’ (72.9%), followed by ‘To be able to have fun’ (71.8%) ,then ‘To have been able to express how I felt about my sibling/whānau member’s whaikaha/disability without worrying about upsetting people’ (71.4%), followed by ‘To be able to spend time with my parent/s - just me and them’ (70.2%) (see

Table **3**). These top 4 unmet needs are also from 4 different domains, with domains FRIENDS, TIME OUT, FEELINGS and FAMILY being represented respectively. All FRIENDS domain items were in the top 25 most reported unmet needs.

The least commonly endorsed need by siblings was item number 41 ‘To have 'time-out' with my sibling/whānau member away from 'the whaikaha/disability'’ (28.9%), closely followed by ‘Information about what happens after my sibling/whānau member came home following treatment/therapy’ and ‘Assistance with managing daily tasks’ (both 30.9%) (see Table 3). Half of the 6 lowest ranked items reported by siblings were from the INFORMATION domain.

Table 3

Mean Percentage of Unmet Needs for Each Item (Ranked form Most Endorsed Unmet Need to Least Endorsed Unmet Need)

Item ranking	Domain	Item wording: I needed:	% Respondents reporting unmet needs
1	FRIENDS	To have had someone close to discuss my feelings about my sibling/whānau member's whaikaha/disability	72.9
2	TIME OUT	To be able to have fun	71.8
3	FEELINGS	To have been able to express how I felt about my sibling/whānau member's whaikaha/disability without worrying about upsetting people	71.4
4	FAMILY	To be able to spend time with my parent/s - just me and them	70.2
5	TIMEOUT	To have had time to look after myself and focus on my own needs	66.3
6	FRIENDS	To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty	65.9
7	FRIENDS	My friends to have understood what I was going through	64.7
8	FAMILY	To know my parent/s had not forgotten about me	64.3
9	FAMILY	To feel that I was as important and valued as my sibling/whānau member with a whaikaha/disability	63.9
10	FRIENDS	To know how to talk to my friends about my experience with my sibling/whānau member's whaikaha/disability	63.5
11	FEELINGS	To have learnt ways of coping with the added stress placed on my family/whānau	63.1
12	FRIENDS	To be linked in with a social support network with others who share a similar experience	60.5
13	INFORMATION	Information about the impact the disability may have on my	60.5

		sibling/whānau member's life in the future	
14	FEELINGS	Help dealing with feelings of frustration and anger about my sibling/whānau member's whaikaha/disability	60.2
15	TIME OUT	Somewhere to go when it got too hard to deal with my sibling/whānau member who has a whaikaha/disability	58.6
16	FRIENDS	To feel supported by other young people who have had similar experience with whaikaha/disability	58.1
17	FRIENDS	The opportunity to have spent time with other young people affected by their sibling/whānau member's whaikaha/disability	57.6
18	FEELINGS	Help dealing with feelings of anxiety and feeling scared about my sibling/whānau member's disability	57.1
19	FAMILY	For my family/whānau to acknowledge this happened to me too	57.1
20	TIME OUT	To have 'time-out' from the extra duties that I had taken on at home	56.5
21	FAMILY	To feel that I could openly talk with my family/whānau about my sibling/whānau member's whaikaha/disability	56.0
22	ASSISTANCE	Access to information about support services that were available to me	55.8
23	TIME OUT	To feel like a 'normal' young person, which it seemed to be affected by my sibling/whānau member's disability	55.8
24	INFORMATION	My teachers and/or boss to have understood my situation and be more flexible	55.8
25	FRIENDS	Support from my friends	55.3
26	SIBLING	To know ways of giving emotional support to my sibling/whānau member	54.9
27	SIBLING	Help to understand how my sibling/whānau member was feeling	54.2

28	FEELINGS	To talk with a counsellor/psychologist/social worker	50.6
29	ASSISTANCE	To have had people around me who could help out by taking over some of the things that my parent/s did not have time to do	50.0
30	FEELINGS	Help dealing with sadness related to my sibling/whānau member's whaikaha/disability	50.0
31	SIBLING	To know ways of giving practical support to my sibling/whānau member	49.4
32	INFORMATION	To feel that health care and disability professionals included me in discussions about my sibling/whānau member's disability	48.8
33	INFORMATION	To be able to get information about my sibling/whānau member's type of disability and the assistance/treatment my sibling/whānau member needs in a way that I could understand	48.8
34	FEELINGS	Help dealing with feelings of guilt related to my sibling/whānau member's whaikaha/disability	47.0
35	INFORMATION	To be informed about my sibling/whānau member's whaikaha/disability – good or bad	46.0
36	SIBLING	To know how to talk to my sibling/whānau member about how I was feeling	42.9
37	TIME OUT	Help concentrating on tasks at school, university, polytechnic or work	41.9
38	SIBLING	Help to deal with changes that occurred in my relationship with my sibling/whānau member	40.2
39	SIBLING	To feel included in my sibling/whānau member's whaikaha/disability experience	40.2
40	INFORMATION	Information about the side-effects of my sibling/whānau member's treatment	35.3

41	FEELINGS	Help with feelings about the possibility that my sibling/whānau member with a whaikaha/disability might die	32.5
42	INFORMATION	To be spoken to by health care and whaikaha/disability professionals in a way that I could understand	31.4
43	ASSISTANCE	Assistance with managing daily tasks	30.6
44	INFORMATION	Information about what happens after my sibling/whānau member came home following treatment/therapy	30.6
45	SIBLING	To have 'time-out' with my sibling/whānau member away from 'the whaikaha/disability'	28.9

Unmet needs for each disability

The disability with the highest proportion of unmet needs was autism spectrum disorder with comorbid Down syndrome or cerebral palsy followed autism spectrum disorder then Down syndrome followed by cerebral palsy (See

Figure 5).

Autism spectrum disorder

The mean number of unmet needs for siblings of children with ASD (n = 32) was 29.2 with a standard deviation of 10.6 and a range of 2-44. All participants endorsed at least two

unmet needs and 96.9% reported 12 or more unmet needs (only one reported less than 12 unmet needs).

An analysis of the domain sample was carried out and it was found that the siblings of children with ASD had the highest percentage of unmet needs in the TIME OUT (86.5%) domain followed by FRIENDS (78.4%) then equally FEELINGS and FAMILY (75.7%). The lowest percentage of unmet needs was for the INFORMATION (51.4%) domain.

Down syndrome

The mean number of needs for siblings of children with DS (n = 25) was 19.9 with a standard deviation of 14.4 and a range of 0-45. The majority of participants (84%) endorsed at least one unmet need and 72% endorsed 10 or more unmet needs.

An analysis of the domain sample was carried out and it was found that the siblings of children with DS had the highest percentage of unmet needs in the FRIENDS (60.0%) domain followed by FAMILY (56.7%), then TIME OUT (46.7%). The lowest percentage of unmet needs was in the INFORMATION (26.7%) domain.

Cerebral palsy

The mean number of unmet needs for siblings of children with Cerebral palsy (n = 6) was 19.5 with a standard deviation of 17.6 and a range of 2-41. All participants indorsed at least two unmet needs and 50% had 25 or more unmet needs.

An analysis of the domain sample was carried out and it was found that the siblings of children with CP had the highest percentage of unmet needs in several domains including INFORMATION, FRIENDS, FAMILY, and SIBLINGS (50%). The lowest percentage of unmet needs was in the TIME OUT, ASSISTANCE, and FEELINGS (33.3%) domains.

Autism spectrum disorder comorbid with Down syndrome or Cerebral palsy

The mean number of unmet needs for siblings of children with ASD plus DS or CP (ASD+) (n = 6) was 34.8 with a standard deviation of 6.3 and a Range of 24-41. All participants had 24 or more unmet needs and 50% had 38 or more unmet needs.

An analysis of the domain sample was carried out and it was found that the siblings of children with ASD+ had the highest percentage of unmet needs in the FRIENDS and FEELINGS (87.5%) domains followed by equally INFORMATION, TIME OUT, ASSISTANCE, and FAMILY (75.0%). The lowest percentage of unmet needs was in the SIBLING (62.5%) domain.

Figure 5

Mean Percentage of Unmet Needs for Each Whaikaha/Disability

Comparison of disabilities for each domain

Using the domain sample, the percentage of unmet needs was greatest for siblings of children with ASD (*n* = 37) across every domain (69.9%) when compared with DS (*n* = 30) who had 41.9 %, followed by CP (*n* = 6) with 42.9 %. Siblings of children with ASD+ (*n* = 8) had the highest mean percentage of unmet needs overall (76.8%) compared to ASD, CP and DS by themselves (see

Table **4**).

Siblings of children with ASD plus DS or CP had the highest percentage of unmet needs for the INFORMATION, ASSISTANCE, FRIENDS, FEELINGS and SIBLING domains compared with ASD alone. CP had a higher mean percentage of unmet needs for the

INFORMATION and SIBLING domains when compared to DS who had the higher mean percentage of needs for TIME OUT, ASSISTANCE, FRIENDS and FAMILY domains (see Table **4**).

The domain with the greatest difference between disabilities was TIME OUT (ASD: 86.5%; DS: 46.7%; and CP: 33.3%), followed by FEELINGS (ASD: 75.7%; DS and CP 33.3%). ASD had a significantly higher number of unmet needs for both of these domains when compared to DS and CP. On the FEELINGS domain ASD plus either CP or DS (ASD+) had the highest number of disabilities (87.5%) compared to each disability alone (see **Figure 5**). The domains FRIENDS (ASD+: 87.5% ASD: 78.4%; DS: 60.0%; and CP: 50.0%) and FAMILY (ASD: 75.7%; ASD+: 75.0%; DS: 56.7%; and CP: 50.0%) had the smallest difference in unmet needs, there were similar high levels of unmet needs across the disabilities (see **Figure 5**), although ASD+ had the highest level of unmet needs overall.

Table 4

Mean Percentage of Unmet Needs for Each Domain for Each Whaikaha/Disability

Domain	Abbreviation	Concerns the Need:	Mean % of Unmet Needs			
			ASD	DS	CP	ASD+
Information about my sibling/whānau member's whaikaha/ disability	INFORMATION	For information about their siblings whaikaha/disability and associated treatment in a easily understandable and age appropriate way.	51.4	26.7	50.0	75.0
"Time out" and recreation	TIME OUT	To have a break or time out away from the disability and be able to do sport or social activities	86.5	46.7	33.3	75.0
Practical assistance	ASSISTANCE	For support with daily living including household chores, education, work and connection with relevant support services	59.5	40.0	33.3	75.0
Support from friends and other young people	FRIENDS	To feel supported and understood by their friends regarding their experience of whaikaha/disability and to be able to spend time with other siblings experiencing the same thing.	78.4	60.0	50.0	87.5
Dealing with feelings	FEELINGS	To be able to express their feelings about their siblings disability and how it has impacted them and their needs for help with their feelings.	75.7	33.3	33.3	87.5
Understanding from my family	FAMILY	To feel supported and acknowledged by their family and be able to tell them about their experience with disability	75.7	56.7	50.0	75.0
My relationship with my sibling who has a whaikaha/ disability	SIBLING	For help with their relationship with their disabled sibling and issues arising in this relationship	62.2	30.0	50.0	62.5
TOTAL			**69.9**	**41.9**	**42.9**	**76.8**

For comparing the differences in the mean number of needs between whaikaha/disabilities for all seven domains, the sample included any participant that included enough responses to have a valid response for any domain. A one-way ANOVA was carried out on the data using SPSS software (see Table 5). A comparison between

whaikaha/disabilities using Bonferroni correction found that there was a statistically significant difference between ASD and DS in the FEELINGS and TIME OUT domains as shown by a p value of less than 0.05. A statistically significant difference was also found between DS and ASD+ in the FEELINGS domain. Further there was also a statistically significant difference between ASD and CP in the TIME OUT domain. Overall, as shown by the TOTAL (all seven domains) there was a statistically significant difference between ASD and DS (see Table 5).

Table 5

Multiple Comparisons Between Whaikaha/Disabilities (Bonferroni)

Domain	Disability	Disability	Mean Difference	Std. Error	Sig.	95% Confidence Interval for Difference	
						Lower	Upper
INFORMATION	ASD	DS	0.247	0.119	0.250	-0.076	0.570
		CP	0.014	0.213	1.000	-0.565	0.592
		ASD+	-0.236	0.189	1.000	-0.749	0.276
	DS	ASD	-0.247	0.119	0.250	-0.570	0.076
		CP	-0.233	0.217	1.000	-0.821	0.354
		ASD+	-0.483	0.193	0.086	-1.006	0.039
	CP	ASD	-0.014	0.213	1.000	-0.592	0.565
		DS	0.233	0.217	1.000	-0.354	0.821
		ASD+	-0.250	0.262	1.000	-0.959	0.459
	ASD+	ASD	0.236	0.189	1.000	-0.276	0.749
		DS	0.483	0.193	0.086	-0.039	1.006
		CP	0.250	0.262	1.000	-0.459	0.959
FEELINGS	ASD	DS	0.423*	0.111	0.002	0.123	0.724
		CP	0.423	0.199	0.217	-0.115	0.961
		ASD+	-0.118	0.176	1.000	-0.595	0.358
	DS	ASD	-0.423*	0.111	0.002	-0.724	-0.123
		CP	0.000	0.202	1.000	-0.547	0.547
		ASD+	-0.542*	0.180	0.021	-1.028	-0.055
	CP	ASD	-0.423	0.199	0.217	-0.961	0.115

		DS	0.000	0.202	1.000	-0.547	0.547
		ASD+	-0.542	0.244	0.175	-1.202	0.118
	ASD+	ASD	0.118	0.176	1.000	-0.358	0.595
		DS	0.542*	0.180	0.021	0.055	1.028
		CP	0.542	0.244	0.175	-0.118	1.202
FAMILY	ASD	DS	0.190	0.116	0.633	-0.124	0.504
		CP	0.257	0.208	1.000	-0.306	0.820
		ASD+	0.007	0.184	1.000	-0.492	0.505
	DS	ASD	-0.190	0.116	0.633	-0.504	0.124
		CP	0.067	0.211	1.000	-0.505	0.639
		ASD+	-0.183	0.188	1.000	-0.692	0.326
	CP	ASD	-0.257	0.208	1.000	-0.820	0.306
		DS	-0.067	0.211	1.000	-0.639	0.505
		ASD+	-0.250	0.255	1.000	-0.941	0.441
	ASD+	ASD	-0.007	0.184	1.000	-0.505	0.492
		DS	0.183	0.188	1.000	-0.326	0.692
		CP	0.250	0.255	1.000	-0.441	0.941
SIBLING	ASD	DS	0.322	0.120	0.054	-0.003	0.647
		CP	0.122	0.215	1.000	-0.461	0.704
		ASD+	-0.003	0.190	1.000	-0.519	0.512
	DS	ASD	-0.322	0.120	0.054	-0.647	0.003
		CP	-0.200	0.218	1.000	-0.792	0.392
		ASD+	-0.325	0.194	0.592	-0.851	0.201
	CP	ASD	-0.122	0.215	1.000	-0.704	0.461
		DS	0.200	0.218	1.000	-0.392	0.792
		ASD+	-0.125	0.264	1.000	-0.840	0.590
	ASD+	ASD	0.003	0.190	1.000	-0.512	0.519
		DS	0.325	0.194	0.592	-0.201	0.851
		CP	0.125	0.264	1.000	-0.590	0.840
TIME OUT	ASD	DS	0.398*	0.107	0.002	0.108	0.688
		CP	0.532*	0.192	0.042	0.012	1.051
		ASD+	0.115	0.170	1.000	-0.345	0.575
	DS	ASD	-0.398*	0.107	0.002	-0.688	-0.108
		CP	0.133	0.195	1.000	-0.394	0.661
		ASD+	-0.283	0.173	0.638	-0.753	0.186
	CP	ASD	-0.532*	0.192	0.042	-1.051	-0.012

		DS	-0.133	0.195	1.000	-0.661	0.394
		ASD+	-0.417	0.235	0.484	-1.054	0.221
	ASD+	ASD	-0.115	0.170	1.000	-0.575	0.345
		DS	0.283	0.173	0.638	-0.186	0.753
		CP	0.417	0.235	0.484	-0.221	1.054
FRIENDS	ASD	DS	0.184	0.111	0.619	-0.118	0.486
		CP	0.284	0.200	0.955	-0.257	0.824
		ASD+	-0.091	0.177	1.000	-0.570	0.388
	DS	ASD	-0.184	0.111	0.619	-0.486	0.118
		CP	0.100	0.203	1.000	-0.449	0.649
		ASD+	-0.275	0.181	0.790	-0.764	0.214
	CP	ASD	-0.284	0.200	0.955	-0.824	0.257
		DS	-0.100	0.203	1.000	-0.649	0.449
		ASD+	-0.375	0.245	0.780	-1.038	0.288
	ASD+	ASD	0.091	0.177	1.000	-0.388	0.570
		DS	0.275	0.181	0.790	-0.214	0.764
		CP	0.375	0.245	0.780	-0.288	1.038
ASSISTANCE	ASD	DS	0.195	0.122	0.687	-0.135	0.525
		CP	0.261	0.218	1.000	-0.330	0.853
		ASD+	-0.155	0.193	1.000	-0.679	0.368
	DS	ASD	-0.195	0.122	0.687	-0.525	0.135
		CP	0.067	0.222	1.000	-0.534	0.668
		ASD+	-0.350	0.197	0.481	-0.885	0.185
	CP	ASD	-0.261	0.218	1.000	-0.853	0.330
		DS	-0.067	0.222	1.000	-0.668	0.534
		ASD+	-0.417	0.268	0.744	-1.142	0.309
	ASD+	ASD	0.155	0.193	1.000	-0.368	0.679
		DS	0.350	0.197	0.481	-0.185	0.885
		CP	0.417	0.268	0.744	-0.309	1.142
TOTAL	ASD	DS	0.207*	0.074	0.042	0.005	0.409
		CP	0.215	0.124	0.518	-0.121	0.551
		ASD+	-0.125	0.124	1.000	-0.462	0.211
	DS	ASD	-0.207*	0.074	0.042	-0.409	-0.005
		CP	0.008	0.126	1.000	-0.335	0.352
		ASD+	-0.332	0.126	0.064	-0.676	0.012
	CP	ASD	-0.215	0.124	0.518	-0.552	0.121

	DS	-0.008	0.126	1.000	-0.352	0.335
	ASD+	-0.340	0.160	0.225	-0.777	0.096
ASD+	ASD	0.125	0.124	1.000	-0.211	0.462
	DS	-0.008	0.126	1.000	-0.352	0.335
	CP	0.341	0.1604	0.225	-0.096	0.777

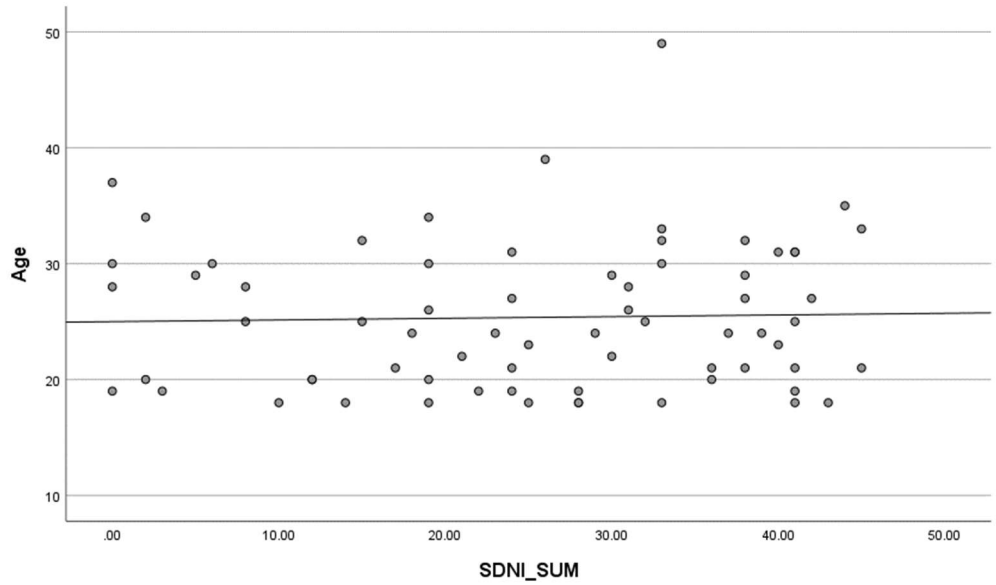
* The mean difference is significant at the .05 level.

Comparison of unmet needs and age

For the comparison between unmet needs and age for all seven domains, the sample included any participant that answered all questions in the SDNI. Data analysis was carried out using SPSS software and the Pearson correlation coefficient calculated (see Figure 6). It was found that there is no relationship between age and unmet needs as Pearson's r is almost zero ($r = 0.031$).

Figure 6

Comparison of total number of unmet needs with age



Comparison of needs between genders

A comparison of the results was undertaken between genders. Results showed strong similarities in unmet needs across all domains on the SCNI. Females had a systematically higher mean percentage of unmet needs across all domains when compared to males, at least approximately 20% higher; the difference was greatest in the FAMILY domain (approximately 40%) (see

Figure 7). Gender diverse (n = 3) participants had the highest percentage of unmet needs across all domains (apart from FRIENDS) when compared to males and females.

The highest percentage of unmet needs for males was in the TIME OUT and FRIENDS domains (41.2%); for females this was the FRIENDS domain (72.7%) closely followed by the FAMILY domain (72.3%). For gender diverse, the highest percentage of unmet needs was the TIME OUT, FAMILY and SIBLING domains (100%) (see

Table 6).

For comparing the differences in the mean number of needs between genders for all seven domains, the sample included any participant that included enough responses to have a valid response for any domain. A one-way ANOVA was carried out on the data using SPSS software (see Table 7). Using the Bonferroni correction, the difference in means between males and gender diverse and between males and females in the FAMILY domain was found

to be statistically significant, where a p value of less than 0.05 was observed. Also, for the TOTAL (all 7 domains) mean proportion of unmet needs there was a statistically significant difference between males and females overall (see Table 7).

Figure 7

Comparison of the Mean Proportions of Unmet Needs Across Domains for Gender

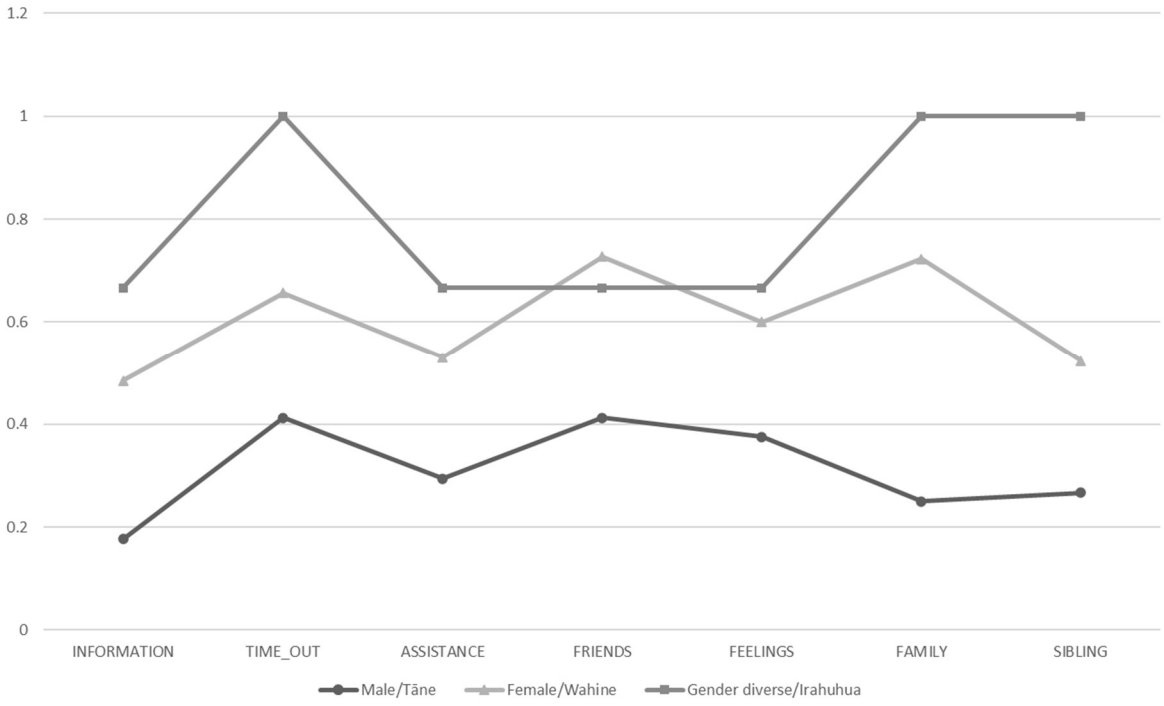


Table 6

The Mean Percentage of Unmet Needs Between Genders Across Domains

	Male	Female	Gender diverse
Domain	Tāne	Wahine	Irahuhua

	(*n* = 17)	(*n* = 67)	(*n* = 3)
INFORMATION	17.7	48.4	66.7
TIME OUT	41.2	65.7	100.0
ASSISTANCE	29.4	53.0	66.7
FRIENDS	41.2	72.7	66.7
FEELINGS	37.5	60.0	66.7
FAMILY	25.0	72.3	100.0
SIBLING	26.7	52.3	100.0

Table 7

Multiple Comparisons Between Genders (Bonferroni)

Domain	Gender	Gender	Mean Difference	Std. Error	Sig.	95% Confidence Interval for Difference	
						Lower	Upper
INFORMATION	Male	Female	-0.292	0.141	0.125	-0.637	0.053
		Diverse	-0.467	0.311	0.411	-1.227	0.293
	Female	Male	0.292	0.141	0.125	-0.053	0.637
		Diverse	-0.175	0.290	1.000	-0.885	0.535
	Diverse	Male	0.467	0.311	0.411	-0.293	1.227
		Female	0.175	0.290	1.000	-0.535	0.885
TIME OUT	Male	Female	-0.232	0.134	0.264	-0.560	0.096
		Diverse	-0.533	0.295	0.224	-1.256	0.189
	Female	Male	0.232	0.134	0.264	-0.096	0.560
		Diverse	-0.302	0.276	0.833	-0.977	0.373
	Diverse	Male	0.533	0.295	0.224	-0.189	1.256
		Female	0.302	0.276	0.833	-0.373	0.977
ASSISTANCE	Male	Female	-0.222	0.144	0.379	-0.574	0.130
		Diverse	-0.333	0.317	0.887	-1.108	0.441
	Female	Male	0.222	0.144	0.379	-0.130	0.574
		Diverse	-0.111	0.296	1.000	-0.835	0.613
	Diverse	Male	0.333	0.317	0.887	-0.441	1.108
		Female	0.111	0.296	1.000	-0.613	0.835
FRIENDS	Male	Female	-0.295	0.129	0.076	-0.612	0.021

		Diverse	-0.200	0.285	1.000	-0.897	0.497
	Female	Male	0.295	0.129	0.076	-0.021	0.612
		Diverse	0.095	0.266	1.000	-0.556	0.747
	Diverse	Male	0.200	0.285	1.000	-0.497	0.897
		Female	-0.095	0.266	1.000	-0.747	0.556
FEELINGS	Male	Female	-0.219	0.142	0.383	-0.567	0.129
		Diverse	-0.267	0.313	1.000	-1.033	0.500
	Female	Male	0.219	0.142	0.383	-0.129	0.567
		Diverse	-0.048	0.293	1.000	-0.764	0.668
	Diverse	Male	0.267	0.313	1.000	-0.500	1.033
		Female	0.048	0.293	1.000	-0.668	0.764
FAMILY	Male	Female	-0.479*	0.125	<0.001	-0.786	-0.172
		Diverse	-0.733*	0.276	0.029	-1.409	-0.058
	Female	Male	0.479*	0.125	<0.001	0.172	0.786
		Diverse	-0.254	0.258	0.984	-0.885	0.377
	Diverse	Male	0.733*	0.276	0.029	0.058	1.409
		Female	0.254	0.258	0.984	-0.377	0.885
SIBLING	Male	Female	-0.257	0.140	0.213	-0.601	0.087
		Diverse	-0.733	0.309	0.061	-1.490	0.023
	Female	Male	0.257	0.140	0.213	-0.087	0.601
		Diverse	-0.476	0.289	0.310	-1.183	0.231
	Diverse	Male	0.733	0.309	0.061	-0.023	1.490
		Female	0.476	0.289	0.310	-0.231	1.183
TOTAL	Male	Female	-0.285*	0.103	0.021	-0.537	-0.034
		Diverse	-0.467	0.226	0.128	-1.020	0.087
	Female	Male	0.285*	0.103	0.021	0.034	0.537
		Diverse	-0.181	0.211	1.000	-0.699	0.334
	Diverse	Male	0.467	0.226	0.128	-0.087	1.020
		Female	0.181	0.211	1.000	-0.336	0.699

* The mean difference is significant at the .05 level.

Comparison between older siblings and younger siblings

A comparison of the results was undertaken between older and younger siblings. Results showed younger siblings had a higher proportion of unmet needs compared to older

siblings across all domains of the SCNI; the largest difference was in the SIBLING (approximately 23%) domain and the smallest difference was in the INFORMATION (8%) domain (see Table 8).

For comparing the differences in the mean number of needs between siblings that are older than their sibling with a disability and siblings that are younger for all seven domains, the sample included any participant that included enough responses to have a valid response for any domain. A t-test was carried out on the data using SPSS software (see

Table **9**). The difference between the means in the SIBLING domain only was statistically significant as a p value of less than 0.05 was observed.

Table 8

Mean Proportion of Unmet Needs for Older and Younger Siblings

	Sibling _____ than you	*N*	Mean	Std. Deviation	Std. Error Mean
INFORMATION	Older	29	0.379	0.493	0.092
	Younger	57	0.456	0.502	0.067
TIME OUT	Older	30	0.500	0.509	0.093
	Younger	57	0.684	0.469	0.062
ASSISTANCE	Older	29	0.345	0.483	0.090
	Younger	57	0.561	0.501	0.066
FRIENDS	Older	29	0.586	0.501	0.093
	Younger	57	0.702	0.462	0.061
FEELINGS	Older	29	0.483	0.509	0.094
	Younger	55	0.600	0.494	0.067
FAMILY	Older	29	0.586	0.501	0.093
	Younger	55	0.673	0.474	0.064
SIBLING	Older	29	0.345	0.484	0.090
	Younger	54	0.574	0.499	0.068
TOTAL	Older	27	0.487	0.395	0.076
	Younger	54	0.630	0.356	0.048

Table 9

Equality of Means Between Older and Younger Siblings (t-test)

Domain	*t*	*df*	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
INFORMATION	-0.674	84	0.502	-0.077	0.114	-0.303	0.150
TIME OUT	-1.691	85	0.094	-0.184	0.109	-0.401	0.032
ASSISTANCE	-1.918	84	0.059	-0.217	0.113	-0.441	0.008
FRIENDS	-1.066	84	0.289	-0.116	0.108	-0.331	0.100
FEELINGS	-1.023	82	0.309	-0.117	0.115	-0.345	0.111
FAMILY	-0.780	82	0.437	-0.087	0.111	-0.307	0.134
SIBLING	-2.016	81	0.047	-0.229	0.114	-0.455	-0.003
TOTAL	-1.642	79	0.105	-0.142	0.087	-0.316	0.030

Comparison of unmet needs between Māori and non-Māori

For comparing the differences in the mean number of needs between Māori and non-Māori for all seven domains, the sample included any participant that included enough responses to have a valid response for any domain. A t-test was carried out on the data using SPSS software (see

Table 11) and the difference between Māori and non-Māori was not found to be significantly statistically different.

However, non-Māori had a higher mean proportion of unmet needs across all domains. The biggest difference in the mean proportion of unmet needs was approximately 20% in the FRIENDS and FAMILY domains. The smallest difference was in the FEELINGS

and INFORMATION domains (approximately 5%). For non-Māori the domain with the highest proportion of unmet needs was FRIENDS (0.706) followed by FAMILY (0.687). For Māori the domain with the highest proportion of unmet needs was TIME OUT (0.556) followed by FEELINGS (0.529) (see Table 10).

Table 10

Mean Proportion of Unmet Needs for Māori and Non-Māori

Domain	Māori	N	Mean	Std. Deviation	Std. Error Mean
INFORMATION	Yes	18	0.389	0.502	0.119
	No	68	0.441	0.500	0.061
TIME OUT	Yes	18	0.556	0.511	0.121
	No	69	0.638	0.484	0.058
ASSISTANCE	Yes	18	0.389	0.502	0.118
	No	68	0.515	0.504	0.061
FRIENDS	Yes	18	0.500	0.515	0.121
	No	68	0.706	0.459	0.056
FEELINGS	Yes	17	0.529	0.515	0.125
	No	67	0.567	0.499	0.061
FAMILY	Yes	17	0.471	0.515	0.125
	No	67	0.687	0.467	0.057
SIBLING	Yes	17	0.353	0.493	0.120
	No	66	0.530	0.503	0.062
TOTAL	Yes	17	0.471	0.425	0.103
	No	64	0.612	0.356	0.044

Table 11

Equality of Means Between Māori and Non-Māori

Domain	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
INFORMATION	-0.394	84	0.694	-0.052	0.133	-0.316	0.212
TIME OUT	-0.634	85	0.528	-0.082	0.130	-0.340	0.176
ASSISTANCE	-0.943	84	0.348	-0.126	0.133	-0.391	0.139
FRIENDS	-1.650	84	0.103	-0.206	0.125	-0.454	0.042
FEELINGS	-0.277	82	0.783	-0.038	0.136	-0.309	0.234
FAMILY	-1.667	82	0.099	-0.216	0.130	-0.474	0.042
SIBLING	-1.302	81	0.197	-0.177	0.136	-0.448	0.094
TOTAL	-1.394	79	0.167	-0.141	0.101	-0.342	0.060

Comparison of unmet needs between number of parental figures

For comparing the differences in the mean number of needs between siblings who have one parental figure and siblings who have two plus parental figures for all seven domains, the sample included any participant that included enough responses to have a valid response for any domain. A t-test was carried out on the data using SPSS software (see

Table 13) and the difference between siblings with one parental figure and siblings with two plus parental figures was not found to be significantly statistically different.

Siblings with one parental figure had a higher mean proportion of unmet needs across all domains and overall. Siblings from one parent families had an approximately 20% to 30% higher mean proportion of needs compared to families with two parental figures or more (see Table **12**).

Table 12

Mean Proportion of Needs for the Categories of the Number of Parental Figures

Domain	Parental Figures	*N*	Mean	Std. Deviation	Std. Error Mean
INFORMATION	1	7	0.714	0.488	0.184
	2+	79	0.405	0.494	0.056
TIME OUT	1	7	0.857	0.378	0.143
	2+	80	0.600	0.493	0.055
ASSISTANCE	1	7	0.714	0.488	0.184
	2+	79	0.468	0.502	0.057
FRIENDS	1	7	0.857	0.378	0.143
	2+	79	0.646	0.481	0.054
FEELINGS	1	7	0.857	0.378	0.143
	2+	77	0.532	0.502	0.057
FAMILY	1	7	0.857	0.378	0.143
	2+	77	0.623	0.488	0.056
SIBLING	1	7	0.714	0.488	0.184

	2+	76	0.474	0.503	0.058
TOTAL	1	7	0.796	0.368	0.139
	2+	74	0.562	0.370	0.043

Table 13

Equality of Means Between Parental Figure Categories

	t	*df*	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
INFORMATION	1.589	84	0.116	0.309	0.195	-0.078	0.696
TIME OUT	1.343	85	0.183	0.257	0.191	-0.124	0.638
ASSISTANCE	1.244	84	0.217	0.246	0.198	-0.147	0.639
FRIENDS	1.130	84	0.262	0.212	0.187	-0.161	0.584
FEELINGS	1.664	82	0.100	0.325	0.195	-0.063	0.713
FAMILY	1.232	82	0.221	0.234	0.190	-0.144	0.611
SIBLING	1.215	81	0.228	0.241	0.198	-0.154	0.635
TOTAL	1.603	79	0.113	0.234	0.146	-0.057	0.525

Comparison of unmet needs between number of siblings

A comparison of the results was undertaken between siblings with one to two siblings and siblings with three plus siblings. Results showed siblings with one to two siblings have a higher proportion of unmet needs compared to siblings of three plus siblings across all domains of the SCNI (see Table 14).

For comparing the differences in the mean number of needs between siblings that have one to two siblings and siblings that have three plus for all seven domains, the sample included any participant that included enough responses to have a valid response for any domain. A t-test was carried out on the data using SPSS software (see

Table 15). The difference between means for the FRIENDS and INFORMATION domains was statistically significant as shown by the observed p value of less than 0.05. There is also a statistically significant difference overall for the TOTAL between siblings with one to two siblings and siblings with three or more siblings.

Table 14

Mean Proportion of Unmet Needs Between Number of Siblings Categories

Domain	No. of siblings	N	Mean	Std. Deviation	Std. Error Mean
INFORMATION	1 to 2	55	0.509	0.505	0.068
	3+	31	0.290	0.461	0.083
TIME OUT	1 to 2	56	0.696	0.464	0.062
	3+	31	0.484	0.508	0.091
ASSISTANCE	1 to 2	55	0.509	0.505	0.068
	3+	31	0.452	0.506	0.091
FRIENDS	1 to 2	55	0.745	0.440	0.059
	3+	31	0.516	0.508	0.091
FEELINGS	1 to 2	54	0.630	0.487	0.066
	3+	30	0.433	0.504	0.092
FAMILY	1 to 2	54	0.704	0.461	0.063
	3+	30	0.533	0.507	0.093
SIBLING	1 to 2	53	0.566	0.500	0.069
	3+	30	0.367	0.490	0.089

Table 15

Equality of Means Between Number of Siblings Categories (t-test)

Domain	*t*	*df*	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
INFORMATION	1.990	84	0.050	0.219	0.110	0.000	0.437
TIME OUT	1.978	85	0.051	0.213	0.107	-0.001	0.426
ASSISTANCE	0.507	84	0.614	0.057	0.113	-0.168	0.283
FRIENDS	2.195	84	0.031	0.229	0.104	0.022	0.437
FEELINGS	1.747	82	0.084	0.196	0.112	-0.027	0.420
FAMILY	1.566	82	0.121	0.170	0.109	-0.046	0.387
SIBLING	1.757	81	0.083	0.199	0.113	-0.026	0.425
TOTAL	2.572	79	0.012	0.213	0.083	0.048	0.379

Comparison of unmet needs of siblings of children with Disabilities and cancer and serious chronic health conditions in Aotearoa/New Zealand

A comparison of the results of a disability sample (n = 84 – 87) and a cancer and serious chronic health conditions sample (n = 174 – 182) was carried out. The samples included any participant that included enough responses to have a valid response for any domain. The cancer and serious chronic health condition data comes from a recent Aotearoa/New Zealand study looking at the unmet needs of this population using a modified version of the SCNI (Armstrong, 2019). This allows direct comparisons between siblings across each of the seven domains. The INFORMATION domain (65.3%) had the highest proportion of unmet needs for siblings of children with cancer and serious chronic health conditions followed by FEELINGS (58.5%) and SIBLING (58.1%). However, for siblings of children with disabilities the INFORMATION (43.0%) domain had the lowest proportion of unmet needs. For siblings of children with disabilities the domains with the highest proportion of needs were FRIENDS (66.3%), followed by FAMILY (64.3%), and TIME OUT (62.1%). For siblings of children with cancer and serious chronic health conditions the

ASSISTANCE (38.0%) domain had the lowest proportion of unmet needs (see Table 16). Four of the seven domains had a higher proportion of unmet needs for siblings of children with disabilities, one domain had a similar proportion of unmet needs for both groups and two domains had the highest proportion of needs for siblings of children with cancer and serious chronic health conditions (see Figure 8).

The top 10 unmet needs for each condition were compared. There were three items that were identified as being in the top 10 unmet needs; these are highlighted in

Table 17. For the whaikaha/disability sample FRIENDS, FEELINGS, FAMILY and TIME OUT are the only domains in the top 10. For the cancer and serious chronic illness sample INFORMATION, SIBLING, FRIENDS, TIME OUT and FEELINGS were the only domains in the top 10.

Table 16

Comparison of the Mean Percentage of Unmet Needs for Cancer and Serious Chronic Health Conditions and Whaikaha/Disabilities

Domain	Cancer and serious chronic health conditions	Whaikaha/ Disabilities
INFORMATION	65.3	43.0
TIME OUT	52.9	62.1
ASSISTANCE	38.0	48.8
FRIENDS	56.7	66.3
FEELINGS	58.5	56.0
FAMILY	52.1	64.3
SIBLING	58.1	49.4

Figure 8

Mean proportion of unmet needs for cancer and serious chronic health conditions and whaikaha/disability

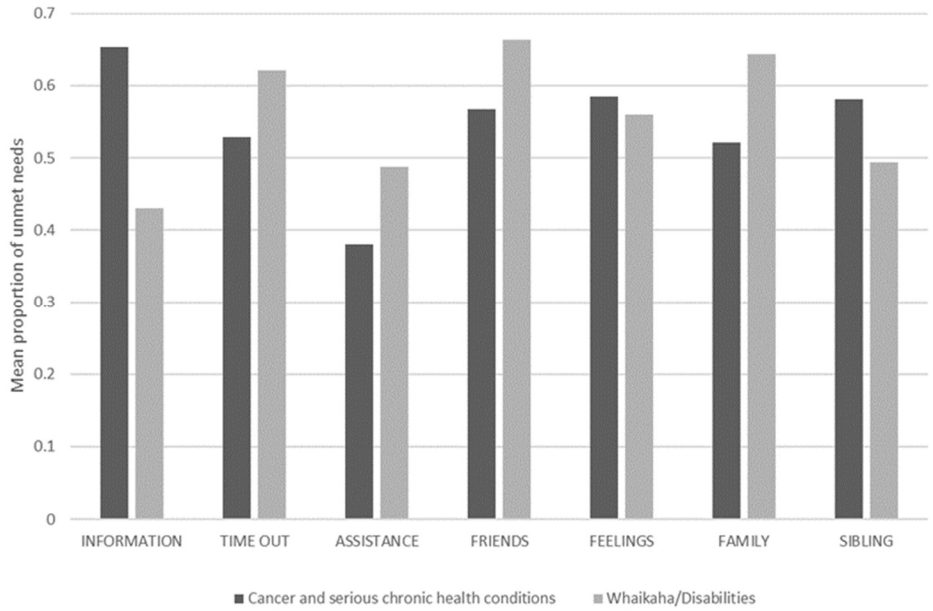


Table 17

Table of the Top 10 Unmet Needs for Each Condition

Item ranking	Cancer and serious chronic illnesses % unmet needs I needed:	Whaikaha/Disability % unmet needs I needed:
1	Information about the impact the illness and it's treatment might have on my sibling/whānau member's life in the future 84.4	To have had someone close to discuss my feelings about my sibling/whānau member's whaikaha/disability 72.9
2	To be informed about my sibling/whānau member's condition – good or bad 80.0	To be able to have fun 71.8
3	To get information about the illness and its treatment in a way that I understood 72.5	To have been able to express how I felt about my sibling/whānau member's whaikaha/disability without worrying about upsetting people 71.4
4	Information about what would happen when my sibling/whānau member came home following treatment 72.5	To be able to spend time with my parent/s - just me and them 70.2

5	To know ways of giving practical support to my sibling/whānau member 69.4	To have had time to look after myself and focus on my own needs 66.3
6	To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty 68.8	To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty 65.9
7	To know ways of giving emotional support to my sibling/whānau member 68.4	My friends to have understood what I was going through 64.7
8	To have someone close to discuss my feelings about my sibling/whānau member's illness 68.0	To know my parent/s had not forgotten about me 64.3
9	To be able to have fun 67.4	To feel that I was as important and valued as my sibling/whānau member with a whaikaha/disability 63.9
10	Help dealing with feelings about the possibility that my ill sibling/whānau member might die 67.4	To know how to talk to my friends about my experience with my sibling/whānau member's whaikaha/disability 63.5

Note: highlighted item occurs in both lists

Comparison of unmet needs and perceived burden

For comparing the differences in the needs between whaikaha/disabilities for all seven domains, the sample included any participant that answered all questions in the SDNI and in the Sibling Burden Instrument. Data analysis was carried out using SPSS software and the Pearson correlation coefficient calculated (see Figure 9). It was found that there is a relationship between unmet needs and burden; Pearson's r 0.792. This is a strong correlation, and statistically significant result at the p-value of < 0.001. This points to being able to be 95% confident that the true value of the Pearson's r correlation lies between 0.684 and 0.866. It was also found that siblings of children with Autism have moderate to severe levels of burden along with siblings of children with ASD and DS or CP, followed by siblings of

children with DS with a mild to moderate level of burden and finally siblings of children with CP who had little to no burden (see Figure 10).

Figure 9

Comparison of the Total Burden Score to the Total Unmet Needs Score

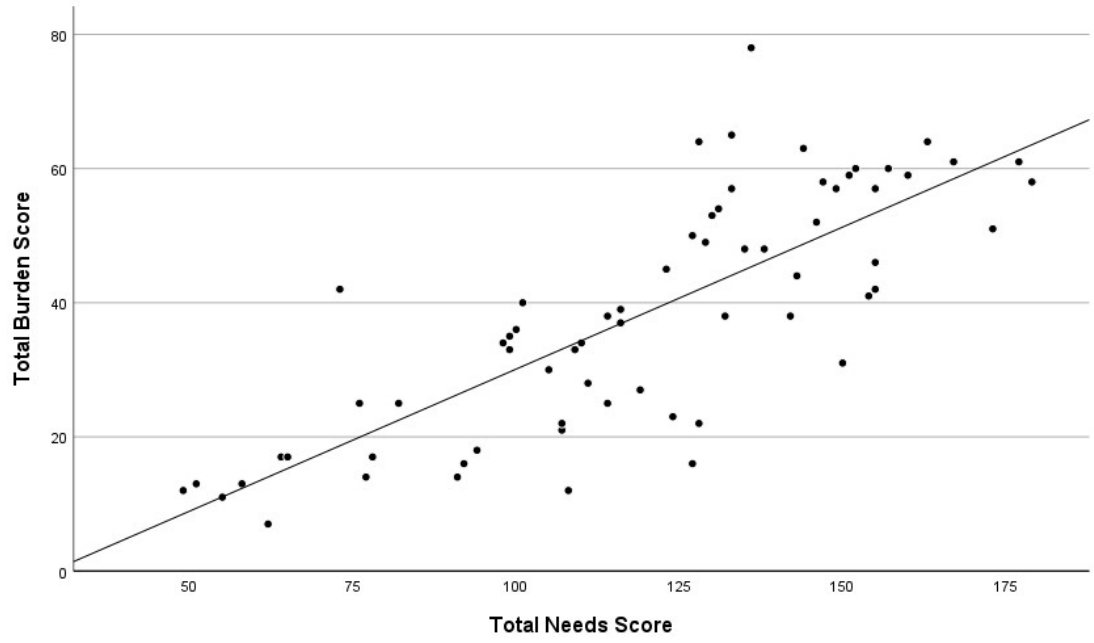
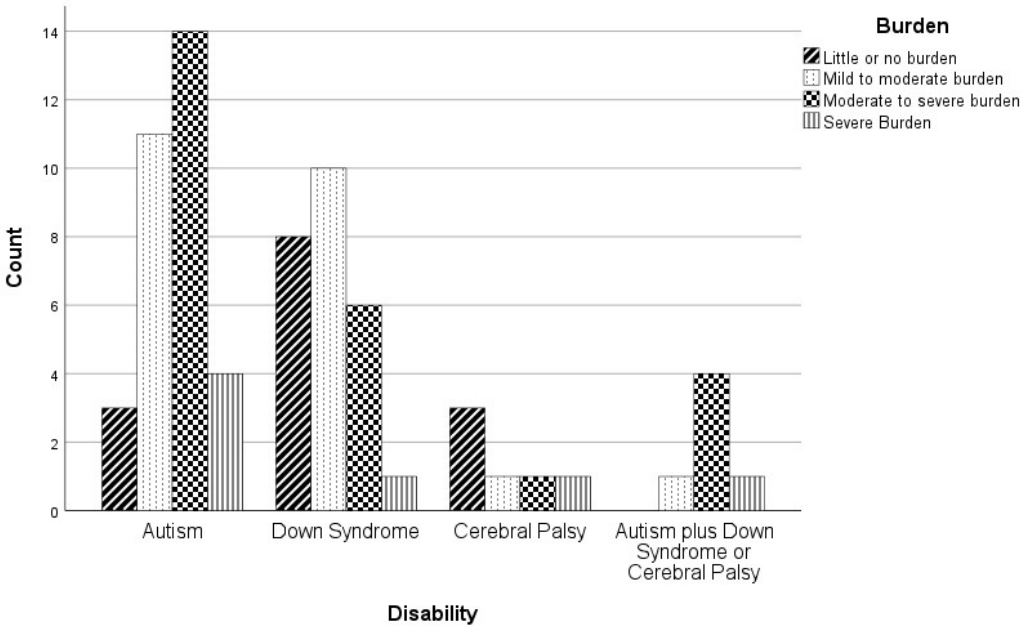


Figure 10

Comparison Between Disability and Burden



Qualitative results

The aim of the present research was to identify the unmet needs of siblings of children with ASD, DS and CP by asking siblings what they need, hence including a qualitative component. The final question in the survey was open ended and said: 'Considering the needs that have been identified, how do you feel your needs would have best been met?'. This gave siblings the chance to articulate their own personal experiences and reflect on their childhood. There were 72 participants that responded to this question; 14 male, 57 female, 3 gender diverse. This group was made up of 43 siblings with ASD, 28 siblings with DS and 9 siblings with CP. Siblings were keen to give a detailed description of their experience, approximately two thirds of participants wrote more than one sentence and half of this group wrote a short paragraph.

Three main themes were identified along with subthemes (see Table 18) after analysing and categorising the data. The main themes were: Taha Tinana, Taha Hinengaro, Taha Whānau, Support needed from outside the family and Psychological Growth. In the following sections the themes and subthemes will be described.

Table 18

Thematic Analysis Themes and Subthemes

Theme	Subtheme
Taha Tinana (physical)	• Physical safety
Taha Hinengaro (mental and emotional)	• Parentification and caregiving • Emotional neglect • Guilt and shame
Taha Whānau (social)	• Support from whānau

Support needed outside the family	• Professional support • Support for whānau • Education of school and community • Siblings need other siblings • Sibling organisation
Psychological Growth	• Psychological strength • Communication and support

Taha Tinana (physical)

Two-thirds of siblings mentioned being physically impacted as a result of having a sibling with a disability. This theme was only identified by siblings of children with autism spectrum disorder and approximately half of these siblings reported being abused or fearing abuse in their own home both physical and psychological. Responses reflect the difficulties siblings have encountered: “I went under the radar and suffered abuse by them physically and emotionally.” (Sibling of child with autism spectrum disorder [ASD]) “When my dad got frustrated or angry at him (we have different dads). I needed help when I was terrified of them arguing and to know that my brother is different and dad is struggling with that.” (ASD) “He at multiple times displayed inappropriate sexual behaviour and made me uncomfortable in my own home.” (ASD) “I was punshed [sic] and shoved off as a child.” (ASD)

For children that encounter physical abuse this can lead to psychological outcomes such as anxiety, depression and post-traumatic stress disorder (PTSD). One sibling detailed this: “I have had years of counselling and ended up with extreme anxiety and PTSD as my brother often had meltdowns in which he would hit me or break things.” (ASD)

Siblings also wrote about needing a break from their sibling due to this physical violence and the consequences: “My sibling would go to respite care periodically but what

about me? When did I get a break from reality?" (sibling of child with Down syndrome and autism spectrum disorder) "Sometimes having a safe place to stay." (ASD) "Time away from home at respite or a friends, relatives to get some time away from my siblings." (ASD)

Taha Hinengaro

Approximately three-quarters of siblings mentioned their emotional and mental health being impacted by having a sibling with a disability.

For a number of siblings their unmet physical needs and the demands put on them led to emotional and mental health consequences. This theme will go deeper into how siblings' Hinengaro was impacted by their sibling's disability.

Parentification and caregiving

Caregiving is a significant part of the sibling experience; approximately 15% of the sample wrote about this and all were female apart from one male. Siblings note undertaking the role of parent or caregiver and taking on adult responsibilities. A sibling of a child with autism spectrum disorder said they had to be "the adukt [sic] in the situation withere [sic] my mither [sic] should have been an adult." (ASD) This parentification also includes household duties, emotional and personal care:

> My mother in particular didn't cope very well in the first few years of my disabled sister's life (I am 16 years older than her and the 3rd eldest of 10, she is the youngest). As a result I took on a lot of the responsibility of raising my other younger sibling and running the house during that time. (Sibling of child with Down syndrome [DS])

Another sibling of a child with Down syndrome said "I was the oldest and took on extra responsibility helping with my younger brother who has Down syndrome." (DS) This

experience was also similar for a sibling of a child with autism spectrum disorder too: "…I would have to partly take on the role of caregiver and also step up to look after my brother sometimes." (ASD)

Siblings also found taking on responsibilities had led them to maturing early and missing out on the ability to be a child. A sibling of a child with autism spectrum disorder said they did not want:

> to be a mini parent at the age of 9 and had a chance to still be a child for longer I also think having more attention so I didn't feel left out and not good enough growing up." (ASD)

> I just needed to have far less responsibility put on me to look after my sister, and then also my brother who was born without a disability. It was too much for a child to have to deal with, and I was punished when I didn't do things right. (DS)

Siblings felt they were unintentionally taken advantage of due to their caring and supportive nature:

> My parents relied heavily on me as an older teenager to pick up the slack around the house and with my sister who has disabilities beyond just autism. This was incredibly stressful for a teenager who had a lot on the go with both school and trying to have a social life, but there was a complete lack of understanding of that. But I loved spending time with my sister, and we were (and still are) incredibly close and have a very close bond. She turned to me first for support and I was like a second mother to her, and took her to after school activities, helped with homework, dinner, bathtime and bedtime. Parents can rely on capable siblings as they get on with work as much as they can which can be a lot on young people. (ASD)

One sibling of a child with cerebral palsy felt that it is important to acknowledge "…that it was hard for the siblings of a special needs child. Extra responsibilities and pressure were put on them." (Sibling of child with cerebral palsy [CP]) "I didn't mind caring for them but I couldn't do it all." (ASD)

Siblings also address the impact on their sense of self due to the responsibility of caregiving and discuss the negative impact this has had on interpersonal relationships: "I am her 'person', her human attachment, and though thats really cool, thats draining on a kid. I feel it almost made me rely on the fact people needed me, so I have always struggled to be alone." (ASD) "A massive chunk of my self worth hinged on the caretaking duties of my siblings for a long time, being acknowledged and adored for something other than that would have been great." (DS)

Emotional neglect

Just under half of the participants described feeling neglected, alone and ignored during their childhood. Siblings of children with autism spectrum disorder said "As the younger sibling of someone with a disablity [sic] (glass child) my needs were often overlooked." and "No one ever asked, so I was left on my own to cope." (ASD)

They described feeling that their disabled siblings' needs were always more important than their own: "I deeply resent my mother as she was overprotective of my brother and put most of her time and effort into protecting him and she still does." (ASD) "I feel like his needs were always above my own." (sibling of child with cerebral palsy and autism spectrum disorder) "The disability was all that our lives seemed to revolve around." (DS) "I always felt like a needed to be good and just get on with things because their needs were more important than mine." (ASD)

> We understood that his needs were/are first. Im [sic] not offended by this and its really all I know. I havent [sic] imagined how things might have been better because the ultimate answer would be, his absence or the absence of ASD. (ASD)

One sibling of a child with autism spectrum disorder described neglect in terms of needing to work extra hard for attention:

> Feeling like i could get praise and attention for doing well without having to be a high achiever, since my brothers had less ability it felt like they got praised for every little thing that went right and I had to work a lot harder to be noticed. (ASD)

Another sibling of a child with Down syndrome described how neglect led to them raising themselves. "[I] was raised by playing playstation and reading books. I was just an afterthought be cause i [sic] was normal. Just expected to grow up and learn to do the right things without any direction." (DS)

Some participants wrote about missing out on activities or being forced into doing activities they did not want to do. This made some siblings feel neglected, unimportant and affected their mood.

> I found it really difficult when they were in hospital and one of my parents, usually my mum, had to be there at all times There were lots of my sports games etc that were missed because mum had not one but two children with special needs and both had no concept of personal safety. (DS/ASD)

> My biggest issue with my sisters disability is she would melt down and then suddenly we had to go home or couldnt [sic] go to an event or I couldnt [sic] go somewhere because she needed to stay home and one parent was busy or it just wasnt [sic]

> plausible. It upset me and made me annoyed at my sister because if I was feeling overwhelmed or upset or didnt [sic] want to do something I was encouraged to just do it or "but your sister wants to do this, then we can go home" or simply stop crying because others are watching. Im [sic] not saying she never got similar treatment but meltdowns from her always vetoed the plans for the day. (ASD)

Siblings detailed the struggle to understand their own emotional world and how to share this with others due to previous emotional neglect they experienced. “I felt like as I got older a lot of my own emotions I had to deal with myself, perhaps that was something that was quite isolating.” (ASD) “if I had more opportunities to share my personal struggles when i was younger; i think as an adult I would be better at expressing my stress and feelings in general.” (DS)

For some siblings, they talked about their experiences resulting in adult relationship difficulties that have had significant consequences for them. “This has impacted many life choices I have made including being in a volatile abusive marriage.” (ASD)

Siblings also found that due to the focus on their sibling’s disability this meant their own struggles got missed. Siblings specifically mention the need for assistance with their own neurodivergence: “It turns out I had undiagnosed ADHD my whole childhood and I think one reason this diagonsis [sic] was missed was because my brothers needs somewhat overshadowed mine. I wish that maybe more screening or attention had been given to the signs I was struggling too, but differently.” (ASD) “Looking into the signs of adhd and autism I see a lot of similarities in myself but as I am over 18 it’s extremely expensive and hard to get a diagnosis, I wish there was more support into looking at diagnosis for family

members of those who are diagnosed as there is a high chance there are other members that need to be tested as well." (ASD)

Guilt and shame

A large proportion of siblings said they felt guilty for having their own needs and felt they were not intitled to ask for help. Siblings reported that they felt guilty for being non-disabled and did not feel they had the right to complain and feared the negative reactions of others if they expressed this.

One sibling thought that it is important for people to know siblings of children with cerebral palsy have "…a lot of guilt around sometimes wishing [their sibling was] born 'normal' for their sake more than anything because you can see their frustration." (CP) A sibling of a child with autism spectrum disorder said, "…young people.... want to help because they love their siblings unconditionally, but feel guilty about wanting to have their own lives. (ASD) They also did not feel their needs were comparable or important, "many of the 'needs' I may have needed were void, simply because they are impossible." (ASD)

Siblings also stated they did not want to be seen as being ungrateful for being non-disabled; which can be conceptualised as being akin to survivors guilt: "I went to SibCamp but I felt guilty complaining about her so never did and when it was my turn to share id just say she was great and our relationship was good." (ASD) "I was known as the perfect child and the reason they decided to have more children which made me feel guilty over how non-perfect I felt." (DS)

Taha whānau

Approximately 80% of siblings reported experiences that came under this theme, which was the most endorsed theme. Siblings wrote about having acceptance for what occurred during their childhood and perceived that their parents had done their best. This position seems to come from siblings looking back on their childhood and gaining perspective, rather than how they felt at the time. “I know my parents really wanted to balance things for all of us but it was difficult in practise” (DS/ASD)

> I feel like my needs were met, there were times when I felt like everything my parents did were for my sister but looking back on my childhood now, they gave my support when i needed it and did everything and more for me. (ASD)

> My Mum did her best and because my sister was good at school everyone knew her and asked about her. I feel like Mum was good but my grandparents and extended whānau all cared about her and not me. She is academic and has a good job and they’re all so proud of her. Me though I’m a tradie [sic], i [sic] have tattoos, i [sic] ride a Harley. They don’t ask my Mum after me how I’m doing. (ASD)

> “I'm not sure how they could have stopped me getting beaten up on the daily” (ASD)

Siblings stated that they wanted to have been able to spend more time with their parents, for their parents to validate their feelings and receive emotional support from them. Approximately a quarter of participants wrote about needing support from their parents. Most of these siblings were female, apart from one male and one participant who identified as gender diverse. “More time individually with my parents away from my brothers.” (ASD) “If my parents had spent more time with me as well as let me express frustration/anger without putting guilt on me for the way I was feeling/thinking” (DS)

> Feeling validated and remembered that things affected me too. Not being made to feel bad for not enjoying or not wanting to do something for once, and just having the acceptance that it was hard being the sibling in its own unique way. (DS)

In addition to the needs identified in the parent/child relationship there are also needs in the sibling relationship. One sibling of a child with autism spectrum disorder spoke about their relationship with their sibling compared to the relationship peers had with their siblings and the challenges this presents.

> I had to mature more at a much younger age than my peers, I had to learn to deal with having a brother that I love who I can't have an actual relationship with. I would never know how he feels about me, it was all one way. (ASD)

Siblings are aware that the relationship they have with their sibling with a disability is not typical, which is important that those around them to be aware of. Siblings wrote about needing education on how to manage their sibling's behaviour as they pointed to this as being important in terms of supporting their whānau and being involved in their disabled siblings life.

> More information and more coaching as to how to best collaborate with my parents to make the house a practical environment to having my younger brother involved without it causing him to have a meltdown. Ultimately a greater education on the needs and work arounds of living with someone with Aspergers. (ASD)

> I would've liked more information on how to support my parents through tough times in relation to my sibling's disabilities and to be more prepared for how difficult the future could get with behaviours and emotional trauma. Also, I needed more coping

> skills for when I would miss out on support from my parents when my sibling's needs were greater than my own. (ASD)

Siblings were aware of the long-term relationship they have with their siblings, and some mentioned having to take over the care of their sibling in the future and move into the role of caregiver. Siblings noted feeling that their goals and inspirations may not be achievable or may need to change due to future caregiving responsibilities they may have.

> Now I had the chance to go to uni [sic] and have a job, I am becoming more aware of how much that care is going to fall to me some day and it will take over my entire life. It is making me put my life on hold. (ASD)

A sibling of a child with Down syndrome talked about their need for "plans and awareness about the future especially once my parents pass and I become the guardian." (DS) Another sibling said:

> As I've gotten older now it would be nice to know more about [my sibling]'s future as well. I'm starting to realise that while [my sibling] is extremely independent and has a lot of support from my parents to ensure he will have a future and will be okay, it is only a matter of time before his caregiving will fall onto either me or my other brother so that is something I would like to be able to learn more about and be involved in the discussion for when it comes time. (ASD)

Support needed from outside the family

Many siblings of children with disabilities indicated that support from outside their immediate whānau/family is important for meeting their needs. Furthermore, siblings wrote about the importance of educating people about whaikaha/disability and the issues that

siblings of these people face. This is particularly important for those that encounter siblings of children with whaikaha disability and support them.

Support for whānau

Fifteen percent of siblings felt that their needs would have best been met if their family's needs for support were met. A sibling of a child with Down syndrome said "…my needs, which are inextricably linked with that of my sibling and family." (DS) Another said:

> I think it's hard to have you own needs met when the parent isn't having theirs met and doesn't have the capacity to fill their parental role. I think Mum needed a lot more support (mental and physical) in order for all of us to have the time and attention we needed. As an adult I still often provide that supportive role to my mother around the care for my sister. (DS)

> Having the family as a whole have enough support would allow less stress on the parents and therefore allow me and other siblings a calmer home life. Having better support from the school my sibling attends would also remove a lot of my mother's responsibility so she was able to look after herself better and then when she is not overwhelmed / exhausted her approach with sibling is more considered and we have less behavioural explosions that effect the whole Whānau. School are not meeting my siblings needs and are always sending him home or basically saying he is too disabled for the unit. And this puts so much added stress onto the family. I wish often I could help more. Also regular therapy to my siblings father would have been highly helpful to all of us as I don't think he ever processed the diagnosis fully. Mostly I didn't need extra support but I wish my siblings parents got more support so out home as a whole coudl [sic] be a more happy place (ASD/DS)

Siblings of children with autism spectrum disorder said "…more support for whānau and siblings who surround and support disabled young people would be incredible, particularly in rural areas which can be hugely isolating." (ASD) Another said "…provide support for whānau of people with disabilities. Mental health counseling [sic] funded for these vulnerable family memeners [sic]." (ASD)

> Early diagnosis and advice to parents. I know something which impacted me personally is that my sibling was not formally diagnosed until with autism until their teen years. After the diagnosis and my parents then getting the chance to learn how they could better handle behaviours, home life improved. (ASD)

"More support systems in place. Ultimately my parents broke up and I moved out of home at 16. I feel this wouldn't of happened if we had all had more support." (DS/ASD)

Siblings identified funding for their sibling's care was a significant need for their whānau and not having enough funding for their disabled siblings care was a significant stressor for the whole family.

> Government support. My parents had to fight constantly to prove my sibling was "bad enough" to require care, and even then it wasn't fully funded. It was either financial burden or time burden requiring a parent to care full time. (ASD/DS)

> I feel my parents weren't (and still aren't) fully equipped to deal with some aspect's of my siblings' care. My parents didn't get a lot of practical respite (they got some funded hours but it was difficult to find a suitable carer) and this made things feel stressful and hopeless for them, and in return us children (DS)

"I feel like myself and my family needed more support, though, from public services, financially and emotionally." (ASD) "More respite care for people with disabilities to allow for more free time with parents" (ASD)

Professional support

Approximately, fifteen percent of siblings mentioned needing some type of professional support, one sibling specifically said a "Professional worker to talk to" (DS). They wrote about needing a professional help with their own emotional and mental health struggles and also for education about their sibling's disability. They stated would have liked "support on how to manage siblings aggression or crisis" (ASD), "understanding of the littles things that just happen to make my sibling upset." (ASD) and "being explained her capabilities not giving excuses of why she can't do things." (ASD) A sibling of a child with Down syndrome said "information to do with how to help my sibling, would have been useful. more information about the psychology of people with down syndrome, I think, would have helped me to meet my needs." (DS)

Education of school and community

Siblings felt their school and wider community needed to be educated about disability and siblings. Siblings perceived people judging them and their whānau and feel this could have been addressed with people knowing more about their experiences. One sibling of a child with cerebral palsy said that "people stare and don't understand special needs." (CP) Another sibling said:

> I was bullied quite severely at school because of my sibling's disability, and I felt I had nobody I could reach out to for help. Teachers didn't seem to care and sometimes participated in ableist slurs which left me feeling isolated and frustrated. (DS)

"More communication between my teachers so they know my situation." (ASD) "School to accept I had to care for sibling," (ASD) "If my wider community had an idea of what was going on at home" (ASD)

Siblings need other siblings

The need for support from people who understand was mentioned by approximately fifteen percent of siblings and mentioned by siblings of each of the three whaikaha. Siblings noted feeling lonely and having no one who understood; they felt guilty for feeling this way and needing someone; and they felt they should not feel this way as they do not have a disability. As also mentioned in the Taha Hinengaro theme, siblings detailed that being connected with other siblings in a similar situation would provide the best support. "It would have been nice to have others who understood, my sibling was the only autistic person I knew then, and my only sibling, so at times it was very lonely." (ASD) "And as I got older having a support network or people that made me feel less guilty or alone about my experiences and feelings about that responsibility" (ASD) "Talking with others who understood my experience." (DS) "Being listened to, having someone that I could talk to as I was going through my own trauma" (ASD)

One sibling found that from their perspective they "needed someone to understand how I felt and why I felt that way, none of my friends did, they tried to sympathise but that hurt more." (CP) and felt that "connecting with other siblings and people with similar experiences" would provide better support, "…having people to talk to and share experiences with that asp had a sibling with a disability." (DS) "Having a space to talk with others going through the same experiences, having a space to be able to 'rant' without guilt about what

living with my sibling was like" (ASD) and "a way for siblings going through the same things to connect." (ASD)

Siblings Organisation

Having an organisation that looks after sibling needs was mentioned as important for siblings. Siblings said it would be useful to have somewhere to go for support that is tailored to them: "If a support network were in place I feel I could have reached out to somebody to advocate for me." (DS)

> I now belong to … which is a great organisation that helps children and siblings learn how to cope. I have been a leader since I was 16 years old and would have been useful when I was younger had it been around (ASD)

One sibling through "programs to help support children who have siblings with disabilities" (CP) would be a great idea.

Psychological growth

In contrast to some of the challenges and significant impacts discussed in the previous themes, in this final theme, approximately a third of participants mentioned that their needs had been met or that they had gained something positive from their experience as a sibling of a child with a disability. These were mostly mentioned by siblings of children with Down syndrome and cerebral palsy; it is worth noting that needs met/positive experiences were often mentioned by siblings at the same time as unmet needs.

Psychological strengths

Sibling wrote about what they personally gained from the experience of having a sibling with a disability and how that shaped them as people. They discussed this in terms of their own personal characteristics, the way they parent their own children, and the way they interact with others and see the world.

> My experience as a sibling has impacted the way I'm raising my own children. My son is the youngest of three and although his needs (his have been more complex than my sister's) do require me to spend more time with him, I do make an intentional effort to spend one on one time with my daughters and meet their needs. It has definitely given me more understanding for my own parents and their journey. (DS)

Some siblings of children with whaikaha/disability reflected on the characteristics they gained from their childhood experiences. “I think it was something where I learned to be patient and to wait my turn and those are traits I'm really grateful to have.” (ASD) “It has allowed me to be more open minded in varying ways and has positively shaped the way I see the world today!” (CP) “Due to my siblings need for extra support from my parents, i [sic] have grown to be very independent.” (DS)

Siblings described what contributed to their positive experiences of being a sibling of a child with disabilities; attention, communication and support were referred to as key to ensuring they had a good outcome.

> I was given just as much attention as my brother. My family has a good understanding of autism and neurodivergence so my brothers always had support and I always have for my ADHD and dyslexia. My mum home schooled my brother so he didn't get the trauma that comes from being at school when your autistic and he got a good amount

of one on one time with my mother. I think I would have gotten less attention overall if he wasn't autistic because my mother would have gone back to work once we where both old enough to go to school. She was always home when I needed to be home sick as a kid and it was a lot. My life would look very different if he was neurotypical and most of those changes would not be for the better. (ASD)

Communication and support

I honestly feel like my parents and whānau dealt with [my sibling's] disability in the best and most loving way that they knew how to. They were always open with us about his health and needs and progress and Timmy himself always had and has such a positive and upbeat attitude that I dont [sic] remember ever feeling left out or unloved or confused or that I had to be secret about Tim. In fact, my parents used to take us out to places all together and I would basically show Tim off to anyone who would listen about how cute and special he was. (DS)

"My parents carried 99% of the load and we had a lot of open communication so I felt I had a very normal childhood considering." (DS)

I think overall, my needs during my childhood were met. Regarding my brother who had cerebral palsy, I had my other siblings and also lots of family around growing up so I never felt that I had been left out or not communicated to about his needs. I'm very family oriented and i [sic] believe thats [sic] a trait carried on to me by my parents. We're a close family and always looked out for each other. Wouldn't have wanted it any other way (ASD/CP)

I had incredible love and support from my parents and siblings. My community helped us and treated my disabled brother equally. I am so grateful to have has such a

great childhood. The blessings surpassed any burdens that came with having a sibling with Down syndrome.. My brother having Down syndrome is no big deal, he participates in many cool organisations and has a great life. Thanks to these initiatives, i have also got an amazing life. (DS)

Chapter Five: Discussion

The current research aimed to address the significant gap in knowledge with regards to the needs of siblings of children with whaikaha/disability in Aotearoa/New Zealand. The current research did this through a retrospective study looking at the unmet needs of these siblings to understand what psychosocial aspects of life siblings struggle with and need support in. This study also sought to understand the similarities and differences between the unmet needs of siblings of children with whaikaha/disabilities and siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand, as both studies used the same instrument (Armstrong, 2019). The current research also looked at the influence of a number of factors on the unmet needs of siblings of children with whaikaha/disability that were highlighted in the literature review, including burden, type of whaikaha/disability, birth order, number of parental figures, number of siblings and culture. This research also sought advice from siblings themselves on how best their unmet needs could be addressed and what support they needed. This chapter will address the aims of the research throughout. Initially the overall findings from this study will be briefly discussed, followed by key findings from the present study, then a comparison between disability and health conditions. Finally, strengths and limitations of the research will be discussed followed by recommendations and concluding thoughts.

Overall Findings

The main aim of this research was to establish if siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand have unmet

needs and if they do, to identify these. This aim arose from previous research, which has consistently identified the negative psychological impacts on siblings, assumed what siblings need and then created an intervention from this, instead of asking siblings about their needs. It was also identified that there is a lack of research in general around the experiences of siblings with whaikaha/disabilities in Aotearoa/New Zealand. The present research suggests that siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy in Aotearoa/New Zealand have high levels of unmet needs. These needs have also been found to be a result of the lack of understanding and support from others rather than from the disability itself (Hanvey et al., 2022). The results from both the quantitative and qualitative results support this conclusion, and this will be illustrated throughout the discussion.

Four of the ten top unmet needs in the Sibling Disability Needs Instrument (SDNI) belong to the 'support from friends and other young people' domain - items 1, 6, 7 and 10 from the list below. Item number 3 comes from the 'dealing with feelings' domain and is included below as it is similar to the other items.

1) To have had someone close to discuss my feelings about my sibling/whānau member's whaikaha/disability (72.9%)

3) To have been able to express how I felt about my sibling/whānau member's whaikaha/disability without worrying about upsetting people (71.4%)

6) To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty (65.9%)

7) My friends to have understood what I was going through (64.7%)

10) To know how to talk to my friends about my experience with my sibling/whānau member's whaikaha/disability (63.5%)

The above unmet needs are examples of siblings' emotions being "overlooked" and "ignored". In the qualitative data siblings wrote about their difficulties expressing their own

“emotions” and “feelings” as “adults” and having to “deal” with this themselves. According to Glickman et al. (2021) this is strongly correlated with depression later in life. Siblings of children with Down syndrome indicated that the ‘support from friends and other young people’ domain had the highest mean percentage of unmet needs for them. This result is also reflected in the qualitative results for the current study. Under the taha hinengaro theme siblings spoke about needing people in their lives that do not make them feel “alone or guilty”, They said “I needed someone to understand how I felt and why” and the “opportunity to share my personal struggles” instead of feeling like they had to “suffer in silence”. They said their friends “tried to sympathise but that hurt more”. This theme is also the most frequently mentioned theme by siblings, indicating siblings feel their emotional needs are neglected. This (along with strong evidence in the literature) shows that siblings struggle with difficult feelings and with expressing these to others. Therefore, siblings need support with their confusing feelings and experiences as well as in their relationships with others.

The following two unmet needs were also endorsed by siblings as some of the most commonly unmet needs in the SDNI. They both belong to the ‘time out and recreation’ domain. This domain had the highest mean percentage of unmet needs for ASD siblings.

2) To be able to have fun (71.8%)

5) To have had time to look after myself and focus on my own needs (66.3%)

This finding was supported by the qualitative results in the current study. Specifically, the qualitative theme taha hinengaro aligns closely with these items. Siblings reported that they “feel guilty for wanting to have their own lives” and fear their siblings care “will take over” their “entire life” in the future. Additionally, several siblings mention difficulties with balancing their lives as well as caregiving responsibilities. One sibling said it was “incredibly stressful for a teenager who had a lot on the go with both school and having a social life”. Another said, “I didn’t mind caring for them but I couldn’t do it all”. To address

this, siblings suggest being able to “get some time away from my siblings” and having “more personal space” would help meet their needs.

Siblings need support to be able to live their own lives and to get a break away from their situation at home. In the qualitative results, siblings talked about the challenges and distress of having to take on a parental role that included caregiving and domestic duties. They speak about the “burden of this” and wanting the “chance to be a child for a little longer”. Thus, it is important that siblings do not feel that their lives have been taken over by the disability and associated consequences.

The following three items were also identified in the top ten as being some of the most frequently mentioned unmet needs siblings have. These items are all from the ‘understanding from my family’ domain and siblings across all disabilities indicated similarly high levels of unmet needs.

4) To be able to spend time with my parent/s - just me and them (70.2%)

8) To know my parent/s had not forgotten about me (64.3%)

9) To feel that I was as important and valued as my sibling/whānau member with a whaikaha/disability (63.9%)

This is supported by the qualitative results, specifically the taha whānau theme, where siblings spoke about wanting to spend more time with their parents and felt as if they were not important. One sibling wished that “attention had been given to the signs I was struggling too”. Another said, “I needed to feel listened to and cared about too”. The current research supports the previous findings of several studies included in a recent literature review where it was found that many siblings speak about getting less attention from their parents (Watson et al., 2021). Siblings need support and understanding from their whānau/family, so they feel they are just as important as their brother or sister with ASD, DS or CP.

Comparison of unmet needs between siblings of children with autism spectrum disorder, Down syndrome and cerebral palsy

Another significant aim of the research was to determine if there are any differences between siblings of children with autism spectrum disorder (ASD), Down syndrome (DS) and cerebral palsy (CP) in Aotearoa/New Zealand. This was an important aspect to investigate due to the significant differences between the disabilities and the lack of research comparing how these differences impact siblings. All disabilities had high levels of unmet needs; ASD had the highest mean percentage of unmet needs overall and across all domains (69.9%) followed by CP (42.9%), and DS (41.9%). It was found that the difference between the ASD siblings and the DS siblings was statistically significant. The 'dealing with feelings' and 'time out and recreation' domains had the biggest differences, with siblings of children with ASD scoring higher than CP and DS. The domains that had similar numbers of unmet needs across disabilities were 'support from friends and other young people' and 'understanding from my family' domains.

Safety of siblings of children with autism spectrum disorder

Siblings of children with ASD have the highest mean percentage of unmet needs when compared CP and DS; this is also the case when ASD is combined with DS or CP. This indicates that ASD siblings are struggling far more than the siblings of other disabilities. The current qualitative research shows that the taha tinana (physical) theme was identified by half of ASD siblings. Only siblings of children with ASD mentioned suffering abuse, violence and aggression at the hands of their ASD siblings, as well as feeling fear. According to Button and Gealt (2009), sibling abuse is the most common form of family violence,

regardless of the presence of whaikaha/disability. This violence and aggression has been found to have significant psychological consequences for siblings such as depression and low self-esteem (Button & Gealt, 2009). Siblings of children with DS and CP on the other hand did not mention being abused or assaulted by their sibling and generally children with whaikaha/disabilities are not violent.

Currently there is very little formal research on violence in children with ASD and the impact of this on siblings, although violence and aggression has been found to be a significant issue for some families who have a child with ASD (Siblings Australia, 2012). Most of the information on ASD violence and abuse is found in the grey literature, where parents and siblings talk about their own experiences and seek support from others through online forums. In one of the only studies on this topic, it was found that physical violence from ASD children makes siblings feel stressed and anxious (Benderix & Sivberg, 2007). Therefore, it is imperative that there is more awareness (and assessment) of siblings who experience violence from a sibling with a disability. Additionally, this study points to the need for specific support being provided to siblings who are impacted by violence.

It is thought that the absence of theory of mind in some children with ASD is a contributing factor in aggression and violence as they are unaware of the consequences of their actions on others (Sabuncuoglu et al., 2015). Sabuncuoglu et al. (2015) stresses that professionals are not very aware of the issue of violence and recommends that families report these instances to professionals. The violence continues throughout childhood and in some cases through to adulthood. Violence also becomes a significant issue during adolescence due to this period of life having many developmental changes and this can be overwhelming for children with ASD as they already struggle to regulate their own behaviour. According to Kanne and Mazurek (2011), 68% of children and adolescents with ASD demonstrate

aggression. This is extremely concerning as this means a significant number of siblings are being physically harmed by their siblings in their own homes and are not safe.

In addition to this, the qualitative results revealed that siblings felt that they and their whānau need support to manage the violence and other negative behaviours. They also asked for a safe place to stay, a break from their sibling and someone to advocate for them and look out for their safety. However, this is difficult for siblings to talk about because they do not want people with ASD to be seen as violent (Murray, 2018). Children are protective of their ASD siblings (Macedo Costa & Pereira, 2019); they are aware that their ASD sibling already faces a lot of stigma and do not want to make this worse. Siblings have to balance their need for support with upholding the dignity of their ASD sibling. This means that siblings are unlikely to ask for support, so support needs to be offered. A literature review by Watson et al. (2021) suggests that siblings should have their own form of respite and have their own support network.

Autism is an invisible, developmental disability characterised by certain traits, characteristics and behaviours. There are no physical disabilities or health conditions that are associated with it. Children with ASD and their families rarely come to the attention of health services and families are left to manage challenging behaviour on their own. This is because ASD is invisible and people do not see immediately that the young person has a disability, and their behaviours can be attributed instead to ‘bad parenting’ (Mitra, 2022). This makes it difficult for siblings too as lack of support for parents leads to a lack of support for siblings too. In the quantitative results siblings point to the importance of meeting their parents needs so their needs can also be met.

DS and CP on the other hand are whaikaha/disabilities that are visible, which means families may not be stigmatised in the same way. Both of these whaikaha/disabilities also have health conditions associated with them and so regularly access health services; therefore

any issues are likely to be quickly identified and support provided. This is a significant difference from ASD which does not have health conditions associated with it. This could mean that DS and CP families are better supported and likely to have more positive experiences than ASD families, due to their regular engagement with a wider range of services.

In the qualitative results it was found that DS siblings were more likely to talk about positive aspects of having a sibling with DS than ASD or CP siblings. For example, a sibling of a child with DS said their childhood had “lots of fun times and adventure”. Another sibling talked about their sibling’s “positive and upbeat attitude”. These siblings both attributed this to having had “love and support” from their family throughout their childhood. This is consistent with previous findings that found sibling relationships where one child has DS are positive. The quantitative results also showed that DS siblings have the lowest percentage of unmet needs compared to the other disabilities studied and this is significantly lower compared to ASD.

Comparison between the unmet needs of siblings of children with whaikaha/disabilities and the unmet needs of siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand

In Aotearoa/New Zealand there was a previous study done on the unmet needs of siblings of children with cancer, diabetes and cystic fibrosis using the same instrument as the current study. In this previous study it was found that siblings have high levels of unmet needs. Therefore, the current study sought to identify and understand the differences between the two groups of siblings. The unmet needs of siblings of children with cancer, cystic fibrosis and diabetes and siblings of children with ASD, DS and CP were similar in some respects and different in others. Both groups of siblings were found to have similarly high

levels of unmet needs overall. There were three unmet needs that were in the top 10 unmet needs for both groups of siblings:

1) ‘To have had someone close to discuss my feelings about my sibling/whānau member’s illness/disability’
2) ‘To be able to have fun’
3) ‘To be able to talk about how I was going (and not how my sibling/whānau member was going) without feeling guilty’

This illustrates that both groups of siblings have a need for a close relationship where they can talk about their own experiences and feelings in a safe atmosphere. Siblings also identify a strong need to be able to have fun and to take a break away from the demands that having a sibling with a disability or serious chronic health condition puts on them. The quantitative results showed that the domain that was most similar for both groups was ‘dealing with feelings’ (whaikaha/disability 58.5%; cancer and serious chronic illness 56.0%). In addition to this, there were four out of seven domains where whaikaha/disability had higher unmet needs than cancer and serious chronic health conditions. Due to strong similarities, it may be that it is appropriate to support both groups of siblings together as they share many similar needs and experiences. This is important as for each condition there are small numbers within each community. The commonalty here is the burden of their experiences rather than the type of condition, disability or health. Thus, combining them together in support services means there is more chance siblings can meet others like themselves in their communities.

Alternatively, the most striking finding from the data was that the domain ‘information about my sibling/whānau member’s illness/disability’ had the lowest mean percentage of unmet needs for siblings of children with whaikaha/disability (43.0%) but had the highest amount of unmet needs for siblings of children with cancer and serious chronic

illness (65.3%). This indicates that siblings of children with cancer and serious chronic illness may not feel as well informed as siblings of children with disability. Therefore, this may be an area where support needs to be different between the two groups of siblings.

The nature of health conditions means that treatment and engagement with services differs from disability. Treatment for cancer is primarily hospital-based involving intense treatment over a short length of time (Jibb et al., 2021). Children with cancer and their families are connected to the health system throughout the cancer journey and a lot of support is provided for them (Jibb et al., 2021). It is also often a fairly visible condition and people have a lot of sympathy for people who are impacted by cancer.

In addition, many children recover from cancer and go on to live normal lives, with a 80% five year survival rate (Erdmann et al., 2021). On the other hand, cystic fibrosis and diabetes are primarily managed in outpatient care, are often invisible, and are chronic, lifelong conditions. Diabetes is a serious chronic condition which persists over time, it can be intense in childhood and may involve some hospitalisations but is eventually managed by the person themselves as they mature (Arffman et al., 2023). Cystic fibrosis tends to get worse over time and treatment increases in intensity and may end in death at an early age, approximately 40 years old (McBennett et al., 2022).

In contrast to health conditions, the whaikaha/disabilities in this study maintain a high intensity throughout the life course and many children with disabilities also do not become fully independent and are reliant on care from others for their entire life. This means siblings are impacted throughout the life span (Dew et al., 2008), including being disadvantaged and discriminated against due to being associated with disability (Murray, 2018). The qualitative results also show that siblings have concerns about what will happen in the future and what roles they may have to step into. Therefore, future research on siblings of children with

whaikaha should look at unmet needs across the lifespan, so that appropriate support can be developed.

Influence of gender on sibling unmet needs

The current study aimed to determine whether there is a difference between the unmet needs of male, female, and gender diverse siblings. The quantitative results show a statistically significant difference was found between the unmet needs of males and females, where females had a greater mean percentage of unmet needs. This is consistent with previous research in Aotearoa/New Zealand on siblings of children with cancer and serious chronic illnesses which also found that female siblings have a significantly higher level of unmet needs than males (Armstrong, 2019). Furthermore, it has been found that female siblings of children with whaikaha/disabilities experience more negative affect than males (Hamama & Gaber, 2021). Females were also found to have a tendency towards undertaking more caretaking duties than their male peers (Donnan, 2020; Marquis et al., 2019). Further, females feel the social pressure towards caregiving and feel it is expected of them (Marquis et al., 2019). The qualitative results of the present study support these previous findings, as it was almost exclusively females who mentioned caregiving.

Influence of culture on sibling unmet needs

This research also aimed to identify if there are any differences in unmet needs between ethnicities. It was found that there is no difference in unmet needs between Māori and non-Māori siblings that were statistically significant. In the present study the proportion of Māori to non-Māori participants was also found to be the same as for the general

population. A previous study on siblings of children with cancer and serious chronic illness in Aotearoa/New Zealand also found the same result, that there are no significant differences between the unmet needs of Māori and non-Māori (Armstrong, 2019).

Correlation between family burden and sibling unmet needs

Investigating the relationship between the burden and unmet needs of siblings was also an important aspect of the present study. This is because the level of disability is thought to be a more significant factor in determining impact on a family member compared to the diagnosis itself (Breslau et al., 1982); disabilities are heterogenous and consequently, the level of impairment differs between individuals. Wang et al. (2004) also concluded that the characteristics of disability and their impact on the family was more important than looking at severity alone, as it is possible for a severe disability to not impact a family much. On the other hand a mild disability could have a significant impact on the family, for example a child's behaviour could be violent or aggressive (Wang et al., 2004). In the present study, the amount of burden siblings perceived was placed on their family was measured so these issues were taken into account. The qualitative results found that burden and unmet needs had a very high positive correlation, which suggests they measure the same under lying concept. Therefore, it is possible that unmet needs also indicate the burden disability places on families.

This is also illustrated by findings in the qualitative research where siblings talk about the burden their family is under due to not having support and this leading to siblings' subsequent unmet needs. Siblings level of unmet needs may indicate how well a family with a child with a disability is supported or unsupported. This points to the wider issue of a lack of support for people with a whānau member with a disability in Aotearoa/New Zealand,

specifically children. The unmet needs of siblings may be an indicator of how much the whole family system is struggling and needs support. This aligns with previous literature that theorised that it is not the disability itself that causes the negative impacts but the wider implications, e.g. extra time, aggressive behaviour and caregiving (Hanvey et al., 2022).

Thus, this research points to measuring unmet needs may be a better (and more acceptable) way to look at how much a family is burdened by having a family member with a disability and would also point to what a family needs. This allows families to voice what needs they have that are not being met without having to say their family member is a burden. This is important because the term burden has associated negative connotations and siblings often mentioned "guilt" in relation to talking negatively of their sibling with a disability or having negative feelings towards them. From this study, in combination with examining research surrounding the concepts of burden and unmet needs, it can be concluded that it may be helpful to focus on unmet needs instead of burden in supporting siblings of children with disabilities.

Influence of family size on unmet needs

In the present study, it was found that participants who had one or two siblings had a significantly higher percentage of unmet needs than participants who had three or more siblings. This suggests that having many siblings is supportive in a family where a child has a disability and leads to less unmet needs. This is potentially because children without disabilities can support each other and meet each other's needs, and that there are more people to help with caring for a whānau member with a disability. This is also illustrated by the qualitative results where siblings talked about the benefits of having a large family that supports each other, shares caregiving and household chores. Siblings who do not have other

siblings may not have anyone to share the load with or any who understands their situation that they can go to for support. This could contribute to a higher number of unmet needs. This suggests the importance of having a support network, either within the family and/or outside the family. Future research therefore should look at developing support for siblings in terms of networking and spending time with other young people who have similar experiences.

Previous research looking at the mental health of children without disabilities found that living in a large family was associated with less mental health issues (Grinde & Tambs, 2016) which is similar to the current findings. In contrast, some studies have found there was no impact on siblings' mental health based on family size (Lawson & Mace, 2010). Many families with a child with a disability are large families and who live in a low socioeconomic situation (Cuskelly, 1999; Donnan, 2020; Emerson & Giallo, 2014; Giallo et al., 2012; Neely-Barnes & Graff, 2011). Families struggle to afford external support so therefore family fills the gap in support for all family members. But for siblings with few whānau members there is no one to fill this gap resulting in higher unmet needs. Since the research is inconclusive and previous research has not looked at the impact the number of siblings has on the mental health of siblings of children with disabilities, research should further examine the impact the number of siblings has on siblings of children with disabilities.

There was no difference between siblings that were older than their sibling with a disability compared to siblings that were younger than their disabled sibling. A previous literature review found that the existing research was inconsistent with regards to the impact of birth order (Marquis et al., 2019), and the current study has also indicated that there is no significant impact.

There was a difference found between the percentage of unmet needs for participants who came from one parental figure families compared to those that came from families that had two or more parental figures. Although this difference was not significant, it indicates

further research is needed with a larger sample on the impact of the number of parental figures on unmet needs for siblings. Research on this from Aotearoa/New Zealand (and internationally) concludes that one parent families of children with disabilities are at an increased risk of living in poverty compared to two parent families (Marquis et al., 2019; Murray, 2018), which may impact unmet needs, including emotional needs. Alternatively, research by Giallo et al. (2012) reported that the number of parental figures was not a factor in the mental health outcomes of siblings. This lack of clarity in the existing literature highlights that further research is needed into the impact of parental figures.

Family Support

Siblings emphasised that they were not the only ones impacted and their parents were too. They said because getting help for their disabled sibling was difficult for their parents, this meant siblings themselves were negatively impacted. For example, siblings took on caregiving, housework and raised themselves. In the qualitative results, siblings talked about the challenges their parents face when it comes to looking after their disabled siblings. Siblings also noted the resulting negative impact this has on themselves as their parents were often stressed and time poor. This finding is consistent with family systems theory because siblings are aware that that the lack of support parents have for caring for their disabled sibling means that they too get less attention and support. Previous Aotearoa/New Zealand research has suggested that funding for families of children with disabilities needs to significantly increase along with support to alleviate stress and give parents more time for their other children (Murray, 2018). Further research is needed into the relationship between parent support needs and sibling support needs.

Positive aspects for siblings

Although this study specifically looks at needs, siblings did share the benefits they experienced from being a sibling of a child with a disability. This was shown in the qualitative results where siblings talked about how the experience had made them more caring and understanding towards others. This beneficial aspect along with the unmet needs already mentioned is consistent with the finding that there are mixed outcomes for siblings which was established in a large literature review (Marquis et al., 2019; Meadan et al., 2009). Although, it is important to point out that the negatives generally outweigh the positives in terms of sibling impact (Marquis et al., 2019).

Study Strengths

Sibling as researcher

As part of promoting the survey for this research I disclosed that I have a sibling with whaikaha/disability. I also disclosed myself as a young carer when promoting my research on the young carers New Zealand Facebook page. Self-disclosure may have contributed to my credibility as a researcher as it let participants know that I have an understanding of where they are coming from in terms of their complex experiences. It may also give the participant the ability to be open and honest about their experiences without worrying that they could offend the researcher. In turn this may have motivated siblings to participate in the research. This was important because the results overall showed that siblings generally felt they were not understood and were dismissed by a lot of people around them. According to Berkovic et al. (2020) there are three main strengths of doing insider research - being able to build rapport with the participants and be seen as equal to the participants, and enhanced credibility due to having a nuanced in-depth view of the topic. Coming from an insider perspective means

participants can expect a more nuanced in-depth view of the topic than would have been possible if this research was done from an exclusively outside perspective, due to the greater depth lived experience gives.

Being a sibling of a person with a disability myself also gives me the ability to portray siblings in a way that is respectful to the way we as siblings see disability. It also reduces the likelihood of misinterpreting what siblings say and maintains the sibling voice throughout the research process. This is important as this research covered some sensitive topics. Therefore, reflexivity was utilised throughout the research process; the experience of being a sibling of a person with a disability was reflected on in conjunction with the existing research. This ensured that I stayed with the participants' experiences instead of being swayed by my own biases and increased the trustworthiness of the current research (Krefting, 1991).

Mixed methods

Using both quantitative and qualitative research methods is a significant strength of this research, providing both breadth and depth on siblings' experiences. This is particularly important as the sample size was not as big as expected due to the challenges in recruiting participants from a population that is generally regarded as invisible (see limitations).

Public response

The public response to this research was mostly positive. Organisations I contacted supported this research and shared it throughout their networks. I also discovered that the New Zealand Down syndrome association is hoping to start a sibling group in the future:

"Did you know that NZDSA are soon starting a sibling support group." (Personal communication, 2023)

Siblings of children with other disabilities made contact via email and comments on the survey's Facebook posts asking to participate. Parents also commented on doing the survey on younger children. This shows people also see gaps in services for siblings in addition to what was found through the literature review.

"All the best with the research. As someone who was a carer of a sibling with Downs[sic] Syndrome in my tweens through to 20s I'm sure it will be interesting." (Facebook, 2023)

"Great idea to research. It's a shame younger siblings aren't (yet) being surveyed too. The impact of a special needs family member within your home, affect all. Best of luck." (Facebook, 2023)

"hey Sarah I would love to participate. My little brother has Williams syndrome- am I able to do it!" (Facebook, 2023)

"Kia ora Sarah, I am interested in participating in your study however my disabled sibling does not have any of the impairment diagnoses you have listed. She has trisomy 18 (Edwards syndrome) which includes an intellectual disability and requires full time care." (Personal communication, 2023)

"Hi Sarah, I would be delighted to share your research, the relationship for siblings is important. As one of 5 siblings it's a topic close to my heart." (Personal communication, 2023)

The preliminary findings from my research were presented at the Australian Psychological Society and New Zealand Psychological Society 2023 Symposium. The focus of the presentation was on the literature review and the qualitative findings. This research received positive feedback from the psychological community regarding this research's importance.

Study limitations

Measure

When the confirmatory factor analysis of the Sibling Disability Needs Instrument (SDNI) was compared with the factor analysis of the original Sibling Cancer Needs Instrument (SCNI) it was found that both surveys supported four factors. However, the factors did not correlate with the domains in the same way in the SDNI compared to the SCNI (Patterson et al., 2014). It was found that some items in the SDNI do not fit in the domains that the SCNI intended, indicating that siblings of children with disabilities do not view their needs in the same way as siblings of children with cancer. Some items were also found to not strongly correlate with any factors on the SDNI, suggesting their inclusion may not be appropriate for siblings of children with whaikaha/disability. However, this measure is an important first step to making sibling experiences visible and has the potential to be able to identify at-risk siblings. Further research is needed to explore the validity of using this measure on the sibling disability population.

Small sample

A significant limitation of this research is the possibility of sampling bias, where some members of the sibling population have more chance of being included in the sibling sample than others and this in turn could have an impact on this research's external validity. For example, this study relied on siblings or whānau members being connected to Facebook, to regularly use this and be part of a relevant group connected to disability, siblings or young carers.

Access to the sibling disability population was a significant limitation for this study. The sibling disability population is rather invisible to society and so finding participants was a challenge. There are no organisations that specifically look after this group; there is only one group on Facebook for this population, which is small and not very active. Since there is a lack of sibling groups to contact siblings through, siblings were recruited through disability organisations and Facebook groups for people with disabilities. This meant data collection relied on parents and people with whaikaha/disabilities themselves passing the survey on to their siblings.

The research was advertised on a neurodiversity related Facebook page where there was unfortunately some negativity directed towards the research. Some people with Autism were not happy with the phase 'sibling with autism spectrum disorder' (person-first language) and instead requested I use Autistic sibling (identity-first language). This is because they felt the word disorder has negative connotations and they preferred identity-first language. Some individuals in the autistic community were concerned the research will further stigmatise them and may place the blame on them for their siblings' struggles. This was the response:

"Thank you for bringing to my attention the language around Autism. I appreciate the time you have taken to share those important points and I take on board your point about

wording. Consequently, I have amended the poster and information sheet to say "Autism" rather than "Autism spectrum disorder". With regards to the research, the focus is on a holistic Family systems perspective where it is important to acknowledge and take into account all relationships and experiences (including strengths) within a family unit - the sibling relationship is one of these important relationships. This research provides an opportunity for siblings to identify and discuss their needs and is inclusive of the varying experiences of siblings"

The aim of this was to reassure people that this research does not seek to blame children with disabilities, but rather to ensure siblings can be supported too. This may have meant that some people with whaikaha/disabilities did not pass the research on to their siblings due to their negative views of the research, which may have impacted the sample size.

Due to the interest in the survey from siblings over 35 years old in conjunction with a low response rate from siblings 18 to 35 years old, the survey was opened to older siblings during data collection. When age was compared with the number of unmet needs it was found that age had no correlation with the level of unmet needs reported by siblings. This means that it is unlikely that there are any cohort effects present.

Despite the difficulties in finding siblings to participate in this survey, the results are much stronger than a past survey on sibling disability in Australia. Siblings Australia did a survey on siblings recently and had had only 50 participants, which is smaller than the present study, despite Australia having a much bigger population to recruit from. However, it is acknowledged that due to the small sample in the present study, the results may not be generalisable to the sibling disability population as a whole.

There could also be measurement error in the number of unmet needs reported by siblings. This is because this study is done in retrospect where participants were asked to

recall what happened in their childhood and respond from this perspective. With this comes the possibility that siblings may not have been able to accurately recall what happened when they were a child. The cognitive bias ‘rosy retrospection’ is also a concern when doing this type of research as people can view the past more positively than it was (Mitchell et al., 1997). This could lead to participants identifying less unmet needs than they had. This could mean that this research is an under-estimation of unmet needs. However due to ethical reasons, including the possibility of childhood trauma, younger siblings were not an option for this study.

Access to existing research

A significant limitation of this study was access to previous research in Aotearoa/New Zealand on siblings of children with disabilities. For example, one of the participants from the current study informed me of some previous New Zealand research on siblings via personal communication.

> Janet Dixon also completed her thesis on experiences of siblings of disabled people. I was interviewed for that, and it might be important to note that when I was interviewed I was unaware I had unmet needs. It is now clear that my emotion and attachment needs were poorly met when I was young, and am now working though that. Also, some services used by everyone can be incredibly beneficial to whānau but isn't considered - e.g. cleaning, because it's considered part of the household unit without recognising that extra labour would be helpful. It might be a useful caveat that people might have needs they're unaware of. (Personal communication, 2023)

In this research Dixon (2012), interviewed siblings of children with disabilities. This research was only available at the IHC library, which houses information and resources on disability. Unfortunately, without the input of this participant this important piece of research would not have been found. Therefore, it is no surprise that siblings in the current study feel invisible given the research about them in Aotearoa/New Zealand is also invisible.

Conclusion

The current study aimed to address the significant gap in knowledge around the psychosocial impact of having a sibling with a whaikaha/disability in Aotearoa/New Zealand. To do this, the present study investigated the unmet needs of siblings of children with ASD, DS and CP in Aotearoa/New Zealand. To understand siblings' experiences of having a sibling with whaikaha/disability growing up, siblings were asked to answer looking back on their childhood. This research aims to gain an understanding of how siblings are impacted and identify areas that siblings feel they need support in to inform future support services for this vulnerable group of siblings. This study also sought to compare the unmet needs of siblings of children with whaikaha/disability with siblings of children with cancer and serious chronic illness in Aotearoa/New Zealand to establish whether it is appropriate to develop sibling support services that can support both groups of siblings.

A thorough investigation into targeted sibling support services in Aotearoa/New Zealand found that there is very little support available for siblings. The quantitative finding from this study suggests that siblings of children with ASD, DS and CP in Aotearoa/New Zealand have very high levels of unmet needs and this is comparable to siblings of children with cancer and serious chronic health conditions. Both groups needed assistance with sharing their feelings and experiences with family and friends and being able to have time out

and recreation. Being female was found to result in a higher number of unmet needs for siblings for both groups of siblings. A plausible explanation for this is females are much more involved in caregiving compared to males. Also having one to two siblings and having a sibling with ASD appear to have a statistically significant influence on the level of unmet needs a sibling of a child with disability has, resulting in a greater number of needs for these siblings. Qualitative results suggest this may be because siblings of children who have whaikaha/disabilities who have a larger number of siblings may receive more practical and emotional support compared to siblings who have just a few siblings; more siblings may fill the gap left due to the lack of support services available to these families. Siblings of children with ASD are thought to be more negatively impacted because of their siblings' socially inappropriate, aggressive and violent behaviour, which made siblings feel anxious, stressed and unsafe. This indicates that support for siblings also needs to be adaptable to the needs of specific groups of siblings.

Burden and unmet needs were found to be highly correlated. This suggests that these are related concepts; therefore, it is suggested that preference is given to the concept of unmet needs as there are less negative connotations and stigma connected with it. Overall, this research shows that there is an urgent need to provide support to siblings of children with whaikaha/disability due to their high levels of unmet needs and the knowledge that leaving these needs unmet leads to significant mental health and wellbeing consequences for siblings in the future. This was also shown through the results of the qualitative research where siblings discussed the negative impact of the resulting consequences that occur because of their siblings' disability.

The current research indicates that a support service that caters to both siblings of children with whaikaha/disabilities and siblings of children with cancer and serious chronic health conditions may be appropriate. However, care needs to be taken as there are some

significant differences between groups in terms of their unmet needs. But it is clear that both siblings of children with whaikaha/disability, and siblings of children with cancer and serious chronic health conditions have very high levels of unmet needs and require support. Therefore, future research should look at developing and providing support to siblings of children with whaikaha/disability along with siblings of children with cancer and serious chronic health conditions in Aotearoa/New Zealand.

Future research should also look at siblings of children with other disabilities and health conditions to understand the impact on these siblings too. Additionally, the sibling disability needs instrument (adapted from the sibling cancer needs instrument) requires further examination as the items were not found to be interpreted in the same way by the two groups of siblings.

In conclusion, there is an urgent need to develop and provide targeted support to siblings of children with whaikaha/disability, specifically to those identified as having the highest need. It is also important to ensure support is holistic, culturally sensitive and has the support of both professionals and siblings. This support should aim to keep this invisible and under-served population safe and protect their health and wellbeing across the lifespan.

Recommendations

The existing research in conjunction with this study reveals that both a non-categorical and categorical approach for siblings is necessary. In Aotearoa/New Zealand it was found that there is a lack of support services for siblings of children with cancer and serious chronic health conditions and previous research found these siblings have high levels of unmet needs. The current research was a replication of this study and found similarly that the gap in support services for siblings of children with whaikaha disabilities was even larger

and unmet needs just as high. Therefore, future research should aim to build on these findings by developing support programs and services to target the unmet needs both groups of siblings have. Findings also suggest that siblings harbour a lot of difficult emotions and experiences and feel a lot of guilt around asking for their needs to be met as they do not feel they are, they also do not know where to go for help. Therefore, help must be offered directly to them.

The following recommendations regarding support for siblings of children with whaikaha/disabilities are informed by the findings from the current research.

- Support and understanding from friends, family and community
- Greater support and funding for parents and whānau of people with whaikaha/disabilities
- Time with parents away from their sibling so they feel important and valued
- Time out in a fun supportive and understanding environment
- Safe space to talk freely about their feelings and experiences without judgement.
- Time away from caregiving responsibilities
- Timeout to focus on themselves, their own needs and future.
- Network with other siblings (Watson et al., 2021)
- Someone close to share their feelings with
- Access to someone that can advocate for siblings.
- A safe space where siblings can go to have time away from their siblings aggressive and violent behaviour.

The final recommendation is specific to siblings of children with autism spectrum disorder, so it is imperative that support is flexible enough to meet specific needs. This

support offered to siblings also needs to be culturally responsive (Lee et al., 2021) and appropriate for Aotearoa/New Zealand which is a bicultural nation.

An appropriate and apt way to close this thesis is with a quote from a participant of a sibling with ASD:

> I think if my wider community had an understanding of what was going on at home, I would have felt more seen……. No one ever asked, so I was left on my own to cope. It would have been so great if someone had reached out and asked what was going on for me too.

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Appendix A

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Kia ora! We would love to hear your voice

SIBLING RESEARCH

We want to better understand the experiences and needs of siblings of children with whaikaha/disabilities, but to do this we need to hear from you

Participant Criteria:

- Have a sibling or someone like a sibling (whangai, cousin) who is Autistic or has Down Syndrome or Cerebral Palsy
- 18-35 years old
- Grew up in Aotearoa/New Zealand

IF YOU SAID 'YES' WE'D LIKE TO INVITE YOU TO DO A 15-20 MINUTE ONLINE SURVEY

Please click on the link, scan the QR code or email Sarah.Knight.10@uni.massey.ac.nz to have it sent to you

Sibling Needs Survey

Appendix B

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

6/03/2023

Dear: Sarah Knight

Re: Ethics Application - SOB 22/62 - The unmet needs of siblings of children with Autism Spectrum Disorder, Cerebral Palsy and/or Down Syndrome in Aotearoa/New Zealand

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 3 at their meeting held on **Thursday, 1 December 2022**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Appendix C

InfoPg

The unmet needs of siblings of children with Autism Spectrum Disorder, Cerebral Palsy and Down Syndrome in Aotearoa/New Zealand

Information Sheet

Researcher introduction

Kia ora, Ko Sarah Knight tōku ingoa, Kei te noho au ki Horowhenua.

Kia ora, my name is Sarah Knight. I have a younger sibling with a whaikaha/disability. I grew up in the Horowhenua region. I am of mixed ethnicity, my ancestors came to Aotearoa/New Zealand as refugees, immigrants, and settlers from all over Europe. I am currently a postgraduate student at Massey University studying towards a Master of Arts (Psychology). I would like to invite you to participate in my research that aims to identify the unmet needs of siblings of children with either Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga, Cerebral Palsy/Hōkai Nukurangi and/or Down Syndrome/Pūira Kehe. Existing research has found that siblings of children with disabilities can have a range of unmet needs in a wide variety of areas including home, school and social activites. For some siblings these unmet needs can lead to feelings of isolation, frustration and sadness; for others these needs may lead to a broad range of difficulties including mental distress. This research will contribute to the future development of support services to promote and encourage health and wellbeing in siblings.

Whaikaha - To have strength, to have ability, otherly abled, enabled.

Participant recruitment

We invite you to participate in this survey looking at the unmet needs of siblings of children with disabilities.

You will need to meet the following criteria: Be between 18 years old and 35 years old. Have a sibling or someone who was like a sibling to you (brother, sister, cousin, whāngai) who is diagnosed with either Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga, Cerebral Palsy/Hōkai Nukurangi and/or Down Syndrome/Pūira Kehe. Grew up with your sibling who has a whaikaha/disability Your participation will help me identify the unmet needs of siblings of children with whailkaha/disabilities. Results of this survey will be analysed and the number and type of unmet needs identified. Differences and similarities between the unmet needs of siblings of children with Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga, Cerebral Palsy/Hōkai Nukurangi and Down syndrome/Pūira Kehe will be compared. The research will also explore whether there are any different needs between different groups of siblings in this community.

Research Procedures

Research data will be collected through an online survey which is expected to take between 15 and 20 minutes to complete. In the first section you will be asked to provide demographic information. In the second section you will be asked questions about the experiences you and your family/whānau experienced; you will then be asked to select how often you felt your sibling's needs affected you during childhood ('never', 'rarely, 'sometime', 'quite frequently',

or ‘nearly always’). In the third section you will be asked about unmet needs you had during childhood. You will be asked to select whether you had ’no need’, ‘low need’, ‘moderate need’, or ‘strong need’ across seven domains. These domains include: information about your sibling’s whaikaha/disability; time out and recreation; practical assistance; support from friends and other young people; dealing with feelings; understanding from your family/whanau; and your relationship with your whaikaha/disabled sibling. You will also be asked a question about how your needs would have best been met.

Support

It is possible that you may experience some level of discomfort from looking back and reflecting on potentially difficult and traumatic times in your childhood while completing the survey. You are welcome to leave a specific question unanswered or stop participating at any time. If you are currently receiving care for mental health issues from a hospital based mental health service, please carefully consider if participating in this research is right for you at this time, as thinking about the needs you had as a child may cause you distress. On completion of the survey, we will suggest some ways to access support should you need them, and they are also presented below. Social support: friends, family, whānau Visiting your GP, counsellor/therapist, or other health professional Youthline; Free text 234, Free call 0800 37 66 33, Email talk@youthline.co.nz, 7 days a week Free call or free text 1737 any time, 24 hours a day. Talk to (or text with) a trained counsellor or talk to a peer support worker. Depression Helpline, available 24/7. You can contact them free via; Phone 0800 111 757 or Text 4202. 0800 ANXIETY helpline 0800 269 4389 - 24 hours a day, 7 days a week 24/7 Helpline, 0800 LIFELINE (0800 54 33 54) or free text HELP (4357) Suicide Crisis Helpline, 0508 TAUTOKO (0508 82 88 65)

Data Management

The data collected will only be used for the purposes of research. All answers to the survey will be anonymous and your name will not be recorded. If the results of this research are published or given in presentations, no identifying information will be included.

If you would like to receive a summary of the findings from this study, you will need to provide your email address; however, this will be kept separate to your survey data, and this identifying data will be deleted once the research has been completed. The data collected in this survey will be stored securely in both the Massey University cloud-based system and on a password protected computer. The data collected from this research (without any identifying information) may be shared with other researchers for future research upon request; after 5 years, this data will then be destroyed.

Participant’s rights

Your participation in this research is completely voluntary. If you decide to participate, you can choose not to answer any particular question and you can stop doing the survey at any time. Completing the survey and submitting your answers implies consent and indicates that you are happy for your survey data to be included in the research.

Contact information

If you have any questions or queries regarding the research, please don’t hesitate to contact the following:

Researcher
Sarah Knight
School of Psychology
Massey University
Palmerston North
New Zealand
Email: Sarah.Knight.10@uni.massey.ac.nz

Supervisor
Dr Kirsty Ross
Associate Professor and Senior Clinical Psychologist
School of Psychology
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Massey University School of Psychology – Te Kura Hinengaro Tangata
Palmerston North, New Zealand
T +64 6 3569-099 ext 85071 : W psychology.massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee:
Southern B, Application SOB 22/62.

If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison,
Chair, Massey University Human Ethics Committee: Southern B,
telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz.

End of Block: Information page

Start of Block: Consent

Consent_hdr Respondent Consent

Consent_inf Thank you for participating in this questionnaire. Your participation implies consent. You have the right to decline to answer any particular question.

Consent 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 (1)
- ○ No (2)

End of Block: Consent

Start of Block: Screening

Screen_hdr Screening

Disability Which whaikaha/disability does your sibling have?
Select all that apply.

- ☐ Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga (1)
- ☐ Down Syndrome/Pūira Kehe (2)
- ☐ Cerebral Palsy/Hōkai Nukurangi (3)
- ☒ None of the above (4)

Age What is your age?

▼ Less than 18 (17) ... 100 (100)

Sibling_LiveWith Did you live with your sibling with whaikaha/disability growing up?

- ○ Yes (1)
- ○ No (2)

End of Block: Screening

Start of Block: Demographics

Dem_hdr Demographics

Gender What is your gender?
Select all that apply.

- ☐ Male/Tāne (1)
- ☐ Female/Wahine (2)
- ☐ Gender diverse/Irahuhua (3)
- ☐ ⊗ Prefer not to say (4)

Ethnicity What is your ethnicity?
Select all that apply.

- [ ] New Zealand European (1)
- [ ] Māori (2)
- [ ] Samoan (3)
- [ ] Cook Islands Māori (4)
- [ ] Tongan (5)
- [ ] Niuean (6)
- [ ] Chinese (7)
- [ ] Indian (8)
- [ ] Other (Please specify) (9) _____
- [ ] ⊗ Prefer not to say (10)

Page Break

Sibling_age Is your sibling with whiakaha/disability _____ than/as you?

- ○ Older (1)
- ○ Younger (2)
- ○ Same (3)

Page Break

Location Where did you live growing up?

- ○ Te Tai Tokerau – Northland; (1)
- ○ Tāmaki makau rau – Auckland; (2)
- ○ Waikato, (3)
- ○ Te Moana a Toi – Bay of Plenty; (4)
- ○ Te Tai Rāwhiti – Gisborne; (5)
- ○ Te Matau a Māui – Hawkes Bay; (6)
- ○ Taranaki, (7)
- ○ Manawatū/Whanganui, (8)
- ○ Te Whanga nui a Tara – Wellington; (9)
- ○ Te Tai o Aorere – Tasman (10)
- ○ Whakatū – Nelson; (11)
- ○ Te Tauihu o te waka – Marlborough; (12)
- ○ Te Tai Poutini – West Coast; (13)
- ○ Waitaha – Canterbury; (14)
- ○ Otākou – Otago; (15)
- ○ Murihuku – Southland (16)

Page Break

Parental_Num How many parental figures in your household?

- 1 (1)
- 2 (2)
- More than 2 (3)

Sibling_Num How many siblings do you have?

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 or more (5)

End of Block: Demographics