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Support Needs of ASD Families in the Manawatu DHB Catchment Area

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Abstract

Autistic Spectrum Disorder (ASD) is becoming increasingly understood as being both widely heterogeneous and complex for the individual on the spectrum (Baranek, 2002; Dunlap & Fox, 1999; Fox, Dunlap, & Cushing, 2002; Fox, Dunlap, & Philbrick, 1997; Gardiner & Iarocci, 2012; Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Ministries of Health and Education, 2008; Oono, Honey, & McConachie, 2013). Similarly, families are also highly variable and complex; they are arguably the most important support unit a child with ASD has, with their own resources, constraints, values and beliefs (Dunlap & Fox, 1999; Fox et al., 2002; Gardiner & Iarocci, 2012; Moes & Frea, 2002). Service individualisation, which accounts for such variances within the individual, and the collective, is broadly seen as critical for service delivery success (Baranek, 2002; Billstedt, Gillberg, & Gillberg, 2011; Dunlap & Fox, 1999; Fava et al., 2012; Fox et al., 2002; Fox et al., 1997; Ministries of Health and Education, 2008; Odom, Hume, Boyd, & Stabel, 2012).

To date, little research has gauged the extent of ASD service individualisation abroad, and an understanding of how this is done in Aotearoa New Zealand is absent. The intent of this research was to investigate whether or not existing services and supports target the uniqueness of both the individual with ASD, and their families to enable them to participate in society. In particular, a key focus was if services are appropriate, accessible and sufficient.

To accomplish the intent of the research a concurrent triangulation mixed-methods design was utilised. Both quantitative and qualitative data was gathered from caregivers of autistic children – firstly, through an online survey featuring several lifespan themes, and subsequently, qualitative data was collected through caregiver interviews carried out with participants recruited from the MidCentral and Nelson Marlborough District Health Board (DHB) areas.

Analyses of the prioritised qualitative data indicated that a variety of service delivery factors prevented families with autistic children from optimal functioning, and participating in society. Furthermore, systemic issues were theorised to be the underlying causes of several of the difficulties faced by autistic children, and their families. The importance of individualised care packages that meet the needs of the families spoken to was emphasised, and the 'wicked problem' (Stace, 2011) of services that are appropriate, accessible and adequate remains ongoing. Recommendations for meeting the needs of individuals with ASD and their families are discussed.

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Introduction

In this section the lingual, social, political and personal environment in which this research was conducted will be discussed.

Firstly, language used when referring to those on the spectrum is discussed, especially in regard to the two main philosophies which underpin ASD language usage. The intent for language usage throughout the thesis is also stated, and the reasoning for the stance taken is provided.

Secondly, the Pākehā social mainstream is discussed in relation to watershed moments, some tragic, which sparked the mainstream development of the New Zealand Autism Spectrum Guidelines (NZASG), which guide the delivery of autism related services in Aotearoa New Zealand.

Thirdly, the course of Māori health through colonisation is discussed before addressing what is presently known in regards to autism service delivery for Māori. Following this, the events which led to the only existing research on Māori and autism are explored, which became part of the socio-political collaboration that produced the New Zealand Autism Guidelines.

Fourthly, my own worldview is discussed, before reflecting upon a series of interpersonal events that led to the research question being developed.

Autism Language

Two general philosophies exist regarding how to refer to, or address, those on the spectrum, which will be central to the language used in following thesis. Person-first language, as was used in the previous sentence is said to be used by those who subscribe to the philosophy that prioritising a person before their disability reinforces the idea that a person is not their disability, and in doing so turns attention to what a person can do, instead of what they cannot (Blaska, 1993; Searing, 2014). The movement for person-first language

has been very successful and is now considered the standard in government documentation, as well as many publications across disability literature, however such language is now being met with resistance (Collier, 2012)

Such resistance is found within the second philosophy of autism language, sometimes described as identity-first, that critiques the first in a number of ways; such narratives are most often sourced among advocate, and self-advocate, sections of the literature, with one of the most renowned examples being Jim Sinclair (2013). The first objection argues that using “a person with autism” infers that the autism can be separated from a person, as an article of clothing can be shed from a body; on the contrary autism is said to be inseparable, as it is hardwired into how autistics think (Kenny et al., 2016; Sinclair, 2013). The second objection is that in saying “a person with autism”, this suggests that even if a person is autistic, it isn’t an important characteristic, and isn’t central to identity (Sinclair, 2013). The third objection is that writing “a person with autism” suggests that autism is something bad, to be kept apart from someone – as people do not use objective to neutral or positive adjectives, such as being left-handed, athletic, or muscular (Sinclair, 2013).

Preference for either type of language is divided, but not uniformly among autistics, their families, and professionals; in Collier (2012), parents of autistics are reported to generally prefer person-first language, while autistics themselves were said to prefer identity-first. This differs from Kenny et al. (2016) who reported that identity-first language was preferred by autistic adults, their families, but resisted by professionals; whereas person-first language was preferred by almost half of professionals, but far fewer autistics and family members.

While recognising that the language debate is ongoing, and is too complex to address fully within this research, the author acknowledges both views in the usage of both language

styles throughout (as used by one autistic advocate cited in Collier (2012)), providing variety and flexibility for style purposes.

The Pākehā social mainstream: Events leading to the development of the Autism

Guidelines

The Pākehā societal mainstream in Aotearoa New Zealand has long drawn upon readily accessible Westernised ways of viewing the world, and also health and disability (in contrast to a Māori customary worldview and holistic way of viewing health discussed later). Much of the mainstream society's awareness of autism is attributable to popular media, especially mainstream news outlets.

A few short months into the development of this research, Aotearoa New Zealand news media was awash with tributes following the tragic death of a young boy with autism, Leon Michael Le Fleming Jayet-Cole, aged five, who passed away in Christchurch Hospital due to serious head injuries (Bayer, 2015). Leon left behind a brother, Lucas (also on the ASD spectrum), a sister, Nadia, mother Emma Le Fleming Roberts, and step-father James Stedman Roberts. In time, Leon's stepfather would be charged with Leon's murder, while his mother would be charged for failing to get medical treatment for him (A. Clarkson, 2016). Charges against Emma Roberts would eventually be discharged, as the prosecution indicated that they were no longer pursuing the matter (A. Clarkson, 2016). For Mr Roberts, however, charges laid against him were formally discontinued approximately one month following his own death, a suspected suicide (D. Clarkson, 2016).

Since then, in 2016, there has been another death of a child on the ASD spectrum at the hands of a parent - Ruby Knox was murdered by her mother in Blenheim. However, the plight of Donella and Ruby Knox, were not unknown to the Aotearoa New Zealand public, as the local edition of the current affairs television show, 60 Minutes, aired two documentaries covering their struggles as a family in dealing with Ruby's symptoms, and other challenges.

Illustrative in the reduced sentence delivered by Justice Williams, was the assertion that he was not responsible for judging the supports offered by the health system, but rather determining whether or not Ms Knox “genuinely believed she had been let down by the system” (Bayer, 2017).

Accompanying the sense of tragedy, for the researcher, was also a sense of déjà vu. Before Leon and Ruby, there was Jim Helm of Nelson. Jim, aged 27, had his life taken by his mother, 70-year-old Nancy, on November the 8th, 1998 (Courtney, 1998). The coroner’s inquest found that Nancy had taken both her son’s life, and her own, because she feared for his future care if she died.

However, it is said to be the case of Casey Albury, of Feilding, aged 17, who was killed by her mother, Janine Albury Thomson, in 1997, that proved to be a catalyst in turning the gaze of mainstream society towards what was occurring for families of a child on the ASD spectrum (English, 1998; Stace, 2011). On the 28th of August 1998, following the conclusion of Janine Albury Thomson’s trial (during which she was found guilty of manslaughter), then Health Minister, Bill English, issued a statement which outlined the Ministry of Health’s review of services for people with autism (completed as the Curry report (Ministries of Health and Education, 2008)), and their families; and also an independent review into the treatment of Casey Albury (English, 1998; Stace, 2011). The Curry report findings illustrated a number of gaps in services, and made recommendations to improve ASD related services (Ministries of Health and Education, 2008).

The Autism Services Interdepartmental Working Group (ASIWG) was formed to implement the changes recommended by the Curry Report, and also committed to supervise the development of a set of guidelines (Ministries of Health and Education, 2008). But it was in September 2002, that the Ministry of Health, and the Ministry of Education, began working with the Paediatric Society of New Zealand towards mapping out the desired

guidelines, which “was seen as a way of providing evidence-based information for health, disability and education professionals and social service agencies for the provision of services for people with ASD, their families and whanau (Ministries of Health and Education, 2008, p. 5)”.

The ASD Cross Government Officials Group replaced the ASIWG in 2004, and put in place the ASD Guideline Steering Group to supervise the guideline project team. The group captured the views of service users through the inclusion of both parents of children with ASD, as well as adults with ASD themselves; this was intended to build the credibility of the project from within, as well as promoting awareness of “of cultural and migrant issues”(Ministries of Health and Education, 2008, p. 12). The group also indirectly sought to capture the views of users through also including representation from a raft of societies, associations, organisations, services, and Ministries (full list in Appendix A). The NZASG is also influenced by numerous articles of New Zealand legislation, various standards, and policies (full list in Appendix B), and its most recent edition (2016 ed.) is part of the present sum of socio-political response to Casey Albury’s death, over 20 years ago; the intent of the Guidelines is stated to be one of a ‘living’ document, whereby, in time, it changes and grows as knowledge of best practice increases (Ministries of Health and Education, 2008).

The NZASG is a world first (Ministries of Health and Education, 2008), and can be utilised by most who come in contact with those on the spectrum who seek to meet their social, health, and educational needs; such as parents, carers, professional caregivers, education professionals, policy makers, funders, specialists, primary care practitioners, and “any others who make provision for individuals with ASD”(Ministries of Health and Education, 2008, p. 2).

Central to any implementation of the NZASG in Aotearoa New Zealand, is the assertion from the Ministry of Health that different people have different responsibilities in

implementing different aspects of the Guidelines, at different levels of society; institutionally, Ministries are argued to be responsible for implementation of national initiatives; but other recommendations are said to operate at local level socially and relate to how people treat one another – the Ministry argues that government funding cannot achieve such implementation (Ministry of Health, 2015).

Furthermore, individualisation, through professional judgement, plays a central role in the Guideline's application, as the guidelines contained are not compulsory. Compulsory guidelines, according to the Ministry of Health, must not replace individual judgement upon individual circumstances; further, it is argued that compulsory guidelines could be dangerous. On the other hand, the non-compulsory nature is interpreted by some as being problematic itself, as there are no guarantees stated for service delivery; one advocate observed that a major problem arising since the were published in 2008, is that most of the recommendations have not been implemented into service delivery (Anonymous, 10 June 2015).

The Treaty of Waitangi, Māori health, and Māori ASD literature

How Māori, and Māori health, are positioned within contemporary Aotearoa New Zealand; and how Māori contributions towards autism literature have been made, are both questions best understood by first establishing a foundation regarding the effects of colonisation. Laying a foundation begins with an additional, or alternative, name; Aotearoa is the first given name to the country New Zealand, and it is most commonly said to mean “the land of the long white cloud” in Te reo Māori, the language of Māori. Aotearoa is situated in the South Pacific, and since 1840, it has been a country primarily consisting of two peoples; the indigenous Māori, and the Pākehā, or non-Māori of European decent.

Modern Aotearoa New Zealand was founded upon the signing of the Treaty of Waitangi (Tiriti o Waitangi) by representatives of the British Crown, and many indigenous Māori chiefs throughout the land. Colonial governorship of the country, and subsequently the

country's own parliament, would see the Crown fail to uphold its treaty obligations, especially in regards to Article 2 of the Treaty relating to tino rangatiranga – which is the right of self-determination, and self-sovereignty (Mason Durie, 1998). As Anglo-centrism prevailed, Māori were forcibly positioned as Other, as Pākehā systems and institutions, importantly including health, were taught and upheld by legislation (Nairn, Pega, McCreanor, Rankine, & Barnes, 2006). The Pākehā governance over Māori health practices was epitomised with The Tohunga Suppression Act of 1907, whereby tohunga (meaning chosen experts over a certain area of expertise, such as wood carving) who were normally engaged in customary holistic healing practices, were prohibited from doing so, as any practice with a spiritual or supernatural element was legislated against. The mismatch of Māori trying to exist within Pākehā systems and institutions has been shown to be devastating to Māori health outcomes for decades, as Māori are overrepresented in many negative health outcomes (M. Durie, 2007).

Honouring the Treaty, and a Māori health renaissance. Central to the Māori renaissance, attributed to occur in the 1970s, is the establishment of the Waitangi Tribunal in 1975, formed for the purpose of honouring Crown obligations to Māori. This period ushered in a commitment to a bicultural nation, although it can be argued that it is mostly Māori who can speak, let alone operate, in both Pākehā and Māori domains (cite personal communication Hukarere / or reference). Although the promised bicultural country has not yet been fully realised, a greater tolerance, in the least, has emerged of things Māori, especially in the holistic way that Māori view health.

Perhaps the most renowned example of a holistic health emerged around this period - *Te Whare Tapa Whā*, a model of health which likens the state of wellbeing to the structural

integrity of a whare, or house (see Figure 1.).

Figure 1. Te Whare Tapa Whā, a Māori wellness model developed by Professor Sir Mason Durie (Tāne Ora Alliance, 2017)

Te Whare Tapa Whā was developed through a hui (conference) of Māori health workers in 1982, and Mason Durie was formally attributed as being responsible for the model's development (M. Durie, 2001; Rochford, 2004). In this model, the wellness of an individual, especially Māori, is attributed to four interdependent sides of the whare, where each must be considered and catered for in order to promote health, as weakness in one wall compromises the others.

- Taha Whānau is the wall relating to the family; however, whānau extends beyond the boundaries of a Western nuclear family, to extended family – even to others who are not directly blood related, indicating the importance of interconnectedness among Māori. Taha Whānau may also be articulated as social well-being.

- Taha Tinana is the wall relating to physical well-being; how healthy a physical body is, how it develops, and how one is able to care for it.
- Taha Hinengaro is the wall designated for mental well-being; how able a person is to utilise coherent thinking process, or express thoughts and feelings appropriately.
- Taha Wairua is the wall which upholds the spiritual well-being aspect to health; how a person is able to identify, and live in accordance, with own values and beliefs.

Māori, autism and the NZASG. Although health models, such as Te Whare Tapa Whā, have been applied in many different health settings in Aotearoa to promote a customary worldview in a contemporary setting, little research has been done to inquire as to how Māori, and their whanau, view autism, how autism is accounted for in their own belief systems, and how customised autism support services are that are delivered, or aren't delivered, to Māori (Bevan-Brown, 2004; Ministries of Health and Education, 2008, 2016). To complicate matters, attempting to consult pre-colonial practices of Māori, to do with wellbeing, is not helpful either, as disability narratives are said to be absent, with Nikora, Karapu, Hickey, and Te Awekotuku (2004) only able to suggest under what communal conditions the unwell and disabled might be well supported and valued.

In contemporary life, the report “Māori Perspectives of Autistic Spectrum Disorder” delivered to the Ministry of Education by Bevan-Brown (2004) stands out as the only definitive point of reference on the experiences and perspective of Māori families with autistic children. Several concerns were raised in the report (full list in Appendix C), such as multiple barriers to establishing diagnosis, a widespread lack of services and resources being made available, a need to further upskill professionals on ASD itself, and a need to educate professionals on Māoritanga (Māori culture, or perspective) to improve service delivery and ensure that it is culturally appropriate. Many similar concerns (Appendix D) were raised in the subsequent national hui (conferences) that were held to provide additional insight beyond

the Ministerial report) into issues surrounding ASD that the Māori present felt important to raise (Ministries of Health and Education, 2008). The entirety of the outcomes and recommendations arising from the hui are incorporated into the New Zealand Autism Guidelines in the intent of providing a “significant foundation from which future research examining Māori and ASD will draw from and build on”(Ministries of Health and Education, 2008, p. 204). To date, however, even considering the 2016 edition of the NZASG being most recently released, no additional research has emerged examining Māori and ASD (Ministries of Health and Education, 2016).

Personal viewpoint

Although I identify as both Māori and Pākehā, my social understanding, and position, is heavily weighted in the Pākehā social mainstream.

My tertiary studies began when I was in my early thirties, and at that point the loudest message (some healthcare professionals disagreed with the diagnosis) our family was being told, was that my twin nephews were autistic. Few university classes offered me the chance to engage with studying autism directly, which was to be expected at an undergraduate level.

Following my Bachelor’s degree, I spent time abroad working after getting married, and waiting for my wife to qualify for New Zealand Residency. I was able to utilise my undergraduate degree to some extent, contracting as a temporary Special Education Needs Assistant in special needs schools in England – before eventually accepting a full-time role at one school. I had the opportunity to work with autistic children across the spectrum; from students who were barely perceptible as having any kind of difference to a neurotypical student, to those who struggled to communicate and had obvious difficulties.

Returning to New Zealand, we relocated near my family and I was able to resume my studies. Postgraduate courses offered far more opportunity to utilise topics of a student’s

choosing, so I developed a better understanding of autism related literature while working through my Master's degree course work.

Throughout this timespan, as a family, we often observed a variation in satisfaction, and outcomes, for different families (with autistic children) in our acquaintance; whether it was the schools attended, the services delivered, the support offered or lack thereof.

But it was an incident which occurred while still abroad which caused the most serious reflection about why some families have different experiences than others in terms of service delivery. One nephew, while on his school camp, fractured a limb. This in itself was not unusual, as children do have accidents. What caused family to be very upset was the child was not in the care of his helper when he was hurt, as promised; and that the accident was not reported, as it ought to have been – and the child remained on camp for the duration with a broken arm. A subsequent internal review at the school would end the matter unsatisfactorily, with the Principal finding that the staff acted appropriately throughout.

However, this school's actions were at odds with the standards of the schools I had been working at abroad; once parents and staff agreed upon a plan, it was followed through as best as humanly possible. Furthermore, staff would always check in with parents to report if anything noteworthy occurred, whether it be successes and achievements, or upsets and accidents.

This begged the question, what was it about schools, services, and supports, that different autistic children, and their families, could have very different experiences? This question led me to this current research, talking to families and caregivers about their experiences. The following chapter first examines what is presently understood regarding the impact, criteria and variability of ASD. Secondly, the literature on regarding individualisation which accounts for the variability of young autistics, and the variability between families is then considered before. Thirdly, the present literature of various ASD services is explored

within the context of an imagined service delivery lifecycle, which draws upon existing family systems theory.

Literature Review

Establishing present ASD diagnostic criteria

Although other standards may be used elsewhere to discern whether or not an individual is autistic, The Diagnostic and Statistical Manual of Mental Disorders, presently in its fifth edition (DSM-V), contains the criteria which is presently in use in Aotearoa New Zealand. The criteria for ASD is outlined as the following:

[Criterion 1] Persistent deficits in social communication and social interaction across multiple contexts, as manifested by *all of the following*, currently or by history:

- Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

[Criterion 2] Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by *at least two of the following*, currently or by history (examples are illustrative, not exhaustive):

- a) Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- b) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
- c) Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
- d) Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

[Criterion 3] Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

[Criterion 4] Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

[Criterion 5] These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

(American Psychiatric Association, 2013)

Positioning present ASD criteria academically and socially

The status of the present ASD diagnostic criteria is perhaps best described as contested, both academically, and socially; particularly in the way in which Asperger's

Syndrome (AS) has been removed as a separate disorder between DSM editions IV-TR, and V, and is presently subsumed under a broader ASD diagnosis (American Psychiatric Association, 2013).

In academic circles there has been support for both maintaining a separate AS diagnosis, as well as support for an all-encompassing ASD diagnostic umbrella. Past efforts to differentiate between HFA and AS have been viewed as unreliable (Macintosh & Dissanayake, 2004; Ministries of Health and Education, 2008), citing considerable overlap in many symptoms, and few qualitative differences (Ministries of Health and Education, 2008).

However, those critical of a removing AS, such as Kaland (2011) and Ghaziuddin (2010), have argued instead for adjusting the diagnostic criteria to allow greater differentiation; Kaland (2011) in particular draws attention to possible differences in language abilities, cognitive functions and neurobiology that warrant further investigation. Additionally, Planche and Lemonnier (2012) found that the cognitive profiles between those who were diagnosed as being High Functioning Autism (HFA), AS, or neurotypical were differentiated, particularly in regards to verbally mediated skills, visual-motor coordination and graphomotor ability. A recent review adds further support for separate diagnoses; Tsai (2013) evaluated 128 publications, 94 of which showed statistically significant levels, or near significant, differences between HFA and AS; 30 publications found no differences between groups; and 4 publications for both similarities and differences between groups. Confusion and overlap, according to Tsai (2013) and Perry (2014), may have more to do with the quality and the training of diagnosticians, and less than actual symptomatic overlap. Based upon the evidence cited, Tsai (2013) goes as far as to state the plausibility of ASD diagnostic criteria to run full circle over the next decade, or two, and for AS to be once again considered an independent disorder worthy of its own diagnosis in future editions of the DSM.

The ASD / AS amalgamation through the DSM-V has also been contested through the public domain; resistance here utilises what Carmack (2014) describes as the social identity argument, whereby those with AS often define themselves as a community, even a culture, complete with their own “monikers, beliefs and customs” (Carmack, 2014, p. 462). The most common self-described title used by such AS communities, is that of an ‘Aspie’, many of whom “want their strengths to be acknowledged and wish not to be ‘cured’” (Singh, 2011, p. 236)

The potential, and eventual, removal of AS from the DSM-V has been reported to be interpreted as threatening to Aspies in various ways (Singh, 2011; Spillers, Sensui, & Linton, 2014). Firstly, this change may pose a threat to personal identity, as those with AS are reported to often fuse their diagnosis positively with their identity (Singh, 2011; Spillers et al., 2014). There is also reported to be a threat to the sense of community, that the change provides leverage for the ASD ‘cure’ movement, which is viewed as intolerant of neural diversity. And finally, there may also be a threat to service eligibility, if evaluated against non-AS criteria

Giles (2014) documented examples located on online self-advocacy forums which showed that while Aspies were deeply suspicious of both the motivation and consequences of diagnostic merging, alternative discourses also arose. In one discourse, many Aspies were open to the notion of diagnostic change, assuming a newer identity of ‘Spectrumite’; in another, the contemporary prestige, or ‘coolness’, of being an Aspie through both media coverage, and other links to historic and contemporary figures, such as Albert Einstein, were seen as important connections worth maintaining. Of particular interest was a discourse which argued that the Aspie community was “now sufficiently powerful to survive independently of professional discourses around mental health and psychology”(Giles, 2014, p. 189).

The prevalence of ASD

The exact prevalence of ASD, and how many lives it affects, is unknown. Estimates reported have ranged between 1% (Ministries of Health and Education, 2008), 1 in every 68 (Baio, 2014), and 60-70 in every 10,000 (Fombonne, 2009). Furthermore, according to Fombonne (2003) in 2003, the prevalence of ASD was shown to be three to four times higher than it was in the 1970s. Although such increases in prevalence have fuelled lay perspectives of an autism epidemic (Gernsbacher, Dawson, & Goldsmith, 2005), there is widespread support for the explanation that diagnostic substitution (the phenomenon whereby the label of a particular condition is replaced by another, causing a decrease in diagnoses in the first condition, and an increase in diagnoses in the second) has played a significant role in increase of ASD prevalence (Bishop, Whitehouse, Watt, & Line, 2008; Coe et al., 2008; Gernsbacher et al., 2005; King & Bearman, 2009; Rutter, 2005).

The impact of Autism

The impact of autism is most often stated from the perspective of caregivers who have reported considerable challenges through increases in stress, challenging behaviours, social isolation, lack of support, fatigue, financial strain, and sibling neglect (Ludlow, Skelly, & Rohleder, 2012; Myers, Mackintosh, & Goin-Kochel, 2009). These are just some of the negatives that have been reported to occur in family life. In contrast, positive impacts of having an autistic child have also been reported (Myers et al., 2009). However, because communicatory deficits are common (Khare & Mullick, 2014), and comprehension about what it means to participate in research is thought to be quite difficult (Lloyd, 2013), little research has captured the considerable challenges as experienced by those who actually have ASD themselves. An often cited quotation from autistic scholar, Dr Therese Jolliffe (Jolliffe, Lakesdown, & Robinson, 1992), is thought to encapsulate the difficulties of existence on the spectrum:

reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear (p. 16).

Variability between individuals on a contested spectrum. Although there is strong criticism of the practice of retrospective diagnoses of ASD for historical figures such as Albert Einstein, Sir Isaac Newton, Andy Warhol, or Hans Christian Anderson (Goode, 2001), regardless of how well received (Giles, 2014), there are ample verified contemporary examples of those on the spectrum who are higher functioning. For example, animal scientist and autism advocate, Temple Grandin; creator of Pokémon, the second most successful game-based franchise in history, Satoshi Tajiri (Bainbridge, 2014; Mortensen, 2009); actress Daryl Hannah (Willingham, 2013); and successful vocalist and talent show contestant, Susan Boyle (Nur, 2012). Although there are also many instances of low functioning ASD, the vast majority of diagnoses of autism are not situated at either polarity of very-high, or very-low, functioning across all symptoms; rather, consensus has been reached that ASD is a highly heterogeneous disorder (Baranek, 2002; Dunlap & Fox, 1999; Fava et al., 2011; Fox et al., 1997; Friedman, Warfield, & Parish, 2013; Gardiner & Iarocci, 2012; Hendricks & Wehman, 2009; Matson & Konst, 2014; Matson, Tureck, Turygin, Beighley, & Rieske, 2012; Ministries of Health and Education, 2008; Moes & Frea, 2002; Roberts et al., 2011; Strauss, Mancini, Fava, & The SPC Group, 2013; Wilczynski, Menousek, Hunter, & Mudgal, 2007), in that it covers a high degree of variability for social, communicative, and intellectual challenges between those diagnosed. Furthermore, such variability of challenges also signifies variability of lived experience, and also variability of personal impact.

Variability in families. Families, arguably the most important support unit that any child or young person on the spectrum will have, are also widely acknowledged as being heterogeneous (Dunlap & Fox, 1999; Fox et al., 2002; Gardiner & Iarocci, 2012; Ministries of Health and Education, 2008; Moes & Frea, 2002). Differences in families vary in many aspects, such as ethnicity, culture, values, configuration and functioning of its members (or as a unit), and socioeconomic status. As Dunlap and Fox (1999) note, each family has their own, “strengths, resources and challenges” (Dunlap & Fox, 1999, p. 49), each of which can be influenced by, or can be influential when, a family member is autistic. Furthermore, as with autistic individuals, no two families will experience the impact of diagnosis and life with an autistic family member in the exact same way.

Service individualisation

Given the individual and familial variability, there is also widespread acceptance in the literature that services need to be individualised (Baranek, 2002; Billstedt et al., 2011; Dunlap & Fox, 1999; Fava et al., 2012; Fox et al., 2002; Fox et al., 1997; Gardiner & Iarocci, 2012; Greenspan & Wieder, 1999; Hendricks & Wehman, 2009; Horlin et al., 2014; Ministries of Health and Education, 2008; Moes & Frea, 2002; Odom et al., 2012; Oono et al., 2013; Roberts et al., 2011; Stahmer, Schreibman, & Cunningham, 2011; Vismara, Colombi, & Rogers, 2009; Wilczynski et al., 2007; Woods & Wetherby, 2003). Service individualisation, which is also sometimes referred to as contextualisation (Gardiner & Iarocci, 2012; Moes & Frea, 2002), or family-centeredness (Fox et al., 2002), refers to taking into consideration the preferences and needs of the young person with ASD (while also taking into consideration the families’ needs, knowledge, value systems, and cultural identity), when implementing services. It is broadly theorised that the more individualised a support service is, the more efficacious a support service is likely to be towards a favourable outcome. However, as most of the literature features the narratives from parents, particularly mothers,

the voices of autistic young people are missing from the broader discourse of how individualised services are, and further, what even constitutes individualisation.

Operationalising individualisation in autism related research. Despite widespread acceptance of the need for the individualisation of services, operationalising individualisation in terms of autism service delivery has not been the subject of much discussion in the literature. This raises concerns regarding how successful efforts are to match the uniqueness of a child, and their family, and what terms of reference one might use to quantify success, or failure. Although not explicitly investigating individualisation, Bromley, Hare, Davison, and Emerson (2004) have demonstrated how researchers might look beyond mere uptake as a way of quantifying the suitability of support services, as they also measured service awareness, accessibility, appropriateness and sufficiency in using a modified version of the Client Service Receipt Inventory.

Individualisation over a lifespan. Relationships between an individual, their families, service characteristics, and broader sociocultural context are thought to overlap and interact with each other (Gardiner & Iarocci, 2012); thus, service receivers may opt in or out of services due to multiple dynamic variables. Furthermore, service policy and delivery may also be viewed as a ‘wicked’ problem, as service providers, family dynamics, the child’s needs, or the suitability of the service may also shift considerably over time (Stace, 2011). Additional tensions arise, from a service delivery point of view, as healthcare providers in Aotearoa New Zealand are conflicted between “treating people as holistic beings, and [operating within] tightly capped budgets” (Stace, 2011, p. 154). Thus, in many instances the question is not only a case of how well fashioned a service is to meet specific needs, but also establishing that a particular kind of support service even exists, given budget constraints.

The author was not able to locate any research which gave caregivers the opportunity to report on awareness, uptake and the extent of individualisation over broad range of

professionally delivered support services, which were offered over a young lifespan: from diagnosis at 2-3 years of age, to transitioning into adulthood. However, coverage on the importance of individualisation is extensively documented across individual studies, which address specific support services.

Since the literature is lacking in regards to research across multiple domains, over a lifespan, the following sections are structured by utilising a reimagined version of the expanded life cycle (see Figure 2.), as proposed by McGoldrick et al. (1999). Changes made to the original model include changes to the theorised vertical stressors, which arguably better reflect the challenges that ASD family systems experience; as well as an imagined integration of services across systemic levels, and over time, to assist the family with both vertical and horizontal stressors (Gladding, 2010; McGoldrick et al., 1999).

Diagnosis – the beginning of any service delivery over a lifespan

The primary event in the ASD journey for young people and families, throughout the literature, is the confirmation of a diagnosis by an appropriate clinical, educational, or paediatric professional. Although there are many screening procedures in place for different health conditions, according to the NZASG (Ministries of Health and Education, 2008), it is considered appropriate in Aotearoa New Zealand, that caregivers and professionals with knowledge of normal development can identify ASD and raise concerns. While identification by a caregiver, or professional, is useful in terms of raising a flag, it achieves little without the next step in the process, which is the timely access to the appropriate referral and subsequent diagnostic appointment (Ministries of Health and Education, 2008).

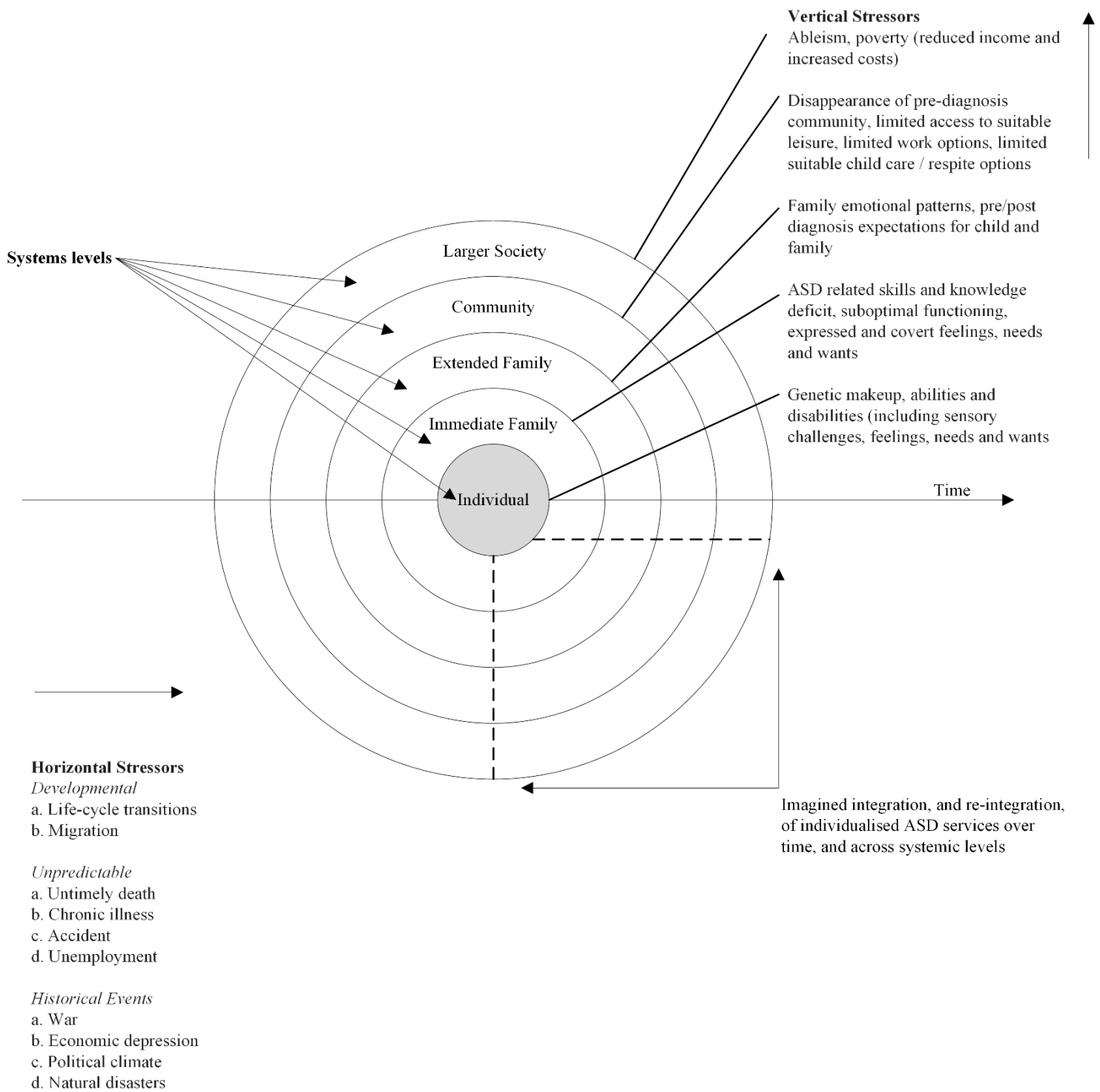


Figure 2. Expanded ASD family life cycle. Adapted from McGoldrick, Carter, and Garcia-Preto (1999) and Gladding (2010)

Delays and discrepancies in timely diagnosis. Having a diagnosis confirmed for a child / young person in a timely manner is considered critical; clinical confirmation may change a great deal about how a child / young person's life is lived in combination with family dynamics, such as the need for information, advice, services, and funding. Prompt diagnosis is associated with better intervention outcomes for child and family (Ministries of

Health and Education, 2008), and may also lower costs for both families (Peters-Scheffer, Didden, Korzilius, & Matson, 2012), and the state (Horlin et al., 2014), whereas delays are seen to be associated with worse outcomes, and increased costs. Lengthy delays for diagnoses have been attributed to a variety of factors.

Ethnic discrepancies in securing diagnosis. Recent literature in the United States has highlighted delays and discrepancies in diagnostic timelines between White Americans and other ethnic groups. Magaña, Lopez, Aguinaga, and Morton (2013) found disparities in access to diagnosis, and eventual treatment (on average, almost a year's difference) between Latino and non-Latino White children. While Mandell et al. (2009) similarly reported significant disparities between the timeliness of the diagnosis of White American children, compared to Black American and Hispanic American children.

Systemic concerns in securing diagnosis. Systemic factors were also reported to be the cause of delays. A review of studies conducted on autism related issues in Brazil highlights a common theme: the systematic postponing of diagnosis for many families in Brazil, as families endured a succession of multiple health professionals to secure diagnosis (Gomes, Lima, Bueno, Araújo, & Souza, 2014). Another study, based in China, by Song, Giannotti, and Reichow (2013) illustrated how systemic interactions between limited providers, and receivers with their own strategies and beliefs, both contributed towards lengthy delays.

Diagnosis delay in Aotearoa New Zealand. Although a look abroad might illustrate disparities between ethnicities, and also systemic issues, being influential in delaying diagnoses, the state of affairs in Aotearoa New Zealand does not appear to be much different (Ministries of Health and Education, 2008). Addressing known practices and services, the NZASG states that there is currently inequitable and inconsistent access to assessment (Ministries of Health and Education, 2008), although it is not understood why.

Providing support services following diagnosis. According to Dunlap and Fox (1999) the effects of diagnosis on a family must be considered from a lifestyle perspective that potentially has a profound impact on the family as a system. Several negative themes are often reported to impact a family following diagnosis, such as, confusion, financial hardship, a sense of loss, uncertainty about the future, a sense of shock, anger, guilt (self-blaming), depression, disagreement, and sadness (Banach, Iudice, Conway, & Couse, 2010; Dunlap & Fox, 1999) On the other hand, however, some families reported positive themes, such as relief, affirmation and increased closeness; as diagnosis can facilitate sense-making in the present for families, after an extended period of struggle (Banach et al., 2010; Ministries of Health and Education, 2008). This extends what is known regarding family heterogeneity to also include event perception; aside from all other characteristics which may categorise, or describe a family, two seemingly similar families may react to diagnosis in very different ways and consequently require an individualised response which will account for such variance.

Early Intensive Behavioural Interventions (EIBI). The type of post-diagnosis support service which appears to receive the most coverage in literature, are EIBIs for the diagnosed child / young person. The gains of behavioural interventions based upon the principles of Applied Behavioural Analysis (ABA) have been well validated empirically (Strauss et al., 2013); however the importance of individualisation of EIBI, and its contextual application in non-clinical settings where problem behaviour may occur has not always been understood.

A comprehensive review of meta-analyses between 2009 and 2011 emphasises the effectiveness of EIBI, and the role that individualisation plays (Strauss et al., 2013). Strauss et al. (2013) show that EIBI leads generally to positive, medium to large effects, for the main three outcome measures, namely: intellectual functioning, language skills, and adaptive

behaviours (Strauss et al., 2013). Although many EIBI programs and studies cited were reported to vary slightly in their approaches, the review's inclusion criteria required that studies illustrated the individualisation of treatment planning. In their summary of findings, the review team also concluded that the individualisation of a child's treatment planning was one of three key active factors which determined EIBI effectiveness (Strauss et al., 2013). A subsequent study by two of the lead authors of the review, Fava and Strauss (2014), further highlighted the importance of understanding the pre-treatment child and the characteristics of the family ecology to elevate treatment efficacy.

Parental support groups. Parental support groups, facilitated by healthcare professionals, are another common avenue of support for concerns arising in family life; yet, little research has been conducted to study the usefulness of parental support groups for those with children on the spectrum, especially post-diagnosis (Banach et al., 2010). Banach et al. (2010) found statistically significant increases in the measures of Family Empowerment, Service System Empowerment, and Community/Political Empowerment, for ASD parent participants. This demonstrates that parental groups could be beneficial for those with ASD children. In contrast, Papageorgiou and Kalyva (2010) found that self-reported needs and expectations in parental groups of autistic children differed significantly according to the gender of parent, the education of the parent, the age of the child, and the gender of the child. These results suggest a cautionary note to the effectiveness of parental groups which do not take into consideration the personal variances between their members.

The extent to which parental support groups are utilised for caregivers of autistic children, in Aotearoa New Zealand is unknown, as is also the perceived usefulness of them from a service user perspective.

Providing information following diagnosis. Providing accurate information following diagnosis (Ministries of Health and Education, 2008), is considered to be a priority,

as it equips families with the best information available upon which decisions can be made, and upon which services may be provided. Reliance upon popular media, to convey accurate information, can be hazardous. Smith (2008) outlines how giving equal coverage of opposing views regarding ASD in different media platforms can equate to the perception of equal credence, even though the evidence on one side is deficient.

Information about autism, following diagnosis, can be accessed from a multitude of sources; Magaña et al. (2013) found that the overwhelming majority of parents sought access from several sources (such as: friends, family, other parents, support groups, educational professional, healthcare professional, books and magazines, and the internet). Additionally, most sources were utilised in significantly different ways between ethnic groups. In contrast, Twoy, Connolly, and Novak (2007) found that friends, and similar families, (other families with members with ASD) were utilised in different ways. 68% of the 55 parent respondents utilised friends for generalised support, whereas 93% of respondents utilised similar families for information and advice relating to living with an autistic child (compared to 80% who utilised professionals for advice).

The process of self-education on the internet has also been shown to be problematic, not only because of the inaccuracy of a great deal of information on the internet regarding autism, but also the need for parents to learn what can be described as a new language, or skills. Thematic analysis by Moodie-Dyer, Joyce, Anderson-Butcher, and Hoffman (2014) revealed that many of the parents in their study had difficulty identifying key online resources, as particular “code words”(Moodie-Dyer et al., 2014, p. 351) were required to achieve desirable results.

An alternative strategy to providing information, is to create information packs that are freely distributed to parents. However, there is little coverage in the literature of pre-constructed information resources which parents are able to utilise post-diagnosis. One such

resource, published by Autism Speaks in the United States, is called the *First 100 Days Kit: A tool to assist families in getting the critical information they need in the first 100 days after an autism diagnosis*. While the *First 100 Days Kit* was perceived as being one of the most helpful aspects of a support group intervention piloted by Banach et al. (2010), there is broad criticism of Autism Speaks as an organisation; accusations from other advocacy groups include, non-inclusiveness of people on the spectrum, and also fear orientated rhetoric about what life entails for those on the spectrum, and their families (Autistic Advocacy Network, 2014).

Education

Education is an important aspect of life for children and young people, which assists them in achieving their potential, and enable them to be able to participate fully in meaningful activity, or employment, later in life – this goal is no different for children on the spectrum. However, for young people on the spectrum, additional help, or consideration, which addresses their unique needs, is sometimes needed to enable them to reach their potential.

Individualised Education Programmes (IEPs). A common approach to attending to a student's individual needs is through an IEP, which is a comprehensive plan that provides a template of actions and steps designed to enable educators, caregivers, and student alike to achieve personalised goals. Wilczynski et al. (2007) argue that while this process is well known, even commonplace, for many education professionals (who are accustomed to drawing upon feedback from parents, consultants, and advocates), the process is often difficult when the IEP is being designed for someone with ASD, because of the heterogeneity of the disorder. Wilczynski et al. (2007) argue that the heterogeneity of ASD may prove difficult for three reasons. Firstly, mental health and education professionals may not have experience in serving young people who have comorbid conditions, such as anxiety, or

depression. Secondly, IEPs may be difficult to develop well as different children / young people are likely to exhibit high variability in symptoms under different conditions, interacting with different people. Thirdly, IEPs are difficult to develop well, as there has not been adequate research on developing IEPs with autistic children; consequently, there are no clear guidelines emerging to govern how practitioners construct an IEP. As a result of a lack of research into IEPs and autism, professionals must draw upon clinical judgement, knowledge of variables in the life of the individual, and what is known of the unique strengths and challenges of an individual, to make educated decisions how to best implement a plan (Ministries of Health and Education, 2008; Wilczynski et al., 2007).

Individualised behavioural plans. The NZASG considers behavioural challenges in an educational setting from the perspective of both the child, and caregivers or educators. From the perspective of the child/young person, parents and educators “demonstrate problem behaviours by putting a child in situations which they find difficult” (Ministries of Health and Education, 2008, p. 119). This may include, making demands which are difficult for a child to comprehend; communicating in ways that are difficult; expecting participation in activities that hold no interest for the child, or the child has no skill in performing; or limited exposure to interests the child does have. From a parent, or educator’s perspective, problem behaviour is exhibited through a child’s non-compliance, disruption, and physical outbursts. If such behaviours persist, the child is at risk of exclusion (Ministries of Health and Education, 2008).

In attempts to avoid exclusion, the focus in behavioural interventions has shifted in recent years, from eliminating a behaviour altogether, to positive individualised behavioural support, which seeks to understanding the functionality of what any given behaviour achieves for each individual child in their environment (Ministries of Health and Education, 2008).

Positive behavioural plans should:

- consider all problem behaviour performed by a child
- be driven by functional assessment outcomes
- be applied across all (or most) of a child's day
- incorporate a number of intervention procedures
- fit the context where they are to be implemented
- emphasise the teaching of positive alternative skills

(Ministries of Health and Education, 2008, p. 123)

Generalisation of behavioural management. Consistency across settings is one of the fundamental principles of applied behavioural analysis; if a behavioural intervention is applied consistently at school, at play / work, and especially at home, the chances of generalisation of desired behavioural changes become greater, as well as the odds of desired changes becoming permanent (Ministries of Health and Education, 2008). To date, there has been only one study to perform an in depth meta-analysis of the difference in outcomes for EIBI interventions; Strauss et al. (2013) found that studies which included staff-based instruction in a centre setting, as well as parental skills generalisation in the home environment, had the highest effect sizes in initial language skills, adaptive behaviours, and intellectual functioning outcomes.

Sensorimotor needs. Most autistic children are said to experience sensory and motor challenges “at some point in their development” (Ministries of Health and Education, 2008, p. 108). Under-reaction, or over-reaction, to stimuli can not only be distressing to the child, but can also interfere with their participation in a learning environment, yet the heterogeneous nature of ASD dictates to what extent for each child (Ministries of Health and Education, 2008). A major review of sensory-motor interventions found that treatments sometimes have “questionable rationale” (Baranek, 2002, p. 415) for their use with children with autism e.g., sensorimotor patterning is based upon neurological theory which has been largely disproven.

Many other studies reviewed failed to establish connections between changes in a dysfunctional sensory mechanism, and changes in functional behaviour (Baranek, 2002). In the absence of data of studies conducted in Aotearoa New Zealand, good practice (as suggested in the NZASG) is that interventions for the child are individualised by an appropriate professional who has expertise in sensorimotor and ASD specific education, and can apply the necessary clinical judgement (Ministries of Health and Education, 2008).

Environmental changes. While schools are tasked with making small environmental and task modifications to assist students with ASD, families may need assistance in making modifications at home that balances the child/ young person's needs with the needs of the entire family (Ministries of Health and Education, 2008); Research is yet to emerge which investigates how effective attempts are to strike such a balance, let alone in Aotearoa New Zealand.

School as a supportive environment. According to the NZASG, the “support of the whole school community is a key factor in the successful education of a child or young person with ASD”(Ministries of Health and Education, 2008, p. 127). Any school community features the complex interaction between multiple parties, such as school management, school teachers, school students (autistic or not), and parents; each with their own role to play to ensure that school is a supportive environment. The research available, in regard to supportive schools, is limited to reporting on attempts at bullying reduction between students, and parental views and expectations of school inclusivity (Ministries of Health and Education, 2008; Owen-DeSchryver, Carr, Cale, & Blakeley-Smith, 2008).

According to the NZASG, to increase the quality of relationships and interactions among students, and to reduce the likelihood of exclusion and bullying, peers of children with ASD need information and support (Ministries of Health and Education, 2008). However, very little research has investigated how information and support might increase inclusion

amongst neurotypical peers and reduce bullying. One pilot study conducted with three children with ASD and their peers, investigated how well a training program would assist initiations and interactions for both parties. Phases of the intervention included the reading and discussing of a children's book about an inclusive classroom with an autistic student; a discussion of the ASD participant's strengths, and the preferences of a classmate with ASD (discussing their own strengths, and weaknesses posed as "things they were still learning to do" (Owen-DeSchryver et al., 2008, p. 19); and a guided discussion which considered several ways in which peers might interact with those with ASD. The results generally showed that there were increases in initiations and responses between both parties. An unexpected outcome reported showed the possibility of the effect of interventions on others in the school environment, where initiations and responses increased between those with ASD and those not participating in the intervention (Owen-DeSchryver et al., 2008). It is unknown how often autistic children are bullied in schools in Aotearoa New Zealand, and what practices are in use to overcome it.

The interplay between adults can be equally as complex as the interplay among students in establishing a supportive environment for unique individuals on the spectrum. A major review of parental views into what constitutes an inclusive school environment highlighted a strong theme throughout the literature; that teachers are viewed as both the main facilitators, and main inhibitors of inclusive schools (Falkmer, Anderson, Joosten, & Falkmer, 2015). However, as the review also noted, it is unfair to state that teachers carry sole responsibility for school inclusiveness, even if they are framed the 'face' of school inclusiveness (Falkmer et al., 2015). Similarly, the NZASG states that teachers do need to have a positive attitude towards those on the spectrum; however, to understand and cater for the unique needs of children with ASD, they themselves need access to the appropriate

training, and skilled professional support, which ought to be facilitated at a management level (Ministries of Health and Education, 2008).

Personal fulfilment – living in the community

Autistic people, even those with considerable social challenges, exist as social beings that need avenues through which to be engaged in meaningful activity, pursue interests that may lead to work, or develop rewarding acquaintances, friendships, or companionships, if desired.

Recreation and leisure. There is much evidence to suggest that recreation and leisure can be very beneficial to autistic people, especially if it is individualised to their needs and preferences. Ending in 2004, Project Autism, a major collaboration over three years in the United States between two nationally recognised programmes - the Department of Recreation and Leisure at the University of North Carolina, and the Department of Psychiatry from Division TEACCH - studied the support required to meet the recreation and leisure needs of those on the spectrum (Ministries of Health and Education, 2008). Among the findings were 18 benefits for those with ASD (including children and young people), which ranged from functional benefits; such as the expanding of interests, enhancing of communication skills, improvement of cognitive functioning; to the personal basic benefits of the enjoyment that comes from mastery, or the relaxation associated with an activity (Ministries of Health and Education, 2008). Importantly, the need to individualise was evident in the recommendations arising from Project Autism, as it produced a manual which provides information to assist getting someone on the spectrum involved with activities of choice, where an individual's "goals and wishes" (Ministries of Health and Education, 2008, p. 174), strengths, challenges, interests and satisfaction are all considered.

While not focusing specifically on autistic children and young people, a more recent study has shown the long term benefits for those with ASD who have effective avenues of

recreation and leisure including increases in independence, competence, satisfaction and social interaction (García-Villamisar & Dattilo, 2010).

Personal interests. Personal interests are said to potentially serve both positive, and negative functions, for people with ASD. During his address to the Autism New Zealand Conference in 2004, Tony Attwood, an internationally renowned expert on autism, observed that the special personal interests of some on the spectrum can be considered as a barrier to participating in recreation and leisure, yet also may serve as positive functions (Ministries of Health and Education, 2008). On one hand, special interests may become problematic towards optimal family functioning, as they may lend towards being obsessive / compulsive, and also may require a sizeable financial commitment to maintain. Yet, on the other hand, personal interests may provide personal enjoyment, relief of stress and anxiety, be a means by which other learning can be initiated, an avenue of increasing social networks, and become a possible avenue worth pursuing towards meaningful employment, or a career (Ministries of Health and Education, 2008). The connections between personal interests and eventual careers has not yet received the same depth of coverage as other forms of service delivery. According to the NZASG, the heterogeneity of ASD, and the particular interests each child / young person has, means that the correct support in managing interests, while promoting interests which enable positive functions, is said to best supported by sound professional judgement – yet how professional judgement is perceived from a service user perspective is unknown.

Relationship support. Friendship, for neurotypical children, has been shown to promote positive gains for children socially, cognitively, and emotionally (Petrina, Carter, & Stephenson, 2014). Making, and maintaining friendship connections with others may be incredibly challenging for an individual on the spectrum, given that many individuals on the spectrum face challenges with social communication or interaction; may have difficulties

regulating emotions; or have repetitive behaviours, or fixed interests that may become obstacles in gaining the same friendships, and ultimately the same benefits, as neurotypical children (Petrina et al., 2014). A major review of the literature of the nature of relationships that children / young people with ASD had, raised several issues about how research was being conducted in this area of interest. In particular, Petrina et al. (2014) noted that there was a lack of diversity in students, as many studies included only higher functioning ('Aspie') participants. Despite a tendency for researchers to include only participants who are considered higher functioning, Calder, Hill, and Pellicano (2013) have recently found that there is variability of relationship satisfaction in children on the spectrum, but overall, there was lower reported relationship satisfaction than neurotypical children. They reported that was "related to neither children's cognitive ability nor their theory of mind ability" (Calder et al., 2013, p. 297). While such findings offer further evidence of the unique nature of individuals on the spectrum through their unique sense of satisfaction in relationships, what supports are on offer in Aotearoa New Zealand, and how suitable they are, is currently unknown.

Close relationship support. Some young people on the spectrum do have intimate, including sexual, relationships; later in life, people with ASD may have life companions, or get married (Ministries of Health and Education, 2008). However, there is a lack of research in this area on either side of the relationship; for partners who are on the spectrum, and those who are not. Furthermore, no academic literature was found which investigated relationships where both partners were autistic.

Just one article, which relies upon the clinical experiences of the author, offers suggestions for how therapists might attempt to attend to the relationship issues that are most likely to occur when one party has Asperger's (Aston, 2012). Best practice, according to the NZASG, is said to be the application of sound clinical judgement utilising ASD specific

knowledge (Ministries of Health and Education, 2008) However, little is known about how successful, and how individualised counselling services are.

Family life

As mentioned previously, each family has their own strengths and limitations, resources and constraints, and modes of living which must be considered (Dunlap & Fox, 1999). Additionally, as individuals, each member of a family, whether they be a diagnosed or undiagnosed child, or a parent, have their own individual needs and concerns which must also be considered, alongside the needs of the collective, if the long-term health of a family is to be optimised.

Financial issues for families. A child/young person having Autism can mean many additional costs for some families, in the form of medications, treatments, interventions and complications with care options. For families who might struggle to make ends meet under normal circumstances, any such additional costs can be potentially devastating (Ministries of Health and Education, 2008).

Loss of provider employment. Although it is a commonly held view that ASD can be costly, in terms of increased family expenditure, the most common reoccurring theme relating to family finances in the literature is the potential loss of income from employment for one or more family members, particularly parents or caregivers (Ministries of Health and Education, 2008). One Western Australian study examining the familial financial cost of ASD, calculated that the median cost for families to be \$34,900 Australian Dollars annually; approximately 90% (\$29,200) of this sum is attributed towards loss of income from employment for a parent (Horlin et al., 2014). In the United States, Myers et al. (2009) also identified shifts in employment as one of 15 negative themes arising from a qualitative study which asked parents how ASD children in their care affected their lives, and their families' lives.

However, the relationship between having a diagnosed child, and the potential loss in employment (and subsequent income), is argued to be complex, depending upon unique family dynamics (Myers et al., 2009). For example, while Myers et al. (2009) found that it was typical for a mother to leave work to care for a child, a father might also work additional hours, or even additional jobs to attempt to make up the financial shortfall. Similarly, Houser, McCarthy, Lawer, and Mandell (2014) found that the choices that couples made about who might stay at home to care for children depended on two areas of concern; which parent was able to make the most money, and which parent was the most suitable to a caregiving role. Unfortunately, married couples, and other two parent partnerships, have been the only family configurations investigated regarding loss of income, with single parents and other kinds of primary caregivers absent from the literature.

Supporting parents to remain in employment. The NZASG recommends that flexible community support services, as well as employer supports, need to be in place to support parents to enable them to remain in work, as well as care for their children (Ministries of Health and Education, 2008). Yet, there are examples in the literature of the trouble parents have in negotiating the appropriate supports for their unique family situation. In one study investigating enabling factors for parents to remain content in the work force, parents reported three key barriers to achieving a sustainable work / home life fits, namely: childcare coordination concerns; after-school childcare quality and concerns; and performance pressure in managing many parental concerns, made increasingly complex by a diagnosis of a child (Houser et al., 2014). Similarly, a study conducted by Haney (2012) found that the majority of parents who took part reported that they had a desire to have such after school care services available to them, yet had faced difficulty in placement for their children because the autistic symptoms that their children displayed were unacceptable to private day care, or because of concerns about the quality of the services available to them.

While addressing supports to keep caregivers in employment, both studies also demonstrate how the usual challenges of parenting are might be amplified by children with unique needs.

Speech / communication management. As with other symptoms associated with ASD, communication deficits can vary considerably; from the profound difficulties to communicate in ways in which others can comprehend, to barely noticeable.

In order to make progress, the NZASG states that children / young people with ASD should have 25 hours of “developmentally appropriate”(Ministries of Health and Education, 2008, p. 93) interactions per week across different settings, including the family home. However, the unique needs of the child, and the unique needs and preferences of the family, should be taken into consideration when decisions are made about what forms of

engagement, in which social domains, and at what intensity and frequency (Ministries of Health and Education, 2008).

For some families, parental training to facilitate increases in communication in the home, is an appropriate avenue to pursue. Parental Training (PT) interventions which focus upon, and address developmental deficiencies, while teaching children in naturalised settings, have been described as more favourable options due to learning situations being low-demand for both parent and child (Elder, Valcante, Yarandi, White, & Elder, 2005). Yet, even with PT as an appropriate option, the literature supports the need to consider the individual needs of the child and the family.

Much research on PT has focused upon mother-child interactions, as fathers have been positioned both socially and academically as secondary child trainers at home (Elder et al., 2005). Fathers are also said to have language skills and interaction styles that are unique (Flippin & Crais, 2011), yet such differences are not well researched, or utilised, as fathers seldom participate in ASD orientated research.

Physical therapy. As with the sensorimotor discussion in an educational setting (mentioned previously in an educational setting), the NZASG argues that physical therapeutic intervention is best judged to meet individual need, by professionals who have expertise in both motor problems, and in ASD, rather than the indiscriminate use of any sensorimotor intervention. While the role of physical therapists features regularly throughout the NZASG (Ministries of Health and Education, 2008), elsewhere, concerns have been raised over the lack of representation of physical therapists in interdisciplinary teams that produce ongoing formulation for the appropriate services for a young person on the spectrum (Mieres, Kirby, Armstrong, Murphy, & Grossman, 2012).

Emergency support. Structure and predictability can be extremely important to many on the spectrum, yet often emergencies in family life, such as an accident, the sickness or

even a death in the family, can negate both of these (Ministries of Health and Education, 2008). Emergency events can affect the structures, routines, and habits that a person on the spectrum would normally be content with. Additional strain can also be placed upon those with ASD, by the introduction of unfamiliar people, and surroundings.

Little research has been conducted to investigate emergency support for those with autism (let alone in Aotearoa New Zealand), and what literature exists has focused solely upon a medical setting. However, two recommendations that do exist reflect the need to take into consideration an autistic child's uniqueness. Firstly, where a child is outside their normal environment, the environment they enter needs to be structured, predictable, and offer the same kind of supports as they are accustomed to having – particularly in care placement (Ministries of Health and Education, 2008). Secondly, when a child is placed in an emergency support setting, then the appropriate staff who care for, and interact with, the child should have the appropriate training as to how best provide support to someone with ASD (McGonigle et al., 2014; Ministries of Health and Education, 2008).

Medical consultation. Not all healthcare practitioners, including doctors, have the expertise which might be vital for some on the spectrum, particularly if the ASD related symptoms an individual has are severe. While no research was found which covers medical consultation in a General Practitioners clinic, for general illness, one study (Lake, Milovanov, Sawyer, & Lunskey, 2015) was located which focused on the consultation process that took place for the prescription of medication, and for the review of medication.

The extent of the use of medication, is unknown, however there is broad coverage of the benefits of the use of some kinds of medications to alleviate particular symptoms (Ministries of Health and Education, 2008), especially for those on the spectrum with co-morbid disorders, such as anxiety disorders. Lake et al. (2015) reported common themes among in their small parental dyad sample ($N=7$) regarding medication consultations and

reviews (Lake et al., 2015). Firstly, most parental couples felt that prescribing healthcare practitioners that they dealt with had a lack of expertise, with three of the couples specifically mentioning a concern about a lack of autism spectrum related expertise. Secondly, most couples reported a lack of support and assistance around the prescription and a review of the medication. Thirdly, several parents raised a concern on the poor standard of communication, as their concerns, suggestions and opinions were given little consideration. Fourthly, four of seven parental couples reported that their prescribing healthcare practitioners were reluctant to take responsibility for the monitoring and ensuring best use of medication; in many cases it was left to “parents to monitor medication effects, adjust dosages” (Lake et al., 2015, p. 169) and report any health concerns. Being tasked such responsibilities, in essence, meant that parents assumed the role of a health professional.

Support for other family members. Research has focussed a great deal on parents and caregivers; however, each member in a family has their own needs, concerns, and desires which must be considered in a complete family treatment plan.

Sibling support. Having an autistic sibling may often mean facing particular demands that those without autistic siblings might not normally be placed under. Contradictory results have appeared throughout the literature, and have been well documented and reviewed (cf. Ministries of Health and Education, 2008; O’Brien, Duffy, & Nicholl, 2009). Some studies report that a sibling of a diagnosed child is more likely to experience elevated stress levels. However, others report there are no significant differences at all and that (despite potential additional demands), having a brother or sister on the spectrum does not necessarily predict a problematic relationship between siblings, or a threat to the well-being of a neurotypical child / young person (O’Brien et al., 2009). Further research is needed to identify which kinds of formal / informal social supports are needed, or which kinds of information are most useful in enhancing unique sibling relationship.

Companionship support. Although it is important to support all relationships in a family, perhaps the relationship which can be most influential is the one between adults, for example, a spousal relationship. The consequences of the dissolution of parental companionships, particularly marriage, can be devastating for any family. However, are parents of those with ASD at a higher risk of divorce/breakup than parents of neurotypical children? Both parents and practitioners often perceive a higher risk of divorce in parents of children with ASD, perhaps due an often-cited statement in the media which asserts that divorce rates for parents of children with ASD is as high as 80% (Freedman, Kalb, Zablotzky, & Stuart, 2012; Saini et al., 2015). However, as Saini et al. (2015) observes, the empirical evidence to support the perception of such high rates of divorce is scant.

One study in the United States did report higher divorce rates in ASD families, but not to the extent of commonly held beliefs. Hartley et al. (2010), compared the timing and occurrence of divorce in a sample of 391 marriages which had children with ASD, against a matched representative sample of marriages, which had children without disabilities. Parents of children with ASD were found to have a higher rate of divorce; 23.5%, compared to 13.8%. Closer analysis revealed a consistently higher divorce rate for ASD parents over childhood, adolescence, young adulthood, whereas the divorce rates in the comparison group of non-ASD parents were shown to ease after childhood.

On the contrary, other research has questioned whether having a child with ASD had any bearing on divorce rate at all. A population based study in the United States identified 913 participants who were parents of children with ASD; after controlling for relevant covariates, multivariate analyses found that there was no evidence to suggest that a child with ASD was more likely to live without both his/her biological or adoptive parents (Freedman et al., 2012). Similarly, in a French study, over a 10-year period, the separation / divorce rate of parents with ASD children was reported to have reached 25.2% (Baeza-Velasco, Michelon,

Rattaz, Pernon, & Baghdadli, 2013). Although the study lacked a control, French census data estimated divorces at 28%, which was viewed as not being all that different from divorce rate of the research groups. Baeza-Velasco et al. (2013) also reported that the divorce rates remained stable over the duration of the study, contradicting the age related differences as reported by Hartley et al. (2010).

Although evidence is ambivalent as to whether ASD diagnoses are risk factors in marital breakdowns, there is a wealth of data which illustrates increased perceived stress levels for parents of children with ASD (Freedman et al., 2012). Lower marital satisfaction, lower marital adjustment, or inter-parental stress have also been reported often (Baker-Ericzn, Brookman-Frazee, & Stahmer, 2005; Gau et al., 2012; Higgins, Bailey, & Pearce, 2005). Similarly, parental stress, or child related stress has also received much coverage in the literature (Baker-Ericzn et al., 2005; Freedman et al., 2012; Gau et al., 2012; Jones, Totsika, Hastings, & Petalas, 2013). Freedman et al. (2012) suggest that it would appear as though marital companionships which have children with ASD do generally stay together; yet many live with increased stress levels compared to families with neurotypical members.

The need to individualise companionship support services can be illustrated by firstly considering research into both gender differences in marital satisfaction of parents of autistic children, and also research into parental differences. Emerging literature points to a correlation between parental stress or satisfaction and marital quality or satisfaction (Benson & Kersh, 2011; Brobst, Clopton, & Hendrick, 2009; Gau et al., 2012; Harper, Dyches, Harper, Roper, & South, 2013; Higgins et al., 2005) with Brobst et al. (2009) in particular reporting that “mothers whose children with ASD had the most intense behaviour problems reported lower levels of spousal support, respect for their partners, and commitment to their marriages”. As traction is gathering for the notion that marital issues for the parents of autistic children may not be successfully treated in isolation from parental issues, previously

reported literature focusing on gender differences in stress levels, (Baker-Ericzn et al., 2005; Gau et al., 2012; Jones et al., 2013; Shtayermman, 2013), and interaction styles, may be considered in a new light. Secondly, it is worth considering that a companionship may have problems which existed before a diagnosis, or independent of it; thus, the correct intervention to support a companionship may require much, little, or no special reference to a child's autism (Saini et al., 2015). Thirdly, most literature has focused upon married couples, which has provided a limited scope to caregiving companionships; de-facto relationships, civil unions / LGBT marriages, and other companionship configurations, as with each family unit, have their own strengths and limitations, resources and constraints, and modes of living which must be considered before support can be truly individualised (Saini et al., 2015).

Family social support. Having an autistic family member can be an isolating and complicated social existence for some families, especially where children / young people may not yet have acquired particular social norm skills. Problems may arise when a child can't yet comprehend when it is ok, or not ok, to touch something, or someone; when it is safe, or not safe, to be somewhere; or how it is important to work in with others, such as waiting in line, or taking turns (Ministries of Health and Education, 2008). Conversely, parents might have trouble with managing outbursts, or unusual behaviour, because of embarrassment.

In an online questionnaire, Myers et al. (2009) asked an open question about how a child on the spectrum has affected the life of parents, and the rest of the family. Qualitative content analysis revealed five negative clusters identified by parents, one of which was social isolation. The reported social isolation cluster featured three components that many of the parents identified with; firstly, that there were restrictions upon what a family could do, or where they could go. This restriction was felt for both commonplace social events, such as going to church, visiting a supermarket, or eating out; and also special events such as visiting relatives, going on holiday, or attending cultural events. Many parents also reported a fear of

dealing with public outbursts; it was often mentioned that families did not attend events together, as one parent would remain at home with the child of concern (Myers et al., 2009) – a concern which has also received coverage in Ludlow et al. (2012). The second cluster featured concerns over loss of parental friends, and loss of social life; not only did parents find it difficult to go places together, but they were no longer welcome in the homes of friends. Similarly, participants in Ludlow et al. (2012) reported that it was problematic to have friends visit their own homes. In the third social isolation cluster, a small number of parents described negative treatment in public by strangers, which caused embarrassment (Myers et al., 2009).

Overcoming isolation and addressing the social needs of a family can vary considerably, depending on the scope and nature of the social event, the family members who might typically take part, and the challenges a child / young person might face. Thus, the types of social support needed may also vary considerably and may require cross-sectional support from both professional and personal domains. According to the NZASG, appropriate social skills can be taught, or enhanced, for those with ASD, however, control, choice and self-determination must be given due consideration also (Ministries of Health and Education, 2008). However, as with other recommendations that have arisen in the NZASG, little is known about how effectively, or how individualised, such suggestions have been once put into practice.

Respite care. As outlined previously, having a child, or children, on the spectrum can be both intensive and stressful for caregivers. Respite care offers an opportunity for caregivers to attend to the needs of other family members, or their own. Few studies have reported on the demands, or the benefits, of respite care for specifically families with ASD children. Bromley et al. (2004) have previously been cited for showing that respite care demands featured in, or could be associated with, three of the top four unmet needs reported

by mothers. Firstly, the results showed that 87% of mothers felt that breaks away from caring for their child with ASD was a need which went unmet; secondly, 93% of mothers reported care assistance needs during holiday periods went unmet; thirdly, 91% of mothers considered being able to do the things they enjoy personally, as a service need that went unmet.

Elsewhere, some of the benefits of respite care have been demonstrated by Harper et al. (2013). Although there were several marital processes which were not investigated, and the study featured convenience sampling (which may represent a high than normal degree of family functioning). This study of 101 mother-father dyads (caregivers to 118 children with ASD) showed that just one additional hour of respite care per week was related to a six to seven-point increase in marital quality (approximately one half of a standard deviation). The study also showed perceived parental stress (as was measured by daily hassles, rather than specific parental stressors), reduced as a result of respite care, and that respite care was positively associated with positive ‘uplifts’ (positive factors to negate / balance out negative factors). Interestingly, parents also reported their children as both a stressor, and an uplift (Harper et al., 2013).

The NZASG affirms that regardless of whether respite takes place in or out of the home environment, “the environment needs to be structured and predictable, and it needs to support the function of the child in communication, personal independence and safe leisure skills” (Ministries of Health and Education, 2008, p. 173). The NZASG also points to the need of people who step in to help to have ASD specific knowledge, as well as culturally specific knowledge, as a starting point towards individualising respite to meet the unique needs of both child and family (Ministries of Health and Education, 2008). Although there is a general acceptance that respite care is beneficial, and needs to be more available to families, what constitutes good respite care for autistic children, or how individualised it might be, has

received very little coverage in the literature, especially in Aotearoa New Zealand, with its bicultural character.

Transition management

Transitional periods can bring uncertainty, stress, and fear for children, young people, and adults. For those on the spectrum, who often prefer predictable patterns and environments, times of transition into the uncertain can be especially trying (Ministries of Health and Education, 2008; J. B. Stoner, Angell, House, & Bock, 2007). Transitions are broadly considered to be divided into two types: vertical and horizontal.

Vertical transitions. Of the two transition types, vertical transitions have received the most coverage in the literature. Vertical transitions are characterised as the predictable, developmentally based transitions that are experienced by all children, such as movement between preschool, primary school, intermediate school, college, post-secondary / vocational programmes (J. B. Stoner et al., 2007).

Vertical transitions through early childhood. Little research has been produced which investigates vertical transitions during early childhood, and what does exist has examined the educational situation of autistic children. Investigating transitional failures from the perspective of educational professionals in both Ghana and United States, Denkyirah and Agbeke (2010) proposed a series of recommendations about how to best facilitate smooth vertical transition, which did include parent / professional collaboration. On the other hand, Quintero and McIntyre (2011) demonstrated many differences in transitional practice preferences between parents and professionals, which raises concerns regarding the comprehensiveness of guidelines that emerge from research. For example, Denkyirah and Agbeke (2010) produced guidelines, which do not include parents, let alone the children themselves. Furthermore, Quintero and McIntyre (2011) highlight a major concern in that

transitional practices were generic in most instances and that a major barrier to individualisation was a lack of time.

Vertical transitions into adult life. The transition into adult status has many possibilities for neurotypical young people, such as furthering education, getting a job, or moving out of home; for young autistic people, the same possibilities exist, especially if the right supports are made available. However, concerns have emerged from the literature regarding the practice and state of transitional services.

Inclusive transition planning. According to Hendricks and Wehman (2009), effective transition planning requires the presence and participation from a multidisciplinary team, caregivers, and the service receiver. However, beyond high attendance rates from special needs educators, and caregivers, active participation from other team members is reported to be significantly lower. It is said that planning transitional services for young people should incorporate their “unique needs, strengths, interests, and preferences” (Lee & Carter, 2012, p. 991), and therefore their active participation in the planning process, when possible, is critical and developmentally appropriate. However, research shows that participation by adolescents in the planning process, for their own futures, has been mostly passive.

Service disconnection. A second concern which has been raised, is the perceived disconnect by families during the transitional period, particularly in the United States. Friedman et al. (2013) illustrate how low-income families, especially ethnic minorities, are disconnected from services following high-school. Similarly, Nancy C Cheak-Zamora, Yang, Farmer, and Clark (2013) report that less than half of young people on the spectrum received any information about transitioning between child and adult based health services, and less than a quarter received anything resembling a transitional service. Additionally, compared to other young people with other special health care needs, youth on the spectrum were far less likely to receive health care transition services. In a follow-up study, 101 parents contacted

through the national autism registry completed a questionnaire which focused upon the receipt of health care transition services; fewer than 15% of youth with ASD received a service, and while 40% took part in a transition discussion, only 3% of youth in the research received all three of the recommended discussions (N. C. Cheak-Zamora et al., 2014).

Systems review. In their review, Watson, Parr, Joyce, May, and Le Couteur (2011) suggest that although there is widespread agreement on the importance of the individualisation of transitional care, inclusive and active planning, and constant connection to the most appropriate services, there is also a lack of evidence to support what best practice is in transitional services as a process, and “what constitutes effective transitional care”(Watson et al., 2011, p. 780). Furthermore, the authors also state that most services they analysed lacked reflexive evaluation in terms of effectiveness, or long term sustainability (Watson et al., 2011).

Horizontal transitions. Horizontal transitions, on the other hand, have received far less coverage in the literature; horizontal transitions are considered to be situational based movements that are unique to an individual, such as the moving to and from home, or school; and also transitioning to unfamiliar surroundings such as a shopping centre, or perhaps the family doctor (J. B. Stoner et al., 2007). Qualitative analysis undertaken by J. B. Stoner et al. (2007) revealed various unique ways in which each participants’ children would react to, and best adapt to, horizontal transitions; furthermore, participants all had a similar strategy set employed in assisting their children through such transitions (identify-observe-explore). However, no research to date has identified to what extent professionals have been able to provide individualised support both parents and autistic children for horizontal transitions.

Summary

Existence on the spectrum is challenging, although the extent and nature of an autistic person’s challenges varies, as consensus has been reached that ASD is a highly heterogenous

disorder. There is widespread acceptance that such diversity in symptoms, and lived experience, for people on the spectrum, requires that services that support autistic people are individualised to meet their needs, and preferences.

Arguably the most important support unit an autistic person will be part of is their family; yet families are also widely regarded as being heterogenous, as each family unit has their own strengths, needs, challenges and preferences. Furthermore, there is also widespread acceptance such uniqueness between families should inform service delivery, to ensure that services not only address the needs and preferences of an autistic individual, and other family members, but also have high family ecology. It is broadly theorised that the more individualised services are, the more efficacious a service will be towards favourable outcomes for both the individual with ASD, and their family. However, individualisation is not static; autistic peoples' needs and preferences, and those of their families', may change over time and through vertical and horizontal transitions – what is presently suitable, may not be so in the future.

Attempting to draw upon past ASD support service research which took into consideration the lifespan of services, and service receivers, was not successful, as no such research was located. Instead, literature was reviewed using a theorised lifespan, which covered areas in which autistic children, and their families, might need support, or typically receive support; starting from the point where a child and family begins the service delivery journey around diagnosis, extending through to the transition into adulthood.

The literature sourced shows that different autism service areas are at different stages of development, both in terms of academic research conducted, and the best professional practice; from well researched and reviewed services, such as post diagnosis EIBI, to many areas where no research has been conducted at all, such as autistic adolescent intimacy. However, even in the well-researched service delivery domains in the literature, very little

has been done to replicate research from abroad within an Aotearoa New Zealand context. Furthermore, although the literature consistently conveys that individualisation is essential in delivering ASD support services, only one study attempted to directly operationalise individualisation.

This research aims to address gaps in the literature; both in terms of knowledge, by pursuing an Aotearoa New Zealand context to the ASD literature reviewed; and in process, by seeking to gain views from caregivers including, but not limited to, mothers. The next section describes how the research aims were carried out in practice.

Method

Design

This research incorporated a mixed-methods design; this combined both quantitative data and qualitative data to achieve the objective of better understanding how well services are individualised for children with ASD, and their families, in Aotearoa New Zealand. The research questions which encapsulated this objective were:

1. Do interventions / services target the uniqueness of the individual (ASD), and their family?
2. Are ASD services in Aotearoa New Zealand appropriate, accessible, and adequate?

The decision to incorporate a mixed methods design emerged during the literature review process, as it became apparent, during ongoing consultation with the research supervisors, that such an approach was needed to answer the kinds of questions that were being raised. The justification for the use of a mixed-methods design was found through increasing support found in the literature for a third research paradigm (R. B. Johnson, Onwuegbuzie, & Turner, 2007). Such a third paradigm is said to be moving beyond the purists' versions of qualitative and quantitative paradigms, and associated culture within

each, “one professing the superiority of ‘deep, rich observational data’ and the other the virtues of ‘hard, generalizable’ . . . data” (Sieber, 1973, as cited in R. B. Johnson & Onwuegbuzie, 2004, p. 14). Rather than attempting to replace either approaches, mixed methods seeks to draw from the strengths of both, while also eliminating their weaknesses.

The need to draw upon the usefulness of quantitative methods became apparent early in the literature review process. With the importance of individualisation broadly stated throughout the literature, and so many researched services that could be offered to families with ASD members, an online questionnaire offered participants flexibility in time, location, and personal experience; its fixed scale-based nature was best suited to collect large amounts of numerical data, from a host of potential participants from across Aotearoa New Zealand.

Yet in the construction of items, and an eventual questionnaire instrument, it was recognised that the way individualisation was being investigated represented a viewpoint drawn from the existing literature which may not necessarily be shared by participants. Additionally, although many of the services contained in the broader themes have widespread support throughout the literature, the researcher exercised a degree of personal judgement about selecting which services, and questions, to present, and in some instances, this included areas that had received little attention. For example, imparting of post-diagnosis information to caregivers was broadly demonstrated to be important; here, Smith, Ellenberg, Bell, and Rubin (2008) frame the dynamics around the quality of information put into the public domain in context of the degree of robustness in the science used; while Magaña et al. (2013) and Tway et al. (2007), provided coverage of the kinds of sources of information available, and the uptake from these sources. In contrast, only Aston (2012) was found to offer insight into how practitioners might respond when providing support for intimate relationships between those with Asperger’s, and those considered neurotypical. Such items may not have held the same value as other services, or aspects of service delivery, which caregivers may

consider superior, and more pertinent to the discussion; however, such a strategy was unavoidable given the lack of research directly focusing on individualisation.

Adding to the quantitative approach of the questionnaire, the inclusion of qualitative data collection through interviews provided an open-ended format which facilitated the collection of data with a greater depth and richness regarding which services were most important to their families, and which themes regarding individualisation were most important to explore.

The mixed-methods design which best suited the intended path of the research, and to answer the questions raised, was a concurrent triangulation design (see Figure 2.), which allowed for the use of two different methods to “confirm, cross-validate, or corroborate” (Creswell, Plano Clark, Gutmann, & Hanson, 2003, p. 183) and even contradict, findings within the same study. Such a design was additionally advantageous given that each method was available to different audiences, as interviews were conducted with caregivers in MidCentral DHB and Nelson Marlborough DHB catchments, whereas the online questionnaire was available nationally.

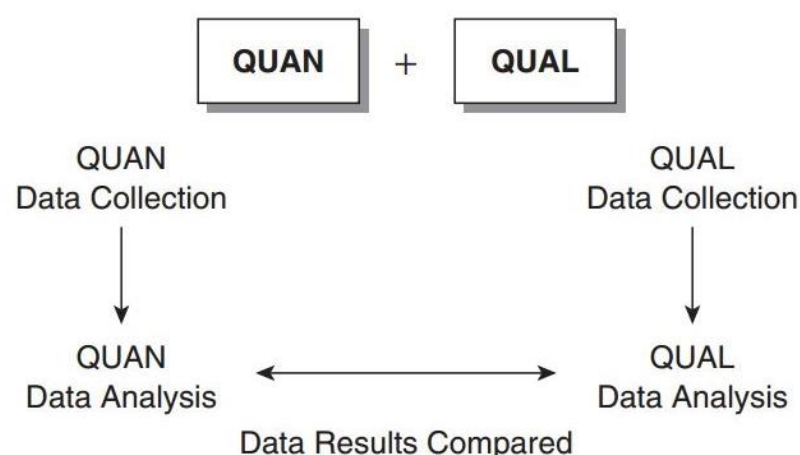


Figure 3. Concurrent triangulation mixed methods design by Creswell et al. (2003)

The key features of concurrent triangulation are the simultaneous collection of quantitative and qualitative data; the ability to prioritise either quantitative or qualitative data, but preferably giving equal priority to both; comparison or integration at either interpretation or analysis phases; and the option, but not the necessity, to operate from a theoretical perspective (Creswell et al., 2003)

Participants

Online questionnaire. The participants for the online questionnaire were primary caregivers, or in the least, co-primary caregivers, of children, or young people, aged between three and sixteen years who had been diagnosed on the Autism spectrum. Although most research has focused primarily on mothers of children on the spectrum (Flippin & Crais, 2011; Hayes & Watson, 2013), inviting primary caregivers allowed a broader spectrum of relationships to a child, which may each feature a primary caregiving, or co-primary caregiving role. Caregivers also were required to be adults (18 years or older) in order to be able to give their own consent for their own participation, and to ensure they were in a primary caregiving role with sufficient maturity to have experienced services and developed views on them.

Three years of age was utilised here as the lowest age threshold, as caregivers, or educators, often notice irregularities in typical development in children between the age of two and three years (Ministries of Health and Education, 2008); thus, ASD diagnosis typically takes place when a child is three years, or older. The upper threshold the child / young person's age was sixteen, to be inclusive of caregivers whose young people on the spectrum are transitioning into further education, or work. Participants with more than one child on the spectrum could participate in the questionnaire, using branching functionality of the Qualtrics™ software to generate questions for each child (see *data gathering*).

Participants were required to have a confirmed diagnosis for their child / young person a minimum of six months prior to take part in the online questionnaire, to ensure that the child did in fact have ASD, and also allow time to pass, during which experience with service delivery would be accumulated. Participants were also required to be currently living in Aotearoa New Zealand, as the research asks about service delivery which occurs in this country; similarly, caregivers must have resided in Aotearoa New Zealand for minimum of six months to have an opportunity to experience service delivery locally. Participants were also required to not be employed as a professional support service provider for those on the spectrum, as this would raise different questions for people with a duality of roles as both providers and receivers of services. Caregivers who did not meet the above criteria were thanked for their interest but were not able to participate.

Interviews. The participants for interviews met all online questionnaire criteria with the added criteria of having lived within the MidCentral DHB or Nelson Marlborough DHB areas for a minimum of six months, and not being employed by the MidCentral DHB or Nelson Marlborough DHB in any capacity. All interview participants were mothers.

Recruitment

Online questionnaire recruitment.

ASD Organisations. Of all the member or client organisations across Aotearoa New Zealand, Autism New Zealand was first approached to offer the online questionnaire to its membership base (in excess of 6300). Autism New Zealand's mission statement is to be "New Zealand's eminent provider of services and support for those on the Autism Spectrum, and those that care for them" (Autism New Zealand, 2013). With representation in 16 geographical regions, Autism New Zealand has a working presence, of some description, in most, if not all, of the DHB zones across the country. Thus, members of Autism NZ were well positioned to provide feedback about service delivery in each DHB catchment across the

country. Despite being unable to secure the support of Autism New Zealand as a national body or the Palmerston North branch, the Nelson Bays / Marlborough branch of Autism New Zealand were able to support recruitment in the advertisement distribution.

In contrast, the IHC NZ was the most responsive national organisation, and approval was obtained through existing internal ethics processes. The IHC NZ is a provider of support and services for those on the spectrum, and their families. At the time of writing this thesis, IHC NZ had 800 families across Aotearoa New Zealand registered in their ASD specific programmes: ASD Plus (0-6 years), Growing Up with Autism (11 – 16 years), and the ASD Communication and Behaviour Service (0 – 19 years); with an additional 400 families on their waiting list (2200 families have completed their programmes). These three programmes have been offered free of charge since 2009, through funding provided through the Ministries of Health and Education. From March 2015, IHC NZ has also offered a series of training workshops tailored to the needs of parents and family members of those on the spectrum (IHC NZ, 2015). The IHC was able to email the advertisement to clients and members by utilising an existing emailing list which included families with autistic members.

Social media. The largest Facebook ASD orientated NZ parental groups that could be located, also aided recruitment. Administrators were contacted through private messaging, then email, in order to secure permission. Group administrators were then emailed a copy of the advertisement poster (Appendix F) which was posted and pinned in each of the groups' respective news feeds for group members to view (Autism in New Zealand, 1100 members; ASD Friendly Group NZ, 602 members; VIPS - Equity in Education NZ, 701 members; Autism Action NZ, 343 members).

Public advertising. The advertisement was then placed in public spaces, such as the Massey University psychology clinic, and libraries; and then offered to clinicians, and other service professionals. Professionals and clinicians had the option of bringing it to the

attention of clients to whom it applied in both the MidCentral DHB, and the Nelson Marlborough DHB areas; however, no pressure was placed upon clients to participate.

All participants who were recruited through the online questionnaire were presented with an information sheet prior to being able to participate (Appendix F), which provided a more in-depth description of the online questionnaire, and of their rights as participants.

Interview recruitment. Recruitment for interviews was initially achieved by an invitation located near the conclusion of the online questionnaire, which was triggered by participants who selected MidCentral DHB as their local DHB. Participants were informed that the research team was looking for participants living in the MidCentral DHB area to participate in interviews and were presented with the choice to accept or decline the invitation to receive further information. If the offer of further information was accepted, then the online questionnaire provided space to record contact details, which was collected independently of a participant's online questionnaire data, to maintain the privacy of participants.

Subsequent interview recruitment, due to an initial shortage of responses, was achieved by utilising an amended version (Appendix G) of the advertisement (approved by the Massey Human Ethics Committee: Southern A), both in the MidCentral DHB, and the Nelson Marlborough DHB (through the Autism New Zealand branch), which directly promoted interview participation.

Upon contact through either method, participants were sent an information sheet (Appendix H) which provided a more in-depth description of the interview process, and of their rights as participants. Before scheduling any interviews, interview participants were asked if there were any aspects of cultural safety which they wanted to observe during the interview; this was achieved by utilising an invitation guideline prepared with the assistance of the cultural supervisor for the research (Appendix I). Although two of the nine interview

participants identified as being Māori, neither wished for a cultural component to be included in the interview process.

Materials

Online questionnaire instrument. The survey instrument used was a questionnaire developed by the researcher with consultation from the research supervisors (Appendix J).

The instrument has its conceptual roots in research conducted by Bromley et al. (2004). In the article, *Mothers supporting children with autistic spectrum disorders*, Bromley et al. (2004) modified an instrument called the Client Service Receipt Inventory to assess the awareness, and uptake, of service that mothers (as participants), and their children, would normally be expected to be exposed to. Additionally, mothers rated services they had received in terms of accessibility, appropriateness, and sufficiency.

The present instrument asked whether or not primary, or co-primary, caregivers (of both genders) had received, or were aware of, a variety of support services. Similarly, the current instrument additionally asked if caregivers found services accessible, appropriate, or adequate (sufficient), even if they did not, or were not, able to utilise them. The ratings system used was a standard five-point Likert-type scale, with a sixth option allowing a participant the right to not answer if they did not know or preferred not to complete a question.

The current instrument took a broad developmental view of service delivery by asking questions which address the earliest of service related events for a child with ASD, and their family, around the time of diagnosis; to perhaps the last service input offered for young people transitioning into adulthood, such as developing social networks, personal interests, and developing meaningful work options.

The questionnaire featured six sections; of which, the first section, (diagnosis) and parts of the sixth (demographics), were compulsory, as both address criteria for participation,

as outlined in the information sheet. The remaining sections feature self-selection tables, where participants were asked to nominate which support services they have knowledge of or have experience with; each section also provided space for participants to give feedback on both the services mentioned, or absent, or the questions posed.

Section 1: Diagnosis as a Life Event. Section 1 focuses upon service delivery around the diagnosis of a child / young person on the Spectrum, such as, the raising of developmental concerns; timeliness and early detection; support services available following diagnosis; and sources of information.

Section 2: Education. Section 2 focused upon the delivery of education for the child, and offers items relating to personalised education plans, behavioural plans, and sensory needs in a school setting. Section 2 also asked caregivers to rate items relating to efforts to promote citizenship, belonging, and respect for those on the spectrum.

Section 3: Personal Fulfilment & Work-Related Services (Living in the Community). Section 3 focused upon the personhood of the child / young person on the spectrum as it covered services which promote leisure, meaningful activity and personal interests; services which assist in turning interests into a job, or career; and services which support different kinds of relationships.

Section 4: Family life. Section 4 focused upon the family unit, and the support services sometimes needed for optimal family functioning with a member who is on the spectrum. Items offered here reflect the multiple implications a diagnosis of ASD may have on interconnected family units, such as assistance with, finances; professional advice; the implementation of learning, behavioural and sensory programs at home; sibling support; supports for caregiver relationships; social support; and caregiving / respite support.

Section 5: Managing transitions. Section 5 focused upon services which assist in the management of transitions across many domains a child / young person with ASD, and their families, may face.

Section 6: Participant information. Section 6 focused upon demographical data, from which a description of the sample is derived. Section 6 also includes screening questions; those who did not meet the requirements of the following items had the chance to complete the questionnaire but would not have their answers included in any data or analyses. Items A) and B) address the criterion of living in Aotearoa / New Zealand for at least six months. Item D) addresses the need for participants to be primary caregivers, or co-primary caregivers. Item G) covers the requirement for children to be diagnosed a minimum of six months before a caregiver was able to take part in the questionnaire; while item H) ensures that an adequate diagnosis has taken place for the child / young person, by the appropriate professional/s. Finally, item I) addresses the requirement for participants to be providing care to children / young people in the appropriate age range (3-16 years).

Interview schedule. The interview schedule echoes the first five sections of the online questionnaire; Diagnosis as a Life Event, Education, Personal Fulfilment & Work-Related Services, Family Life, and Managing Transitions (Appendix K). Items were intentionally open ended, to capture the views, thoughts, feelings and experiences of caregivers on different support services, which a questionnaire would otherwise fail to encapsulate. Items on the schedule were also organised in a hierarchy of prompts; the briefest prompt is first conveyed to participants, and lengthier prompts are subsequently used if a participant is not forthcoming with dialogue. The hierarchy of prompts still allows a participant the right to not answer any particular questions or talk about any particular subject. Time was given before, during, and after each section covered, to allow participants

to elaborate on matters relating to service individualisation, which they considered important to raise.

Qualtrics. The Qualtrics survey system was utilised to construct and host the online questionnaire. The key features of this platform include security of the highest standard (secured using Transport Layer Security (TLS) encryption for all transmitted data), user friendly interface for questionnaire participants, and the ease of use in data file production after data collection closed.

SPSS v22.0 & 24.0. The Statistical Package for the Social Sciences (SPSS) produced by IBM is a software package which is in common use, that is capable of complex data manipulation and analysis. This package was utilised to provide quantitative data analyses, utilising the data file obtained through the Qualtrics online survey system.

NVivo. The NVivo software package, developed by QSR International, is marketed as a support program for those undertaking qualitative and mixed-methods research. Key features for the purposes of this research, was the ability to find, organise, compare, and encode reoccurring themes in interview transcripts and questionnaire feedback sections.

Data gathering

Online questionnaire. The Qualtrics survey was operated by an IT technician at the School of Psychology, under licences held by the School of Psychology at Massey University. Use of Transport Layer Security (TLS) encryption (also known as HTTPS) for all transmitted data allowed for the survey was configured so that all data was anonymised when submitted, including IP addresses. All data was held by the Qualtrics server system for later collection by user code/password access that was available to the technician only. This data file was not accessible by other external internet browsers during data collection; or by any other persons, until data collection was complete, ensuring the integrity of the data collected.

Interviews. All interviews were recorded using two digital voice recorders and were transcribed by the researcher. Transcripts were then sent to each participant for clarification, amendments, and finally approval, before being included in the data set for analysis.

Data analysis

Quantitative data analysis. All numerical data obtained through the Qualtrics™ data file was analysed using SPSS software (versions 22 and 24), which provided descriptive statistics such as means, modes, and standard deviations. To maintain the integrity of the data, all questionnaires which did not meet the minimum requirements (as outlined above) were excluded before analyses took place.

Qualitative data analysis. Of the different methods available with which carry out the qualitative analysis, thematic analysis was chosen. According to Braun and Clarke (2006), thematic analysis is a method, if used correctly, that is able to produce a rich, detailed and complex narrative of the data set. While a foremost consideration was that this method of choice enabled the researcher to answer the research questions, thematic analysis also offered the following benefits.

Firstly, an important feature of thematic analysis is the ability to search across a data set to find and interpret broad patterns of meaning, including both similarities and differences. Given the necessary exploratory nature of the research, because of the scarcity of research addressing individualisation of ASD service, such an analytical strategy was considered important in order to answer questions raised when the literature was initially reviewed.

Secondly, while other methods of qualitative analysis such as grounded theory, or interpretative phenomenological analysis, also provide the same pattern seeking function across a data set, both alternatives are theoretically bounded. For the author who was a novice qualitative researcher, the choosing of thematic analysis, as the ‘named’ qualitative method,

provided an accessible form of analysis that did not require the “detailed theoretical and technical knowledge” that the aforementioned qualitative methods, and others, require. Additionally, because there were not fixed pre-existing theoretical ties, thematic analysis provided the flexibility to adopt a theoretical approach of choice.

All text based data collected through questionnaire feedback sections, and interview transcripts, were thematically analysed using the following template of phases of thematic analysis as put forward by Braun and Clarke (2006):

Phase one: familiarity with data. Data familiarity began through the collection process by transcribing verbal data into text. While transcription is argued as an interpretive, not mechanical, act where meanings are created, the importance of data keeping ‘true’ to its original nature is convention which was adhered to. Further immersion in the data through repeated ‘active readings’, and looking for meanings and patterns also took place as ideas for later coding were organised.

Phase two: generating initial codes. Working from an initial list of ideas about what was meaningful in the data, initial codes were generated to assist organising data into meaningful groups.

Phase three: searching for themes. When all data has been coded and collated, the focus shifted to a broader level of themes, as different codes were sorted into potential themes, and also several codes were considered to combine to produce overarching themes, and supporting themes within overarching themes. Codes of interest, that at the time appeared to be ‘loose ends’, were sometimes also considered to be themes to be reconsidered at a further level of analysis.

Phase four: reviewing themes. During this phase potential themes were revised further; through elimination, combining with other potential themes, or dividing potential themes into smaller themes.

Phase five: defining and naming themes. Here, further analysis of the themes identified the essence of each theme, and organised each of them into a coherent account with accompanying narrative, which fitted into a broader overarching narrative.

Phase six: producing the report. During this phase the final analysis, during the writing of research, took place. Here it was important to effectively convey the story that the data tells, “within and across themes” (Braun & Clarke, 2006).

Ethics

Ethics committee approval was gained from the Massey University Human Ethics Committee: Southern A, for both the initial application, and the revision required for recruitment purposes (See Appendices L and M). Māori cultural consultation was also undertaken, and was approved by the same ethics process.

Quantitative Results

Demographics

Demographical questions were put to participants that focused on themselves, the broader family, and the child on the spectrum.

Caregiver / family demographics.

Location and duration. Of the 34 respondents to complete the questionnaire, all reported living in Aotearoa New Zealand, with 32 of 34 respondents living in their present location more than six months. Most participants lived in either urban ($N = 13$), or suburban areas ($N = 16$), with the minority of participants living rurally ($N = 4$), and one participant who preferred not to answer.

DHB area. Table 1 presents the DHB locations of questionnaire participants and their families. Most DHBs were represented by at least one participant, although the Waikato, Taranaki, Whanganui, Wairarapa, and West Coast DHBs were not represented.

Table 1
Caregivers' DHB catchments as a percentage

	Frequency	Percentage of Respondents
Northland	3	8.8
Waitemata	3	8.8
Auckland	1	2.9
Counties Manakau	5	14.7
Bay of Plenty	5	14.7
Lakes	1	2.9
Tairāwhiti	1	2.9
MidCentral	1	2.9
Capital and Coast	4	11.8
Hutt Valley	1	2.9
Nelson Marlborough	4	11.8
Canterbury	1	2.9
Southern	3	8.8
Total	34	100

Ethnicity. Most participants identified as Māori ($N = 12$) or Pākehā ($N = 25$), with fewer identifying as Sri Lankan, English, Native American, and Samoan ($N = 6$), with one participant preferring not to respond.

Gross household income. Table 2 presents the combined household income of participants, which shows the income bracket that was most often reported was \$70,000 or more.

Table 2
Caregivers' combined household income as a percentage

Income (New Zealand Dollars)	Frequency	Percentage of Respondents
\$20,000 - \$30,000	5	14.7
\$30,000 - \$40,000	3	8.8
\$50,000 - \$60,000	6	17.6
\$60,000 - \$70,000	2	5.9
More than \$70,000	11	32.4
Would rather not say	7	20.6
Total	34	100

Education. Table 3 presents the level of education among caregivers, most of which had a tertiary related qualification, or some form of trade or profession related certification.

Table 3
Level of education of participants as a percentage

Highest attained qualification	Frequency	Percentage of Respondents
School certificate (NCEA 1)	3	8.8
Bursary / Higher school certificate (NCEA	3	8.8
Trade certificate	5	14.7
Teaching / Nursing certificate or diploma	1	2.9
Undergraduate certificate or diploma	5	14.7
Bachelor's degree	8	23.5
Postgraduate degree	5	14.7
Would rather not say	4	11.8
Total	34	100

Relationship to child. Of the 34 respondents, 31 identified as the child's mother while only one as the father, uncle and grandmother. Un-utilised relationship response options were aunt, grandfather, foster mother and foster father, as well as the option to report caregiving relationships not presented.

Child demographics

Age of child. Table 4 displays the age of autistic children in the participants care ($N = 31$, $M_{\text{age}} = 9.45$ years, age range 3-16 years), with a minimum of three years, maximum of 16.

Table 4
Age of autistic child in care as a

Years	Frequency	Percentage of Respondents
3	1	3.2
4	3	9.7
5	1	3.2
6	2	6.5
7	1	3.2
8	1	3.2
9	8	25.8
10	1	3.2
11	2	6.5
12	5	16.1
13	4	12.9
14	1	3.2
15	0	0.0
16	1	3.2
Total	31	100

Gender of child. Males ($N = 27$) were most often reported as the gender of autistic child in care, as compared to females ($N = 7$).

Time elapsed since diagnosis. Table 5 displays the time elapsed since diagnosis autistic children of participants ($N = 34$, $M = 4.88$ years).

Table 5
Time period in years elapsed since diagnosis as a percentage

Years	Frequency	Percentage of Respondents
<1 year	4	11.8
1 year	1	2.9
2 years	4	11.8
3 years	5	14.7
4 years	3	8.8
5 years	5	14.7
6 years	2	5.9
7 years	1	2.9
8 years	2	5.9
9 years	3	8.8
10 years	2	5.9
11 years	1	2.9
12 years	1	2.9
Total	34	100

Diagnostician. Developmental paediatricians ($N = 13$) and multidisciplinary teams ($N = 11$) were the most frequently reported diagnosticians (multidisciplinary teams typically consist of two to three of the following professionals who are experts regarding autism: paediatricians, psychiatrists, psychologists, speech and language therapists, occupational therapists). Clinical psychologists ($N = 8$), and psychiatrists ($N = 2$) were also reportedly utilised.

Likert-type scales

Participants and multiple response sessions. The use of branch logic, with the Qualtrics™ survey system, allowed for participants to report the number of autistic children in their care, and then allow customised responses for each child, with successive questionnaire sessions. Of the total respondents ($N = 34$), 28 participants reported having one child with ASD, while the remaining 6 reported having two. None of the six parents with two autistic children opted for a second questionnaire session.

Post diagnosis information. Table 6 shows the number and percentage of caregivers searching for information before, during, and after diagnosis in various sources; the most common source of information was the Internet, followed by Books and Magazines, and Support Groups. Other sources of information were accessed at similar levels, with Religious and Spiritual Leaders being the least accessed.

Table 6
Sources of information accessed by caregivers as a percentage

Source	Accessed	Total Responses	Access Percentage
Internet	31	32	96.9
Books and Magazines	22	31	71.0
Support Groups	22	31	71.0
Other Caregivers with ASD children	16	32	50.0
Facebook	15	32	46.9
GP / Family Doctors	16	31	51.6
Education Professional	16	30	53.3
Family Members	11	31	35.5
Religious or Spiritual Leaders	4	32	12.5
Friends	10	31	32.3

Table 7 shows the number of responses to rate usefulness, and the rating of perceived usefulness of each of the informational sources before, during, and after diagnosis. Table 7 also shows that the Internet, Books and Magazines, and Support Groups were perceived as the most useful, while Religious and Spiritual Leaders were perceived as the least useful. The most, and least, accessed sources in Table 6 were also the most, and least, perceived useful in Table 7. This suggests that caregivers may have resolved which information sources are perceived as the most useful, and accessed the most useful sources accordingly.

Table 7

Perceived usefulness of information sources as a percentage

Source	Useful	Total Responses	Usefulness Percentage
Internet	24	30	80.0
Books and Magazines	18	27	66.7
Support Groups	18	24	75.0
Other Caregivers with ASD children	15	24	62.5
Facebook	15	21	71.4
GP / Family Doctors	10	24	41.7
Education Professional	8	25	32.0
Family Members	7	26	26.9
Religious or Spiritual Leaders	2	19	10.5
Friends	7	25	28.0

Personal stress level. Participants were asked to rate their own stress levels over the diagnosis period; over the group who responded ($N = 34$), the average ($M = 1.56$) response tended towards being moderately stressed. The modal response for caregiver stress was very stressed (23 of 34 respondents).

Kaiarahi / caseworkers. Participants were asked to rate how desirable a kaiarahi, or guide might be, in line with the NZASG recommendations. The average response tended towards viewing a potential key support worker as moderately beneficial ($N = 32$, $M = 4.28$). The modal response was: very beneficial (23 of 32 respondents).

Aotearoa New Zealand orientated information package. Caregivers were asked to consider how useful an information package would be, that was similar to the design of the Autism Speaks' *First 100 Days* package.

Across respondents ($N = 32$, $M = 4.50$), the average response tended towards viewing such a package as between moderately, and very beneficial for families, while the modal response was very beneficial (24 of 32 respondents).

Accessibility, Adequacy and Appropriateness. Most items in the questionnaire targeted the three constructs of interest (Accessibility, Adequacy and Appropriateness) across different themed subsections: Education, Living in the Community, Family Life, and Managing Transitions. The construction of graphs (see Figures 4 and 5) from the data taken from these theme sections illustrated the data for the Accessibility and Adequacy constructs to be clearly and consistently bimodal indicating that most caregivers thought services were moderately accessible or very inaccessible, moderately adequate or very inadequate. These contrasting views made many quantitative analyses inappropriate. It was subsequently decided that the most useful information would come from qualitative interviews which sought to further understand these extreme differences.

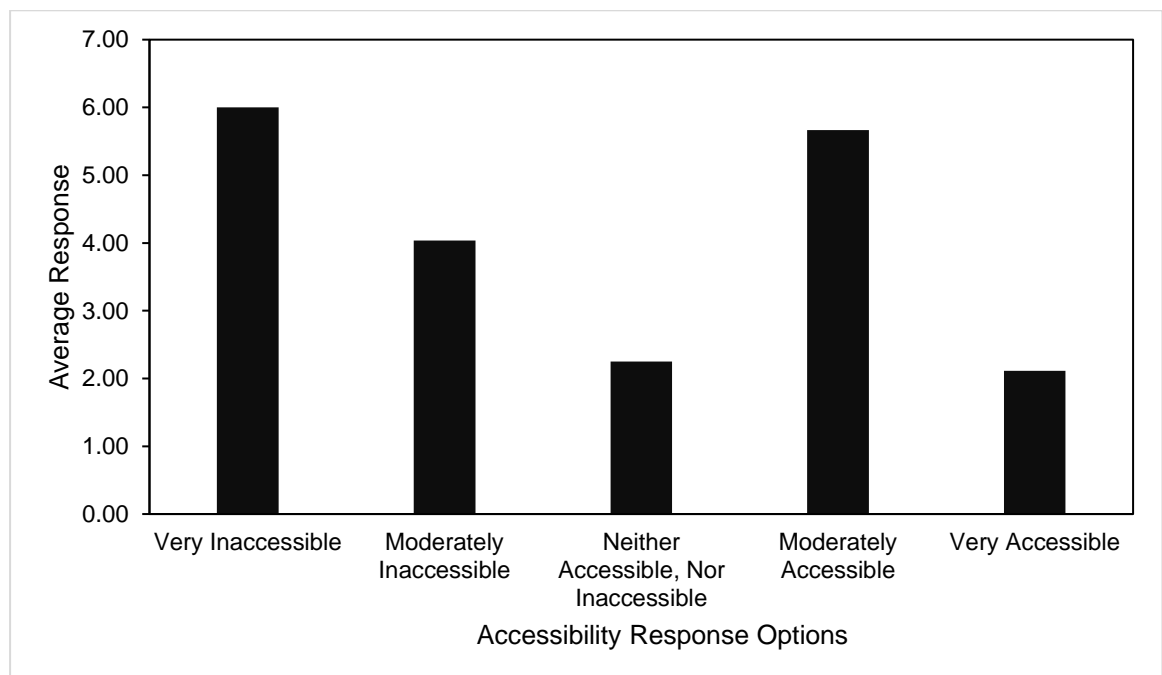


Figure 4. Mean responses of perceived Accessibility across Diagnosis, Education, Living in the Community, Family Life and Managing Transition themed sections.

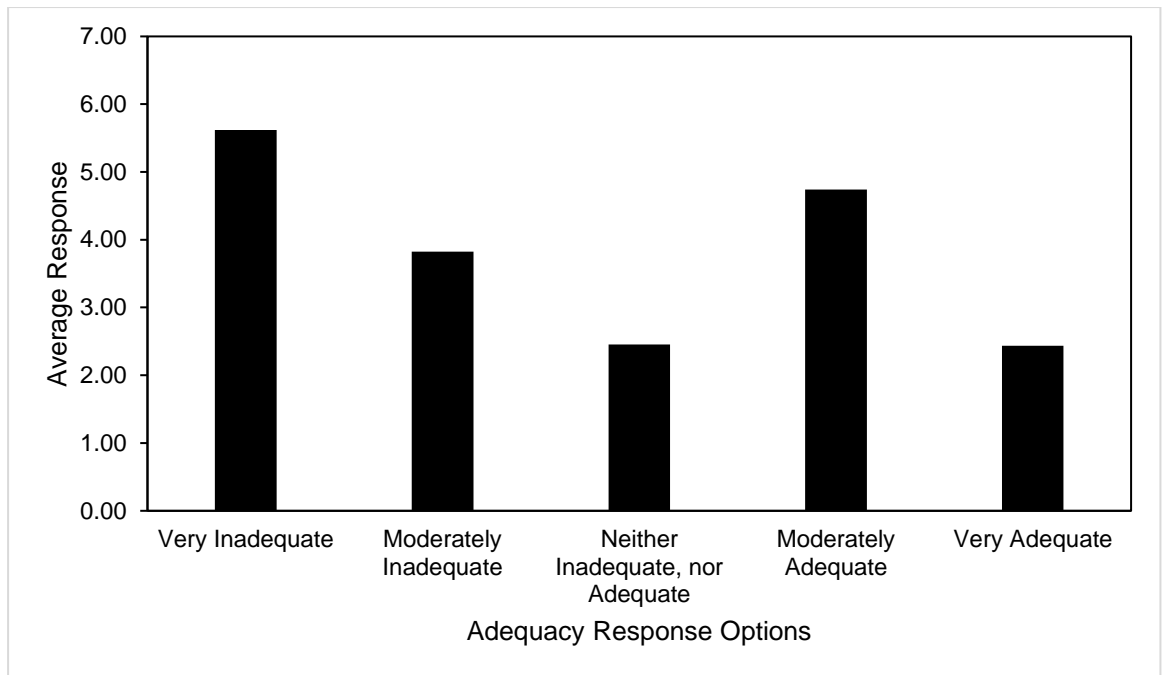


Figure 5. Mean responses of perceived Adequacy across Diagnosis, Education, Living in the Community, Family Life and Managing Transitions themed sections

As shown in Figure 6, the construction of the graph for the Appropriateness construct from the themed sections did not present the same bimodal characteristics in the data, as the mean response for Appropriateness tended towards being moderately appropriate.

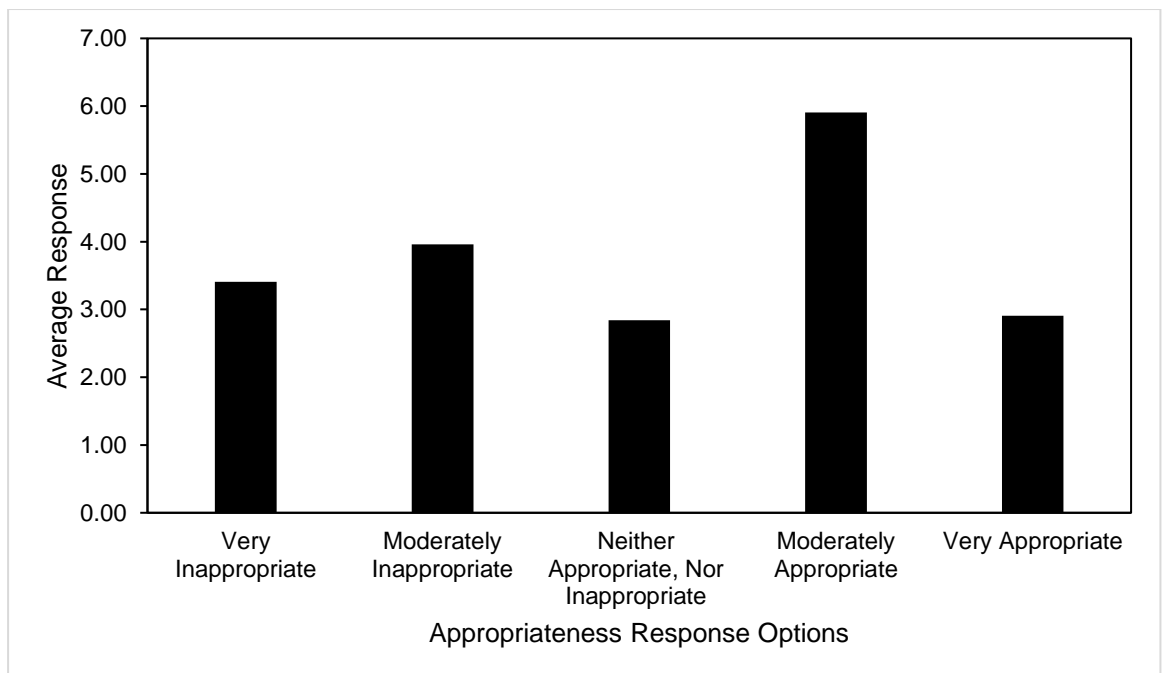


Figure 6. Mean responses of perceived Appropriateness across Diagnosis, Education, Living in the Community, Family Life and Managing Transitions themed sections

Table 8 shows the number of participants who responded to questions posed in each of the themed sections regarding Appropriateness, and the mean responses for each of these items. Many of the items had small numbers of responders and it was decided that little could be concluded from these responses as a result. Of the items that had larger numbers of responders, all averaged around the middle of the range.

Table 8

Mean ratings of Appropriateness across service delivery themed sections

Source	N	Mean
Diagnosis		
Assessment period service delivery	33	3.09
Assessment process	33	3.06
Post-diagnosis support	33	2.76
Education		
Education programmes	23	2.78
Behavioural programmes	21	2.57
Sensory needs	16	2.75
School citizenship	19	3.37
Respect for neurodiversity	22	3.32
Living in the community		
Recreation and leisure	12	3.50
Personal interests	6	2.33
Friendship support	7	1.57
Close relationship support	2	2.00
Work related interests	2	1.00
Family Life		
Financial assistance		
Child	24	2.50
Family	24	2.54
Professional advice	22	3.41
Respite care	15	2.40
Child care	7	2.86
Physical therapies	10	3.50
Speech / Communication therapies	22	2.77
Behavioural intervention training	19	3.16
Sensory management	11	3.36
Sibling relationship support	5	2.80
Sibling support	5	3.00
Caregiver companionship support	7	2.71
Family social support	3	2.00
Emergency support	1	1.00
Doctor visits	16	3.56
Medication consultation	17	3.41
Managing transitions		
Transition supports	25	2.76

Qualitative results

Acknowledging alternative language and perspectives

Despite openly stating in the research process that three constructs (appropriateness, adequacy, and accessibility) were being utilised to investigate how individualised services are, participants sometimes resisted their use in classifying the concerns they had, preferring other language, or the use of other perspectives, to articulate the problems they faced.

Accessibility. ‘Accessibility’ was used as a construct to draw attention to the degree of ease in which caregivers were able to initiate service delivery, given their own unique family circumstances. Participants mostly accepted the label of ‘accessibility’ as an appropriate way to describe events that occurred prior to service delivery taking place, although sometimes ‘funding’ was seen as a better descriptor.

Researcher: So, most of those kinds of things [access to counsellors or therapists], there are accessibility issues?

Participant 1: Yeah, funding issues.

Accessibility was also related to discussions around awareness, as awareness, or lack of it, could influence accessibility.

Adequacy. ‘Adequacy’ was used as a construct to draw attention to the volume, potency, length or duration of service delivery. Adequacy was also both accepted, and challenged, as a way to describe service shortfall; ‘funding’ was also seen as an underlying reason why a service ended prematurely.

Participant 1: I think it’s a funding issue. They have to fund something specific, and obviously there are tonnes of other people, with all sorts of other things, and they have to fund them as well. So we have to maintain that, day to day. I think a hang of a lot of it comes back on the parents.

Participant 5: I would say they are underfunded, and stretched by the seems a bit.

Yeah, that was my impression. She gave us as good as she could, in the limited time available.

Appropriateness. Appropriateness was used as construct to draw attention to family ecological fit of service delivery, through variances in culture, religion, and world view. It also incorporated the ethical standards to which service providers operate under. When raising service delivery concerns which appeared to be ethical in nature; addressing the degree of suitability for ASD service receivers, or the extent of family ecology for service provided; participants often used ‘appropriateness’, or ‘inappropriateness’, as descriptors,

Participant 3: Look, I’ve had such inappropriate stuff from people, from being asked out, to, you know? I used to prefer to work with women, it’s just silly, not so much now that I’m older, but ten years ago, I was a lot younger and a lot more vulnerable. How much more can you step over a line? It’s happened twice

Participant 7: I felt, very strongly, that the service being offered by this paediatrician to assess my child – they were setting it up to fail, by not turning up on time, by offering a little waiting room that was totally inappropriate, then having a child on the spectrum wait, and wait, and wait, and thinking they can do an accurate and fair assessment.

Other participants preferred other language to frame their concerns; Participant 4 sometimes chose to use ‘acceptable’ or ‘unacceptable’.

Participant 4: He wanted, therefore we should give it, and you know, at one point when we had the really bad social worker involved, she was basically saying that we should give the money, and someone else should sort it out for him; we could just be the person who pays, and we wouldn’t have to have any contact, he wouldn’t have to ask us for things, he wouldn’t have to acknowledge that we had given him stuff, and

he wouldn't have to thank us for it. We would just keep handing it over, I didn't think that was acceptable.

Participant 3 used 'professionalism' to articulate the issue of appropriateness,

Participant 3: well, to me, this is professionalism! I have had heaps of really inappropriate behaviours, I felt. All throughout all of the services.

Diagnosis as a process

The theme of diagnosis featured prominently in many narratives shared by participants, both in terms of the volume of data collected on the topic, and also the primacy it held in their views, and experiences. Although diagnosis is recognised as a key event in the lives of those on the spectrum, and their families, it is also useful to consider it as a process - a number of step-like contributions from both family members, as well as professionals, that are made throughout the diagnosis journey over a variable period of time. While no two experiences of diagnosis were identical in the data collected, many carried similar characteristics.

Something isn't right. The diagnosis journey, for most participants, started long before seeking consultation with healthcare professionals; it was often the case that caregivers observed over time that their child was not developing as they would expect, or was displaying behaviours that were considered outside the norm. The issues raised by parents underlined both their deep concern, and a desire for what was best for their children, in terms of their safety, wellbeing and progress,

Participant 5: [my son] was always quite obsessive about water play and things like that; and when we moved [here] 5 years ago, he was having kind of big meltdowns, hitting himself in the face and he was sort of; you couldn't get through to him when he was in this state, it was quite worrying.

Participant 7: I picked up immediately, from birth, that something was different. But it becomes difficult to say what is normal, what is abnormal at birth because you are constantly being told that, “they achieve at different levels, don’t worry, every child is different, don’t worry, don’t worry”.

For me, it probably wasn’t until the child, she reached two and a half? Because we were living rural, on a farm, so I had no interaction with playgroups, or anything like that. So about two and a half I got particularly friendly with a woman who had a child about eighteen months younger, a year to eighteen months younger, and it obvious to me that there were developmental delays in my child that weren’t happening.

Seeking confirmation or diagnosis. The most common narratives shared that as behaviours, and development, continued to be outside of the norm, caregivers frequently sought confirmation and validation of their concerns from healthcare, and educational, professionals. Some parents sought to have their suspicions confirmed about their child having ASD specifically,

Participant 5: I had long suspected that it might be the case, and I talked online to people about certain scenarios, like my child having night terrors, or whatever, and just getting feedback and thinking, oh my gosh that does sound like [ASD].

Participant 9: Particularly, as his mother, I knew that [...] it was case of trying to do the detective work; and basically, in both cases, the diagnosis was because we, or I, basically diagnosed them. I went out there and researched and found out what might explain, and it was only confirmed by paediatricians.

Other parents sought confirmation, in broader terms, that things weren’t as they should be,

Participant 3: Two years old, I went in there because he wasn't speaking. We had gone to the audiologist, that was great, but there was no lead up to this diagnosis.

Participant 7: So I spoke to the Plunket Nurse who had been the provider of that Well Child care from birth, so it was the same person; I guess because I was a healthcare professional, and we worked together before the baby was born, I was able to say to her, "this child is not normal, when can we access services for an assessment?"

Delays in diagnosis. One of the most often mentioned aspects of service delivery raised by participants, was the considerable delay experienced before receiving the diagnosis. Although accounts varied, delays in securing a diagnosis ranged between several months,

Participant 6: it was just a slow process, it probably took, oh six months or more, which seems slow to me, but probably wasn't, with some people, I know their diagnoses take a lot longer.

To several years,

Participant 9: two of my four sons – my eldest and my third [both were diagnosed with ASD], and part of the problem was that they were diagnosed very late. For my eldest, he was finally diagnosed about the age of twelve, even though we knew there was something about him [since he was a baby], and there were multiple opportunities, particularly through the health system, that could have picked it up much, much sooner. And in my third son, he would have been about fourteen [...] when he was finally diagnosed, so late diagnosis was part of the massive failure that has been out there, for this particular family.

Waiting lists. Despite early intervention being widely accepted as vital for adjustment, intervention efficacy, progress, and long-term outcomes, most participants spoke of delays in diagnosis, and in other forms service delivery, and in doing so, often expressed a sense of frustration,

Questionnaire participant: I first brought my concerns to my Plunket Nurse when [my daughter] was 18 months old. We were dismissed and told the assessment wouldn't even get looked at until she was 2. We finally got a referral at 2, but didn't get access to services until 2 1/2. Then we finally got a diagnosis at nearly 3. Then we get drummed into us how important early intervention is!? Seems pretty backward and was incredibly frustrating.

Often participants shared how long delays on waiting lists meant that the need was addressed by alternative means; whereas other times a concern became more deeply entrenched, and became harder to resolve,

Questionnaire Participant: Applied Behavioural Analysis waiting lists were so long that by the time we got a person, the behaviour was resolved.

Participant 2: yeah he's got severe sensory issues, and we did a feeding therapy when we first moved here, but that just made it worse. They think it (the feeding therapy) was left too long.

Differences in waiting lists were also said to emerge from different DHB areas,

Participant 7: It was definitely the Speech Language service that couldn't even see us within a couple of years, and by this stage we had moved to [the new DHB area].

When the [former DHB area] speech language person contacted me, I had to say that I had moved to, and then she did a referral [for the new DHB area], who clearly didn't have huge waiting lists, and someone came to see us straight away.

Barriers to diagnosis. Participants offered a number of reasons for the delays they had experienced in securing a diagnosis for their children, prior to any service delivery being able to take place. Although the nature of the perceived barriers varied across participants, a common strategy to overcome barriers was to 'go private', as is demonstrated by different

participants in this section. One form of barrier reported was the number of sequences, with several professionals, that were required to get a diagnosis,

Participant 1: First of all it had to get a referral through her kindergarten, and then someone came and assessed her, and it went somewhere else, and then we had to go through the GP, and then we went to a speech therapist who referred her to the psychologist, and then, No. Speech therapist then the paediatrician at the hospital and from the paediatrician at the hospital, to the only person who could give the diagnosis was the child psychologist. That took a year.

Another barrier demonstrated was the reported lack of engagement, or follow through, from healthcare professionals; this exacerbated their goal in seeking clarification, or conformation, regarding their child's symptoms,

Questionnaire Participant: It would be helpful if the public health system had a particular department to deal with children with ASD. I found [the local hospital] really unhelpful and a complete waste of time. I have since placed two formal complaints about the way they treated my family. We ended up paying for a private diagnosis.

Questionnaire Participant: I have a daughter with autism, and we were the ones who initiated the diagnosis. I could hardly get a referral from the GP. After we were diagnosed the Public health nurse told me that she suspected something like autism, but she never recommended we go see the paediatrician.

Other participants shared how services to facilitate diagnosis were not available where they resided, and that isolation made it difficult to access; both in terms of periodical visits from outside clinicians, and visiting clinicians from other areas,

Questionnaire Participant: We don't have a diagnosis team in our area and there are not enough SLT (Speech / Language Therapists) or OT's (Occupational Therapists),

and the clinical psychologist travels from [quite a distance] (she is absolutely amazing - I cannot speak highly enough about her) so the waiting list is ridiculous - we waited 8 months to see her with our son but we have been waiting over 12 months to see her with another child

Questionnaire Participant: There were no support systems available when we went through the process of getting a diagnosis. The paediatrician didn't want to know so we ended up seeing a child psychologist privately over 300km from our home town, at our own cost.

Another barrier to decisive consultation and diagnoses being conducted, was the lack of training in current practice for assessment, such as the ADOS (Autism Diagnostic Observation Schedule) assessment,

Participant 5: So I took him to the doctor, we got a referral to the hospital paediatrician, we actually ended up seeing him twice over a couple of years; and both times he said, “no, he’s not on the spectrum”. The second time he said, “he looks at you, he makes eye contact, and he talks, and he smiles, so no, he’s not”. There was clearly something wrong; very, very wrong, and it was just the old school thinking of: if you aren’t rocking in the corner, drooling, you’re fine. You’re either autistic, and severely autistic, or you’re fine, there is no middle ground. Yeah.

Implications of receiving a diagnosis. Securing a diagnosis has the potential to change much for an autistic child, and for all parties and systems connected to an autistic child. The impact of diagnosis on people is discussed in the next section, while here the meanings and consequences associated to diagnosis, as a process, are discussed next.

Diagnosis is a gateway to assistance. Diagnosis was consistently reported as more than just a psychological process, and as a service in, and of itself. Rather, the diagnostic

label that is applied to a child post-diagnosis was seen by participants as being the bare minimum required to unlock further services.

Participant 5: Without a diagnosis you miss out on help, you miss out on potential Disability Allowance, you miss out on respite care, you miss out on help at school.

[...] Some children are perceived as naughty and disruptive; it's just quite important.

Although diagnosis reportedly opened service delivery doors for some, it did not do so for all, as participants reported both on the supports, or lack of supports, offered post diagnosis,

Participant 6: I think there really was [a need for support post diagnosis], I struggled a long time by myself. We've only just seen someone from [a specialised behavioural support service] in the last few months, and this is like a year and a half, two years on, and that's sort of been the first help that we've had. I know there are people out there needing help more urgently, but yeah.

Participant 7: She (diagnostician, post diagnosis) made herself available, gave us a list of community things that we could access. She totally supported our application for her to be home-schooled, even though the Ministry of Education's psychologist did not support it.

Who should I tell? Disclosure, stigma and labelling. The usage of diagnostic terms is double-edged; while it can be important to put a name to challenges people with autism face in order to be able to organise supports to assist them, it may also facilitate stigma, and exclusion from the neurotypical general public. Participants often told their immediate family, and sometimes professionals, of the diagnosis given to a child, yet also sometimes chose to hold back the diagnosis from others, for fear of a label causing their child being prejudged and restricted,

Participant 1: I didn't tell people, I didn't tell – apart from my family, and the teachers at school knew, but I didn't meet people and say, “this is my daughter, she has Asperger's”, and I found in my research that the people that did do that, that was there way of mitigating the behaviour of the child, so they would automatically say to people straight away, “oh, my child is on the spectrum”. I did the exact opposite, I didn't want to tell them, because I didn't want them to put something on her straight away, “oh she is going to act like this, this, and this”. So I just didn't tell them.

Researcher: Prejudging and giving her.....?

Participant 1: Yeah, yeah. The labelling thing.

Participant 6, in particular, demonstrated how parents could be selective of who they told outside of the immediate family, as she chose to tell a theatre group of her son's diagnosis, yet also chose to withhold the same information from her son's martial arts instructor,

Participant 6: Yes. I told the guy that runs it (the theatre group), about [my son], right from the beginning.

Participant 6: He does [martial arts], he's done that for the last couple of years, which has been good for his confidence, but, I didn't tell his instructor, anything about his autism; I just said he is not a very confident kid, when it comes to other kids.

It was also shared that in some situations it was considered necessary to explain to others a child's diagnosis, such as a dentist's visit, where safety concerns were present. The importance of safety was also spoken of in tandem with Participant 6's own knowledge of her child, admitting there were possible reactions or outcomes that she could not foresee,

Participant 6: The doctor he is not so bad with, because he has been there more. The dentists are different story, especially when they get their little tools out – no one likes

the dentist anyway! They would be his more anxious times, and I have found that they are pretty good here, but I do have to explain to them.

Participant 6: Or something else goes wrong, I'm not saying I know every inch of his behaviour, because there might be times where he would react, and I have never seen that reaction before, because we have never had that happen, whatever has led up to it.

Collective impact of diagnosis

Having a child diagnosed on the spectrum holds a number of consequences for caregivers, their relationships, their families, their social connections, and the broader community. However, each of these stakeholders does not share the same degree of interconnectedness with the autistic child, and therefore, each is likely to be impacted by the diagnosis in very different ways.

Impact for child. The most immediate impact is for the diagnosed child, as the lives they lead are often very challenging because of symptoms that they have, and the degree of awareness and acceptance, or lack thereof, of the parties listed above.

The 'autistic' label, and the disclosure decision. Diagnosis, for an individual with autism, means a label, or a term, that will arguably be with them for the rest of their lives (given there is no cure for autism), which facilitates healthcare and other professionals to provide services appropriate within this classification. Children with autism may find that there is explanatory power in diagnosis towards understanding how they might be feeling and thinking differently than others. However, some on the spectrum are not necessarily aware (from not being informed by others), or are unable to comprehend how they might be different from others because of their uniqueness.

The decision about what to tell autistic children themselves was conveyed as a delicate one to make by some caregivers. Information that autistics received about their own

diagnosis could be perceived and put into practice in different ways in their day to day lives, which could empower or shame, enable or inhibit.

Acceptance and rejection of own diagnosis. Having the decision made to disclose the diagnosis to their child, caregivers shared that the information was important to impart in terms of clarity, volume, and age appropriateness. Sharing such information was thought to equip an autistic child with a healthy sense of self, while also helping them understand that others may think, act, or process aspects of life very differently. According to Participant 4, the professionals in the disclosure process in Aotearoa produced a sense of vagueness, did not convey information effectively, and lacked insight into life consequences, which was below the level of service she had received abroad. Looking to the future for her son, sequential connections were also drawn between diagnosis, disclosure, acceptance, and ‘moving on’ with life. However, moving on with life had since become problematic, as rejection of diagnosis from the young person coincided with a rejection of support services. The dilemma of helping someone with complex needs, who doesn’t want to be helped, is also raised,

Participant 4: when we received our diagnosis [abroad], it was very clear. They told us precisely what they found, how they found it, and they told us what the likely prognosis was; and while that was hard to hear, you know at least you are standing on solid ground with it.

Participant 4: The vague discussions that I had here, and the lack of information to parents, it’s really, really hard. And when you have an older child, the lack of information given to the child is also really difficult. My son refuses to accept that he’s got ASD, he actually told [his psychiatrist] that while he respected his opinion, he was wrong. And that is really difficult, if you do not accept that you’ve got ASD, and you therefore don’t accept services, and the way people behave toward you is so incomprehensible, how can you possibly move on? I think that what needs to be done

with a young person, who has been diagnosed, so that they understand why the diagnosis has come into place, and the impact that that is going to have on their life.

Although her son was not in the same state of denial, Participant 3 shared how he was able to detect he was different from others, and how he resisted his diagnosis and didn't want to be grouped with other children on the spectrum. Furthermore, his efforts to be with neurotypical children were shown to be damaging to him, despite the lure of being with those he felt drawn to. Resistance to be socially involved with autistics, and being drawn to those who are neurotypical raises the issue of where children feel they fit in, and how variations in diagnoses affect self-identity,

Participant 3: They (Autism NZ) do bowling, they've got groups for kids with disabilities, but my son doesn't want to have a disability, he doesn't want to have autism, he doesn't want to have a disability. He hates having autism. He is not autistic enough to go, or whatever, he hates it, he is aware that he has something different, and he is desperate to be like any other kid. So he doesn't want to go to these groups.

Participant 3: The thing is, people that he can get attracted to, are the people that you don't want him attracted to, you know. They will 'utilise' him, because he loves scootering, so a couple of them have 'utilised' him for his scooter parts. I say 'utilised' in a really nice way. There are just a lot of really mean kids out there, and kids like mine are vulnerable to that. So, communities, you're torn between letting him go, and possibly getting hurt, and keeping him wrapped up.

However, rejection of their own diagnosis did not occur in all circumstances; in contrast, Participant 6 recounts her decision to delay telling her child about his diagnosis, and how the assistance she received greatly helped to strike a balance between what might be helpful to the child, while avoiding what might lead to self-limitation, or hurt. Furthermore, pride in being autistic was found by her son,

Participant 6: I had written on the board that we had an appointment with the paediatrician, and he's going, "why do I have to go to there, I'm not sick"? And I think, oh shit, what do I tell him? Because I had never told him up to that point. I thought, shit, I don't know what to say; I said you're going to have a check-up every so often, just to make sure everything is alright. So I went to [our Ministry of Education support worker], and said, "what do I say to him"? So she gave me a DVD to play to him, without me having to explain to him, without going into too much detail, because I didn't want to tell him too much, but I wanted to tell him enough, so she helped me with that.

It cracked me up, he thought he was so special, to have autism, and he couldn't wait to go to school with the DVD, and play it in front of the whole class, so he is not shy about it! He doesn't think it is a bad thing, he was actually quite proud of it.

Although acceptance of diagnosis did not prevent all the frustration her child felt, acceptance was thought to at least provide a foundation to work from when her son struggled from time to time,

Participant 6: [Since then] he has been pretty good, the odd time since he has yelled at me, saying, "why do I have to be like this"? Because I think sometimes he doesn't quite understand how he is feeling until we sit down and talk about it, but I can't do what with him until he has calmed down.

Such differences between such instances of disclosure raises questions about differences in skill level in professionals and caregivers, the variability of ASD, the variability of social identity, the complex and changing nature of symptoms as children age, and just how challenging it might be, in order to be effective as a professional during disclosure.

Impact for caregiver participant. The complexity of the impact that diagnosis can have was reflected in the personal impact that participants, predominantly women, experienced, as they were able to draw upon their own unique, and sometimes contradictory, thoughts and feelings as caregivers of children having received ASD diagnoses. Combined, the variability of the following responses suggests that healthcare professionals need to consider the individuality of each family, and how each family's reactions may vary widely from the next.

Emotional impact. The deeply emotional impact, as experienced by some of the following participants, could explain why some assessors might be apprehensive in an immediate, full dissemination of findings, even if it is preferred by many caregivers. Participant 3 described her experiences as being traumatic, and of going into physical shock upon hearing the diagnosis; not only because of the nature of the diagnosis, but how the diagnosis was disseminated, given her particular circumstances,

Participant 3: I was a mother, in trauma, yeah, I was just a mess. That was my first introduction into all of it, I had to go home and process it. I was on my own, I was actually physically in shock. So I have an issue with how that service is provided, for a start.

My mother actually had to fly down, and my sister had to fly down and look after me, I was, I went into shock, I couldn't function. I couldn't do anything, it was a really horrific experience, which of course starts you off on this series of experiences, so, for me, right from the beginning, right from that first diagnosis, I was just told – bang. I remember just grabbing my son, and holding him to me, and walking out.

The importance of an assessor being mindful of the person's circumstances when considering the best way to deliver the news is additionally demonstrated by another

participant, who reported the strain as being the cause of gaining a permanent medical condition,

Questionnaire participant: The time of diagnosis was so stressful that I ended up with a permanent medical disability. Wish there had been more support.

Participants also reported how the diagnosis, whether they suspected ASD or not, was a very emotionally charged experience, and many reported being reduced to tears,

Participant 1: I was upset about it, I cried. Because that's what you thought it is, but hope that it's not. You know, you hope they're gonna go "no actually, it's something else", and "they'll grow out of it", and they don't.

Participant 2: I actually didn't know anything was wrong with him, I just thought he was a little shit. I was really upset, I cried, and cried, and cried, and cried, and was so upset. I rang my dad as soon as I left, walking down the road, bawling my eyes out, and, Dad just said to me, "you know, well, it's what it is", and I said to him, "I don't know if I can do this".

Other participants described the post diagnosis impact as grief, or a grieving process, as life post-diagnosis was foreseen to be very different to the life first imagined,

Participant 4: it's almost like a grief, because they didn't hold out a lot of hope for him at that point. He was quite severe then, and then they told us he would find it difficult to hold down a job, that he probably wouldn't have a sense of humour, that he wouldn't be able to play team games; that our life was going to be very, very different from the life that we had planned. That was hard, and we went through grief, but they were very, very supportive.

Participants also reported how the diagnosis received made them feel fearful, or uncertain, of the future; and raised doubts about their own ability to cope with an unexpected and unknown future.

Participant 6: Initially the diagnosis, for me, was quite scary, my husband, he had done the runner by then. It was like, "oh my God, my worst fear, of being a solo mum, has come true, and now I have a child that's going to be challenging for me, am I going to be able to handle this"?

Participant 1, in particular, highlighted the anxiety that came with a perceived loss of possibilities that caregivers expect, or hope, their children to be able to achieve. The perceived severity of ASD is articulated here by comparing ASD to cancer; although very different things, some aspects of ASD, such as the course, elements of control, and predictability of it, were viewed as being worse than cancer as parents were placed in a seemingly new world with no clear protocols,

Participant 1: It's all the uncertainty; are they ever going to live by themselves, are they ever like, going to get married, or have children? Everything changes.

Everything changes! And it's not a medical condition, like cancer, where you can go, "Ok, well, there is a protocol to follow", so, "ok, you've got this, it's in your body, we're going to go have an operation and take it out, have chemotherapy", it doesn't work like that, you don't know what the future is going to look like. Most people haven't dealt with the huge range of professionals, and neither had I.

Delayed and ongoing impact. Although many participants recalled how upset they were immediately following the diagnosis disclosure, for some the greatest emotional turmoil was delayed,

Participant 1: And it's still impacting, it's not something that goes away, maybe it does with other people, you're only one person – other people deal with things differently. But the actual diagnosis, at the time it was kind of like, "nnngghh" (lesser response) and then 24 to 48 hours later, it kind of kicked in.

Furthermore, emotional upset relating to the diagnosis was not restricted solely to the period immediately following diagnosis; rather, it was reported to be an ongoing process.

Participant 1 outlined how the initial emotional turmoil is revisited as time passes, as typical lifespan events occur with other children, but not necessarily with her own child,

Participant 1: Its ongoing, so, you'll go through a period of time, and then something will happen, and it'll cause you to grieve again, well for me it does. So, she's just hit Intermediate [school] and now I'm starting to see the other girls, because she's a girl, are becoming more teenager, and starting to get interested in boys, and stuff like that; and she's still interested in My Little Ponies, so, that's another stage of grief.

Participant 9's account differed in that she experienced relief and optimism initially, but like Participant 1, she also shared how her personal pain came later on as her son opted out of school.

Participant 9: with our elder son, it was different, it was probably a relief – that now there was an understanding of what it was, that that could be helpful, and I was optimistic. The agony came later when he stopped going to school.

Relief and vindication. In contrast to emotional turmoil and grief, participants also frequently articulated a sense of relief that came with confirmation of diagnosis, after a period of anxiety associated with both suspicion of something being amiss, and the unknown. For the following participants, there was a sense of relief, or vindication, that their concerns were legitimised through diagnoses.

Participant 5: it was more of a relief, and sort of a vindication that I wasn't just some crazy mother, making up some wild story. It was mostly just relief really.

Participant 7: I have to say, sitting outside, I kept thinking, "she is going to come out and tell me she is normal". "This is going to be another waste of money, and time"; and I have to say, I felt nothing but relief when after I sent the child out to the car, her

father was waiting, and she said, “she is clearly different, isn’t she?”, and I thought, “yay”.

Questionnaire participant: I think that there was a lot of stress in the lead up to diagnosis as I was questioning myself as a parent, but after receiving the diagnosis (via public system) and how help could be attained, it was a relief.

Given the etiology of ASD is widely regarded as neurobiological in nature, another positive impact was a reported sense of vindication, as diagnosis was shown to act as a counterpoint for blame from others, or self-blame, as a child’s behaviours weren’t a result of bad parenting,

Participant 4: One of them was that [my son] had very clear problems from birth, and when diagnosed it helped us to know for sure that it wasn’t bad parenting, it wasn’t that we were doing something wrong, it wasn’t that we weren’t capable.

The positive impact of diagnosis was also articulated as both as an answer, or explanation, to past events and behaviours, and a starting point to the future,

Participant 8: I think it gave me an answer to know what was wrong with her, and working out where you went from there. I think you go through the thing where, “yep, well, what am I going to do, how am I going to deal....”?

Spousal impact. Alongside caregiver participants, who were predominantly women, the most immediate impact felt following the autistic child themselves, is that of a second caregiver, who were predominantly represented as men, who were husbands or partners. Gender differences were reported between parents, as males and females were reported to react differently to diagnosis. For one participant, the impact of diagnosis also included the immediate loss of spouse,

Participant 2: I went home and talked to his dad, and his dad packed his bags and left; “I’m not prepared to be the father of a special needs child, that’s not what I signed up for”, and it’s the last time we saw him.

In another parental relationship, the mother doubted that the father of the child had come to terms with having an autistic son, even several years later, which suggested different coping strategies have been employed over time by each parent. Such differences in strategies highlights the differences in gender norms for parenting,

Participant 6: I don’t even know now whether he has [....] come to terms with it. But [my support worker] told me that that would happen anyway, that most men do struggle with that, but women get on with it, because we have to, it doesn’t stop for us, we haven’t got time to wonder about it, you’ve just got to move ahead, so that’s what we did.

The role cultural norms play in parental impact was also raised within the context of ‘Kiwi’ (New Zealand) culture. Typical expectations regarding fathering, and father engagement; and typical expectations of childhood, and the expected feedback from a child; all had to be rewritten, as the reality of the present situation did not align with the expected ‘Kiwi’ norm. According to Participant 1, this meant that father’s expectations of interaction and play had to be realigned to what their children were actually capable of doing,

Participant 1: But I think for a lot of Kiwi males, especially if it was a boy, there would be issues. Because they have ideas in their mind, you know, they are going to play rugby, and do this thing, and the next thing, and the kid just can’t do them.

Spousal relationship. While previous sections address the impact experienced by individual caregivers, this subsection focuses on the relationship between caregivers, predominantly mothers and fathers. For those who commented on their marriages, or other forms of union, diagnosis took its toll and was described as a stressor,

Questionnaire Participant: very little if no support available when going through this with your child. It is extremely hard on the family and has caused us a lot of stress in our marriage.

Participant 4: This is the way we live, and it's devastating for [my husband]; I honestly think that most people's marriages would have failed at this point.

Narratives describing the stress experienced in caregiving relationships also posited possible avenues of support; the most common avenue being couples counselling. However, what was talked about as 'Kiwi' culture, and expectations and preferences which Kiwi men were supposed to align with, suggest that counselling was not expected to be fruitful resource for relationship assistance,

Participant 1: if they said, when you got the diagnosis, you are allocated, as a couple, because it does affect marriages - as a couple you are allocated, or we are going to give you five hours of psychology time, for the siblings they can be allocated x amount psychology time, or counselling time, or counselling might even be better than psychology. But something for the whole family, because it affects the whole family. And I'm sure you have read the statistics of couples on the spectrum.

Counselling, couples counselling, totally, yeah. Huge. My husband is from overseas and so he would probably have a different take on it than possibly a Kiwi male.

[Men] don't get a chance to work through their feelings, they don't get the chance to talk it through, or they never had to go to counsellors, or used one, again, because Kiwis and counsellors (doubtful sound) type of thing?

Sibling impact. In theory, after caregiver parents, siblings of children with ASD are next in terms of immediacy of impact of diagnosis. Siblings can be challenging for each other at the best of times, without adding a disorder which is defined by differences in thinking, processing, and communication. For neurotypical children, who are often conscious of being

like everyone else and fitting in, having a sibling who is quite different was sometimes perceived as a source of embarrassment.

Participant 1 observed how she, herself (as an adult) was impervious to such embarrassment, but her neurotypical daughter, being at a different developmental stage, was susceptible to embarrassment due to some of her sister's behaviour in public. However, the neurotypical daughter in this family could assume different kinds of roles, depending on the place and circumstances: from embarrassed teenage sibling when out with family, to an empathetic staunch defender from others at school when her parents were not present,

Participant 1: She (older neurotypical daughter) like doesn't like going out in public with her, so if we are going to go out and do something, I think this is a teenage thing too, coming from a teenager.

She says, "no I don't want to go out with her", because if she has a meltdown in the store, [...] our other child, standing there embarrassed because she feels like she is being judged. I have got to the point where I'm relatively impervious to people judging me, but she's 15. So she is very aware that people are looking at us and like, "oh, that mother can't control her child", because she's down on the ground. It has affected her. I think because we have a good mother-daughter relationship, and she'll tell me, "oh mum, I'm embarrassed" or, "actually I find this really hard", or [her sister] is having a really hard time at school it'll affect her too, because she is quite empathetic, and she gets defensive about her. You know, "who told you that, I'll go and find them".

For some, delineating between sibling impact, or inter-sibling issues, and other potential sources of turmoil was problematic. Participant 2 spoke of the age gap between her children, and how her neurotypical daughter struggled with her younger brother, and

questioned how much of the struggle was due to him being on the spectrum, and how much of the struggle was due to other factors – such as difference in age,

Researcher: has there been any need for support between the two of them? For a sibling relationship?

Participant 2: well, there isn't one

Researcher: there isn't one?

Participant 2: No. I don't know if it's because of the autism – there is a large age gap as well. There's nearly 9 years between them, so, she just doesn't cope with him, she just doesn't understand why he does what he does. She's also got a child of her own, you know we spent more time directing, him away from [his niece], then. Although, developmentally, they're probably the same level, and so when they are nice together, they get along really well, and my granddaughter enjoys it. But then he can flip his lid, anytime, without any warning, so it's hard to know....

Similarly, the distinction between an ASD diagnosis impacting a sibling, and other factors impacting a sibling was discussed by Participant 4, who demonstrated the difference between ASD meltdowns (from not being able to cope), and deliberate physical abuse by her autistic son, which were discernible to both siblings and parents,

Participant 4: I think that during the time that we were just dealing with normal ASD frustration meltdowns, that it was manageable, because that's what my other kids have always known, and because he was physically smaller, and it was easier to contain. But as his frustration increased, and his anger increased, his behaviour became more deliberate, you know, he was making a choice to be violent, and he was making a choice to be nasty, that was different.

The children knew the difference, they knew before that when he was having a meltdown that they could walk away; yeah, it was loud, and yeah, it was scary, but

you know, it would soon be over, and it would be ok, but it got to the point where the violence and the abuse towards them was relentless.

Family impact. Families are often viewed as systems, and participants spoke of the family as collective, the components or subsystems within the whole – and what implications diagnosis held for a family as a system. Participant 1 reflected on how family life, and family identity was imagined, and geared towards particular ways of living, and specific goals; yet an entire family's direction can be altered significantly with diagnosis of one of its members,

Participant 1: Your whole family identity – a lot of people don't realise that they have a family identity, but people generally with their children, and the way that they run their families are working towards a certain goal, and suddenly their goals disappear, and you don't kind of know what to do with it.

Similarly, the complexity of ASD manifesting itself so very differently among those on the spectrum was also connected to how different one family with an autistic member could be from others,

Participant 4: You know, this is not solely about, the child that's received the diagnosis. If you have received a diagnosis, that your child has autism, or ASD, every single aspect of your life will be different from the next family's.

Participating in society (inclusion and exclusion)

Increasing the wellbeing of those with autism has historically been promoted as the need to promote 'autism awareness'; yet more recently calls have been made, especially through self-advocacy networks, to transition public awareness to public acceptance and inclusiveness of autistics (Kassiane, 2012). Having received a diagnosis for a child, caregivers are then tasked with the wellness promotion for their children, within the context of each family, by trying to help children do what other children typically do, as well as

possible; such as, get an education, explore interests, have friends, have the chance to part of a broader community, and have the opportunity to grow into their best selves.

Barriers to societal participation in the following subsections are argued to have both an absence of individualisation (especially the constructs of accessibility, appropriateness, and adequacy), and a systemic foundation (as articulated in the following section), as illustrated in Figure 7.

Role acquisition. Coverage in the following subsections draws attention to several additional roles (outside that of a typical caregiver) that participants were expected to assume, or had to assume out of necessity, in parallel to the services provided, or the services absent. For the various roles that were negotiated, participants often remarked on their own limitations to fulfil them. For example, Participant 9 struggled with expectations to be a therapist and teacher, on top of being a mother,

Participant 9: I can only be their mother though, I can't be their teacher, their therapist etc. I'm not equipped to do that, as I have to work to support the household.

Whereas Participant 8 grappled with (among other roles) medication monitoring with various psychoactive medications, which placed her in the position of acting beyond her capabilities in a situation that was laden with risk,

Participant 8: [I was told to] use it as you require, well I don't know when to give her extra medication. Back to mum monitoring, mum doing everything, mums responsibility. You've got a worn out, tired mother, making all these decisions, and when things go wrong, you know who they are going to look at.

Yet, perhaps the primary role least discussed by participants themselves is that of an ASD services expert, as parents develop expertise of ASD and determine what they feel is helping, or hindering, the progress of their child and family.

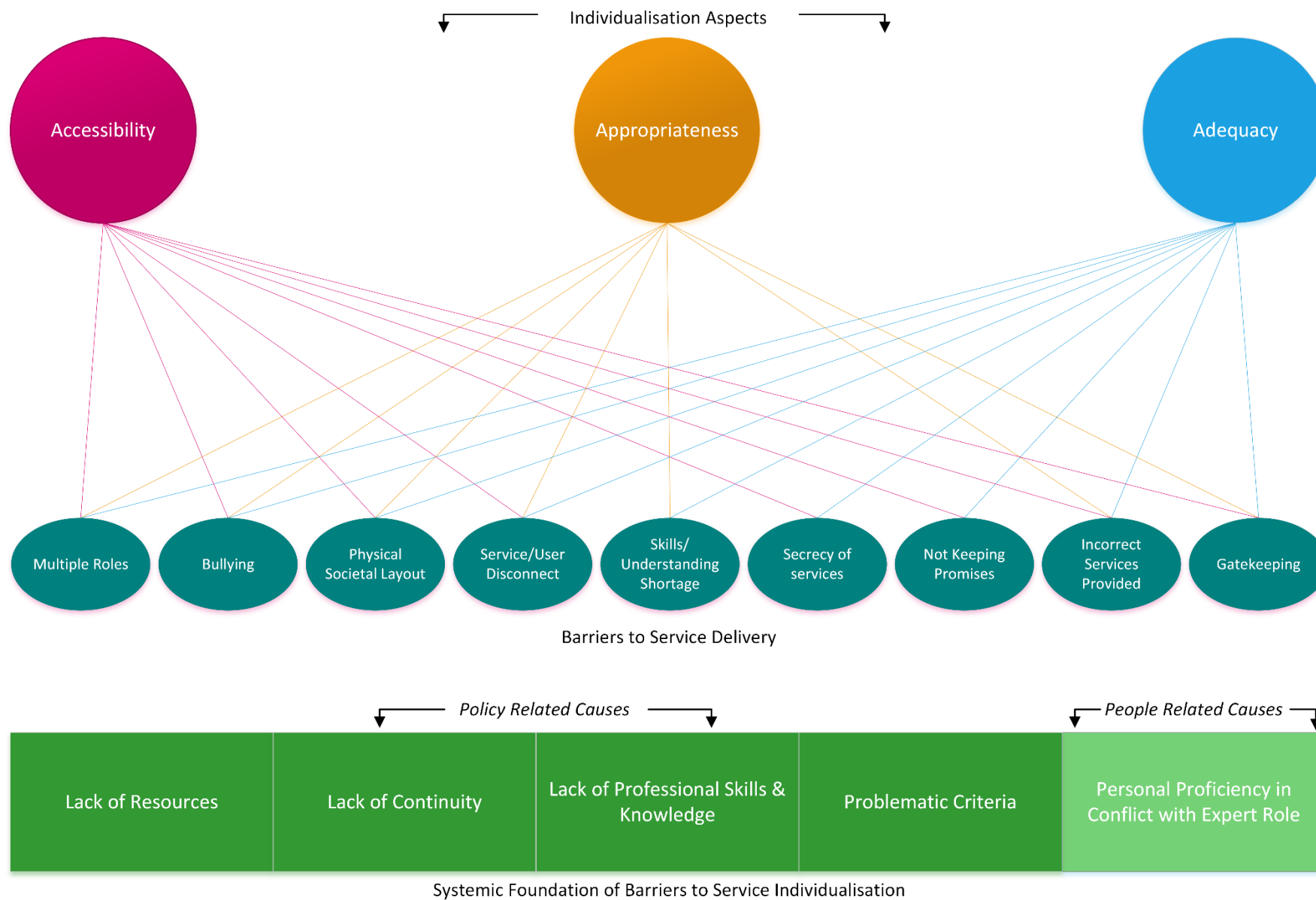


Figure 7. Theorised systemic foundations, and individualisation aspects of barriers to service delivery

Bullying – physical and emotional violence. This section relates to what is considered the very opposite to awareness, acceptance and inclusion that so much literature, and so many advocates raise calls for, in the sense of exclusion from mainstream society that arises when autistics are subjected to bullying in any of its forms. Caregivers frequently raised concerns of their child being subjected to various forms of bullying from other children, particularly physical abuse, which predominantly took place in, and around, school. Parental concerns reflected both the abuse received, as well as professional response, or lack thereof,

Participant 2: when we first started school, he was not verbal until he was seven and a half, and he, at five and six, would come home with strangle marks around his throat, welt marks across his back, and bits of skin missing where kids had dragged him across the concrete, because he was so tiny they could pick him up and drag him. And the principal would do nothing, because, [my son] couldn't talk.

Participant 6: It ended up being the one kid, it came to a crux a few months later, [my son] came home from school one day and said, "[other student] and his thugs got me at morning tea, and held me down, and kicked me in the nuts", and that was it for me. So I marched to the principal and said, "you've got to do something, this kid is not only bullying [my son], and your answer was to put [my son], to have his lunch outside the staff room, so that [other student] would keep clear of him"?

"In the end", I said, "that is punishing [my son] for something he hasn't done, he hasn't done anything wrong – that other kid should be sitting there, not my boy".

The effects of bullying extended beyond physical abuse, as participants' narratives demonstrated how other forms of bullying, such as emotional abuse, could be used in concert against autistic children as they were pushed to the point of lashing out,

Participant 9: he was being physically assaulted on a daily basis – we were actually scared for his physical safety, when he was at Intermediate. So we took him out of that school. [My son] would retaliate, because he had been so goaded, for so long, and then he was in trouble for having hit back. Exactly the same thing happened with his older brother.

Participant 6: when I finally got it out of him, it was down to one kid in class that was picking on him. But he was doing it sneakily, so the teacher didn't see it. Of course, with [my son], you only have to push his buttons so much, and he will just explode like a little volcano, of course that is what he would do, and of course I would say, "the teacher doesn't have the time, necessarily, to stop and sort you out – so he will just kick you out of the classroom, and focus on the other 26 kids in the class".

Connections between physical abuse, which was directly observable, and hidden long-term psychological trauma were also made by participants, as the violence Participant 2's son reportedly experienced, had ongoing consequences for his day to day living; memories of being physically abused were said to be with him always, as he was said to live in fear of other children,

Participant 2: The problem with [my son] is that he, he lets things pop into his head that happened years ago, but in his head, he thinks it has happened now. You know it's not something that's, to him it's not a memory, he remembers from years ago, to him it's something that's happening now.

So, he is terrified of other kids, because he is absolutely certain they are going to hurt him. Like on the weekends of school holidays, he won't let me take him anywhere, I can't get him out of the house.

Caregiver bullying. Bullying was not limited to actions of children towards autistic children only, as caregivers themselves were reported to be on the receiving end of bullying behaviour. Bullying, for adults, was broadly reported as an exercise in social intimidation and control, but not violence. The element of social control is demonstrated by Participant 8, who frequently spoke of attending successive Family Group Conferences (FGC), and not being allowed to speak, having been silenced by healthcare and other professionals present at the meeting, as well as perceiving she was being unfairly blamed. Control, here, is demonstrated as a constructed social environment, with a set of unspoken rules which privileges professionals over caregivers,

Participant 8: We go to this FGC meeting, and they are allowed to talk about the things that they have done, and they've done nothing; and I go to talk, and I get told to shut up.

Similarly, Participant 7 spoke of being in a group conference environment, where she felt the physical setting was constructed to intimidate her, both in terms of room configuration, and the number of people sitting in on the meeting, who were said to be ready to oppose her, and her perceived 'negativity',

Participant 7: I went to the IEP meeting as one person, with possibly six other people – educational professionals around the table ('ringed around' hand gesture), so it sets up a culture of intimidation, and negativity towards the parent who is asking for too much, or expecting too much. The whole environment was constructed to intimidate, really, that would be my experience of it.

Being unheard. Being unheard is a form of bullying experienced by caregivers, as they sought to access others and things outside of their homes, and control, in order to ensure their child and family's needs are being met. While assuming the role of child advocate, problems were shown to occur when the dialogue with others, particularly professionals,

broke down and participants felt their legitimate concerns were not heard; this also raises the question of privilege in interactions between service providers and participants. Being on the wrong side of privilege in such exchanges was articulated by Participant 9 as an isolating experience, which separated her from the outside world of the mainstream community. The effect of isolation was said to have more than one follow-on effect, in that it built resiliency and survival, yet such resiliency was not always a positive for the child,

Participant 9: just a great screaming silence from the outside world, basically, and if anyone needs support, its parents with kids with ASD. Yeah, I know there are many other things, and some of them very hard, and yeah, they need their help too, but, yeah, it has been a very long, hard, lonely road with no – just a vacuum, just nothing, so yeah, you have to become resilient, but it's not the best thing for the child.

Feeling unheard was also demonstrated by being denied the conversational space available in social exchanges to say what caregivers wanted to say. Participating in research was shared as being important to participants, as they were able to utilise the conversational space to be heard on issues they felt were important,

Participant 3: So for me, I came here to talk about me, I don't get many opportunities, I don't even know how to talk about me sometimes. You know? People should shut up and listen! I said that to one, I said, "you need to shut up, and listen, I don't want to hear anything else. Don't want you to talk to me".

Feeling unheard was also raised in terms of the voice of service providers being talked about as being heard and prioritised in discussions and consultation processes above caregivers' own voices, as little value was placed in the knowledge and judgement of caregivers; in effect, being constantly overruled,

Participant 7: They kept saying, "she was fine", and she would "hold it together at school." The most recent school experience here, at the IEP meeting. I said she

“wasn’t holding it together at home”, and they said, “no, she’s fine, she’s fine”; and then what happened was there were a couple of incidences where she was lashing out at the other students, and I said, “well, I did tell you that would happen.”

That’s sort of when I said, “enough is enough”. She is going to get herself into strife, because you are not listening to us, about the triggers that are setting her off.

Similarly, feeling unheard was demonstrated by professionals reportedly acting contrary to instructions given by caregivers,

Questionnaire Participant: We found that when we placed instructions in the hands of teachers at the school they were regularly ignored by a certain group of individuals.

One occasion leading to one of our children being held on a school camp with a fractured limb.

Being unheard was also articulated by participants as service providers listening initially, only for concerns to later fall upon deaf ears; Participant 2 shared that it presently felt like no one seemed to care about her son as he aged,

Participant 2: When we first moved here, we got help for him, but no, just as he’s gotten older, no one wants to know, they just, put him in the too hard basket.

A layered effect of being unheard was also pointed out by one participant, as participants can be unheard through engagement with a service, and then secondarily unheard as the desired platform to have grievances heard was minimalised in the complaints process,

Questionnaire Participant: When the Ministry of Education staff don't listen to the parents, and subsequently the reports, it is very stressful and frustrating. When you write a letter of complaint about it you get fobbed off.

Being heard and reducing power distance. Contesting privilege and power was a productive avenue for some participants, as they sought to be heard. Participant 1 theorised about the dynamic between professionals and caregivers, as most professionals in her experience operated with power distance – until the use of particular language signalled a reduction in power distance, which enabled a different kind of exchange or relationship. For Participant 1, the reduction of power distance was influential in being heard; however, this was something that was taken, and not given freely,

Participant 1: Yeah, like, you know what you are talking about. In social anthropology we call it power distance, so the power distance has got a heck of a lot shorter, you are close to me, you have got the same education as me, or close to the education as me. It was the same with the psychologists, or the speech therapists, the whole game. Usually before I would go to an interview I would research, what speech therapists do? What do they read? The language, using the same language.

Participant 1 also described how her own attributes, and being able to “talk back” enabled her to question professionals, which facilitated different conversations with professionals. During the process of conducting her own research into ASD, she came to the realisation that these skills of hers were something she had taken for granted, and that other parents without similar expertise might not fare the same,

Participant 1: I think because I went into the meeting with the Ministry of Education, I told them about my research, and what I had done, and if they came up with things, I’d go, “yeah, but such and such has researched this, and they found this”, and they would kind of look at you like, “oh, shut up, I didn’t know that”.

When I did my interviews, you see I took this ‘talk back’ for granted, because that’s who I am as a person, and have always been.

Previous experience (personal or professional) and the pursuit of qualifications was also shown to influence how caregivers viewed and challenged service delivery, and challenged the role of experts. Participant 7 shared that her experience in her career as a Health Care Provider enabled her to openly challenge a Plunket Nurse, and insist upon her daughter being checked,

Participant 7: I guess because I was a healthcare professional, and we worked together before the baby was born, I was able to say to her, “this child is not normal, when can we access services for an assessment?” So that probably didn’t happen until her three, three and a half year Plunket check.

And at that Plunket check she said, “no, she is fine, there is nothing wrong”.

“I said, yes, there is”.

And she said, “I’ll go through these standard tests that I’ve got” and she went, “oh, I see what you mean”.

Society isn’t configured with autistics in mind. Privilege and power, albeit covertly, also has a role to play in how society is configured, particularly in social environments, as the needs and demands of neurotypical people are taken for granted as ‘normal’, while the needs of others are often overlooked. Participants reported often that there were various aspects of their community environment which affected their children, particularly through the physical barriers that aggravated ASD related sensory challenges they faced, and caused them to have fewer opportunities to be active in their communities than they otherwise might,

Participant 2: He likes swimming, but he doesn’t like going to the aquatic centre, because it’s too noisy, like during the holidays and weekends, there are so many people there and he can’t cope, last time we took there he spent two hours hiding under the table, that was during the Christmas holidays.

Participant 7: We’ve go to the stage where we can barely go out for a coffee because

of the hideous loud music. We can't go shopping for clothes for her, because of the hideous loud music, you can't get in the doors. I know I'm not alone, in saying that.

Infrequently, participants did mention sensory-awareness based initiatives to promote social involvement for autistic children,

Participant 7: We were getting together at [a pottery place], early on a Saturday morning, again, no music on, nothing. It was a low impact and stimulation environment. The girls went off and did their pottery painting with people; the staff were lovely, very accepting, and the mums could have a chat.

However, such initiatives were described as having a limited lifespan, often due to funding concerns,

Participant 7: I'd like to see more environments in which they can interact, that are socially appropriate. The autism support group clearly recognise this, and they did have funding, but it seems to have stopped. We would go, once a term, to ten pin bowling, with all the children, who wanted to go, and the ten-pin bowling wouldn't put their music on. We would go at nine o'clock in the morning when nobody else was there, they didn't put their music on, and the children bowled, and they had a wonderful time, and they talked as much as they could.

Different forms of planning were evident in the configuration of social places. Long-term planning (especially in the construction and consent process of public spaces), and short-term planning (such as planning that preceded 'disability appropriate' community events) were both the subject of criticism. According to one participant, autistics are not properly considered in either sort of planning,

Questionnaire participant: How about asking whether planners take any consideration of sensory issues when they put a 'disabled' toilet between the main gent's and women's, with the hand dryers on the middle wall so the disabled toilet gets the noise

from both of them? Or automatic fan systems with no off switch in disabled toilets?

These are all community issues that are not considered. How about all the lovely Lions clubs etc. who do 'families with disabilities days' that are inaccessible to ASD kids due to the clowns, balloons, bands, and increased number of people etc?

Meeting the family at their level. In order to provide support that is inclusive, degrees of flexibility in approach should allow for variances between the ecologies of different families, which meets them in the manner in which they operate, rather than a 'one-size-fits-all' approach. The literature is broadly supportive of services and interventions that are consistent with the uniqueness of families, such as variations of worldview, or spiritual, religious and cultural identity. Thus, it is important for professionals and support services to be able to both identify, and respectfully connect with families, and promote their inclusion in the broader community, even when views and beliefs are not shared. This subsection relates to professionals' efforts in connecting with the family in a manner which is respectful to family ecology. However, as with the experiences of Participant 7, it was most frequently shared that professionals and services were unable able meet her family on common ground – which was said to be a concern that was not limited to ASD or child related services but health services generally,

Participant 7: we can't narrow it down to child services, because when my husband was ill, and dying of cancer, we had the same combined problem because the services, oh what's it called? The hospice, the people before.... palliative care, the palliative care nurse, the GP, and the specialist were not meeting us at our Christian level.

Religion was similarly a point of difference between provider and receivers of service in the service delivery for Participant 4, whose son's symptoms were not attributed to his diagnosis, but to the parent's belief system, as the specialist was shown to be unable to bypass his own worldview to attend to the needs of a service receiver,

Participant 4: I have seen [my son] file, I have read what they have written about us, and...the first psychologist that [my son] saw, who did the diagnosis of Asperger's, and of Major Depressive Disorder left shortly afterwards; he then had another psychologist who basically seemed to seek to blame us, the family, the parents, our parenting, and our religious beliefs on [my sons] problems. I read this in the file.

Parents / caregivers as part of the 'problem', or the 'solution'. Beyond culture, or religious affiliation, participants shared a number of reasons why they felt as though they were personally framed as the barrier to inclusion. In participants' experiences, professionals were preoccupied with concerns that were not important, which prevented meeting the family at their level and addressing things that were most important. Participant 2 noted how her marital status as a single mother dominated discussions which could have been otherwise directed towards helping her son,

Participant 2: She (diagnostician) just mucked around, and mucked around, a lot of it was because I'm a single parent, and she kept wanting to discuss that. In those two years, she only saw my son twice, the rest of the time, the appointments were with me [...]. Now it might just be me, I get the sense that being a single parent is detrimental towards getting any help.

Participant 2 was of the mind that she was in some way viewed by professionals as the core of the problem, because of her marital status. This view was said to come about due to the remarked contrasts in scrutiny from two visits to the hospital; one visit after her husband had left, compared to another from when she and her husband were still together,

Participant 2: Before they (hospital staff) even checked her out, they asked me about her living situation, I said that I was a single parent, and they assumed straight away that I had abused her, and that she had a broken hip, [and] they were insisting I had thrown her at the wall or something. My children have never been smacked in their

lives, and I kept telling them, “I don’t smack her”, blah, blah, blah, and they called the police in and everything, and I wasn’t allowed in. When they did x-rays, and tests, they discovered that she had a septic infection in her hip, I hadn’t done anything, so the police left, and she’s in hospital getting treatment for that.

It was just a different experience that you get, straight away. Like, you get treated so different by the medical professionals, compared to when you are a single parent, they just judge you, you know. I feel that way with getting help for him, that, if his dad were here, maybe things would be different in getting help. I just don’t know

Another participant reflected upon how parental age seemed to be perceived by service providers as influential when gauging a parent’s ability to cope. It was inferred that younger parents were less likely to cope, whereas older parents were thought to be more able. Despite being an older first-time mum, Participant 3’s theorised that her perceived ability to cope was rated a lot higher by others, than what she personally thought it was herself,

Participant 3: What I’ve found all the way, is that people feel ok to give you information; because I’m older, they seem to think that I can handle stuff, and you know what? I actually can’t. This is my boy; this is my life.

Some ways of engaging with the system, and service providers, were thought to be more beneficial than others, underlining an unspoken responsibility for caregivers to engage with others in ways that are conducive towards building relationships and securing optimal service delivery, rather than a service individualising its approach to maximise the chances of inclusivity taking hold for a family. Participant 1 described how parents in her acquaintance, through the ASD community, who come across as having a ‘fighting the system’ approach were met with resistance, while her own alternative strategies were well received; supporting

the idea that particular ways of engagement were better received by service providers than others,

Participant 1: I'm like, I know there are 30 other kids, I know you can't spend all your time with her, so what can we do together, so we can help you, and you can help us, and we can cooperate together rather than "give me my services!" you know? Which I have found amongst the community of autistic parents, that there are quite a few parents like that are going to fight the system.

Researcher: Like the 'warrior parent'.....?

P1: Yeah like the 'warrior parent' thing, like, everyone is out to get me, and I'm going to fight the system.

Preferred methods of engagement were also described by Participant 6, who shared how openness and allowing professionals' help was important, as was framing input from professionals as a form of assistance, not a direct criticism of child, caregiver and family. However, prioritising one style of engagement over another has the consequence of attributing some blame to parents who did not fit the preferred way of engaging with a service,

Participant 6: I said, "honestly, you have been so helpful to me and [my son], and the reason he is so successful now is down to everything you did to help me".

And they said to me, "it's not us, it was the fact that you were open to letting us help. We have so many parents who don't want to know, that think that we are being negative about their child, or whatever – they take it all the wrong way, and they back off a hundred miles an hour". She said, "if all parents were like you, we would have a lot more successful kids".

Service providers lack understanding and skills This section draws attention to the feedback surrounding the state of key competencies for professionals; as the NZASG

consistently states that those who work with people on the spectrum ought to have the necessary understanding of ASD – no matter the service domain. However, participants consistently raised the problematic issue of those entrusted to provide services for children and their families lacking fundamental understanding about ASD, and what life is like living with an autistic family member, which proved a barrier to helping families achieve their goals,

Participant 4: there has to be more understanding, of what the real world is like, when you have a child with ASD. I think if there is one thing that really needs to get through to all of the agencies which work with kids with ASD, is that there is no set way to work with kids with ASD, you have to be able to maybe just try to change your perspective a little bit, because you are dealing with someone's perspective is beyond your understanding. There is this thing where I told him this, but just because you tell someone with ASD something, it doesn't mean that that is what they heard, at all!

Unknowledgeable professionals. The NZASG outlines that service providers and professionals ought to have the necessary understanding and knowledge in order to work with people on the spectrum. Yet another consistent theme raised by participants was that service providers and professionals lacked ASD specific professional knowledge that enables service providers to work effectively with people on the spectrum, both in terms of assessment tools to diagnose ASD, as well as aspects of intervention efficacy. Aotearoa New Zealand service delivery was perceived as being 'behind the times' in best practices,

Participant 2: The paediatrician gave us an 'unofficial' diagnosis, so we got speech therapy involved, but we didn't get the official diagnosis for, two years?

In those two years, she only saw my son twice, the rest of the time, the appointments were with me, and then the paediatrician got sick of it, he got us seen by a specialist from [out of town], and she would come down for clinics, and she came down and

spent two hours with us, playing with him, and doing stuff with him, and said to me that she agreed with the paediatricians diagnosis, and far as she was concerned, and then asked the psychologist why she hadn't made the definitive diagnosis, and the psychologist told her that no one was trained in the ADOS assessment.

[The specialist] said to her, "how do you run a child development unit with no one trained in the ADOS assessment"? And she oh, "we just diagnose them with autism spectrum disorder".

Questionnaire Participant: So far, the services we have encountered fall far below standard, few if any providers have recent, current knowledge about ASD. Most are unfamiliar with what is happening internationally with ASD research, literature and intervention efficacy. Many service providers will not provide services.

The inability, or lack of skills, of a professional to work with an autistic child could also lead to service cessation; some participants shared that while some professionals might otherwise be very competent in a generalised role, the lack of specific expertise relating to ASD put them at odds to provide services for their children and families. This was the case for Participants 2 and 7, who both recalled how an occupational therapist, with no experience of working with autistic people, disengaged soon after beginning work with their children,

Participant 2: We had an OT (occupational therapist) come through CAFS (Child, Adolescent and Family Service), CAHMS (Child and Adolescent Mental Health Service), you know, and she was lovely, you know she sat here on her second visit and said that she had never worked with children before. I was like, "oh, ok, that is going to help me how"? [She said] "I'm used to working with adults who have had strokes", and then after a few visits she said to me, uhm, "I'm going to stop working with [your son]".

Participant 7: I think the person doing the [occupational therapy] assessment showed a

lack of understanding of ASD conditions. I think they showed a lack of knowledge of how that might present, in a child of that age. Because at that age, at that time she was probably about four and a half, it was before school. So because of that, the service was stopped, because the written report was along the lines that, “there isn’t anything I can help with because this child is defiant and won’t follow instructions”. So that was stopped.

Professionals need additional training. In line with the lack of professional skills and ASD specific understanding, participants further conveyed that many professionals needed additional training in order to be in the position to be helpful and effective; however, in some instances people working with autistic children were said to have little, or no training at all. One participant demonstrated the need for training, by sharing how autistic children can spend the most time with professionals who were said to need training the most,

Questionnaire Participant: Learning programmes and resources need a much more flexible approach along with better trained teachers and especially teacher aides.

Teacher aides (if you're lucky enough to get one for part of a day) spend the most time with ASD kids whom they are assigned to, but they are the least qualified of staff and often are very inflexible and not appropriate.

Participants 5 and 6 both were reportedly in the position of having to educate professionals that were working with their children, illustrating that among other roles caregivers had, they also assumed the role of educator,

Participant 5: I guess there is a lot of educating other people, about certain things, even teachers and health professionals. A lot of people don’t seem to be very knowledgeable.

There was a fill in teacher for over a month, and she didn’t really get ‘it’ either. Like things like [my son] needs to have a snack after lunch time is finished,

because he is a real slow eater, and if he doesn't, his blood sugar goes down and when I pick him up he will have a screaming meltdown for half an hour, and she didn't get it, she said, they just had lunch, he should have eaten.

I think teachers could be a bit more educated about these various special needs of children, because it's not uncommon.

While Participant 5 did report existing expertise to draw upon while educating professionals, Participant 6 reported that she was placed in a position of having to assume the role of educator when she was learning about ASD herself, which she did with some reluctance, and out of necessity,

Participant 6: [I would recommend] that all teachers, and principals, in schools have that basic understanding of autism, and autism-like disorders. I would have loved not having to not being the one to teach them, especially when I was only learning about it myself. But I knew if I was only learning about it, how the hell were they going to cope with it, or understand it?

I think that it is really important, perhaps, that these teachers get this basic training, or understanding, and maybe that happens when they are training to be a teacher.

Not knowing where to look for help. Participants talked about experiencing a sense of the unknown when it came to seeking services and support. Both immediately post-diagnosis, and long-term, many participants shared that they were unsure, or completely unaware of the services that exist to support either their child, or their family. If they were somewhat aware, participants expressed a lack of certainty of their entitlement to them, or how to go about accessing them,

Questionnaire Participant: Information on the condition is not hard to come by in this day and age of the internet. Information on the process of diagnosing your child and

what comes after is next to impossible to find. No one is willing to share this with you and no one will commit to any kind of timeline or take responsibility.

Questionnaire Participant: There have been times when I have felt completely lost as to where to go/turn to for questions and information.

For some, services and entitlements seemed to be kept ‘secret’, which suggests that services were not just difficult to find and access, but that they are being deliberately withheld,

Questionnaire Participant: The services in New Zealand are very fragmented and unacceptable, and it’s like it’s all a secret to what you are entitled to.

Services have the appearance of being designated on the assumption that service receivers had received all they were entitled to up until a current service was assigned, with little provision towards individualised extra care for those who had ‘slipped through the cracks’. For those participants who eventually found that their family situation qualified them for assistance, the scope of service delivery was viewed as very fixed and little consideration was given to what a child and family had missed out on, and what might be needed to get a child on track,

Participant 9: apparently, there was a child support payment that we could have been getting all the way along, which could have really helped with some extracurricular activities, for example – you just don’t know what you don’t know, as a parent, and you miss out on so much.

What has happened relatively recently, although there was a major fail in the initiation of it, was, he has got a social worker, who comes in for an hour or so, twice a week, and he is starting to [build a social connection and encourage a social outlook]; it hasn’t really got him out much (yet), he’s just trying to build a connection at the moment. That’s been, honestly, the one thing that has happened, and its

threatened with cessation, because CAMHS has withdrawn and they said you can have him (his social worker) for six months. Yeah, but it's like, he might need longer than that.

Advocacy and coordination services were reported as critical for informing caregivers of the options they were entitled to access. However, coordinators were positioned as gatekeepers, who held a lot of power; while some coordinators might identify and connect with clients, those who did not share the rapport might not have the same level of service,

Participant 5: I was allowed to re-contact her but, yeah, she knew all the things available, I think she did a questionnaire to find out what we needed, and so she knew; having someone who knows what's available, and how to access it, would be good, because I guess a lot of people miss out, because I didn't even know about the specialised behavioural support service – never heard of them.

Questionnaire Participant: [it depends] on your relationship with that person and how easy it would be to change if things weren't working out communication wise. Some people just don't get on and that might affect the supports/services you receive (no matter how professional you are, it can still happen).

Being informed, or learning where to look for assistance were both reported as being critical, and often difficult. The importance of knowing how, and being able, to reconnect with coordinators was also raised, as tired parents get into a routine of barely coping, and don't access as much as they could in order to be living and flourishing,

Questionnaire Participant: Initially we were made aware of support services that were available for parents to take a break etc. It's easy to lose track of entitlements, offers of support, etc. It would be helpful to have a reminder sent out to remind us about the options available to us. Sometimes as parents we just get used to coping instead of taking the break we probably should take.

Honouring commitments. Service providers were also frequently reported as not upholding commitments they had made to service receivers, which increased delays in eventual service delivery. Lack of follow through was said to be symptomatic of funding shortages in public (health and education) systems,

Questionnaire Participant: The public system for this spectrum is basically non-existent, and they never follow up when you have been to see them, the waiting lists are far too long and staff under resourced.

Failing to deliver on commitments went beyond the hurt and frustration that might normally be associated with not receiving what is needed. For Participant 3, service delivery failure also had a detrimental effect on how she felt about herself. Failure to honour commitments here also connects with role acquisition, as the erosion of trust adds pressure to assume additional roles out of necessity, when caregivers feel they cannot trust others in assuming a critical role in their child's life.

Participant 3: I can't think of it just now, but there have been a few times where I have been absolutely gutted, because someone said they would do something, but then they've forgotten.

The thing is, when they forget, it affects me and how I feel about myself - aren't I important enough to remember? Which is probably some of my shit from childhood. But it brings me down. I hate asking, I've asked for this, and you have said, no? or you said, yes, you will, then you haven't? It's hard to trust.

The importance of trust, and reliability, of service providers were also brought into question by Participants 1 and 2 in particular, as they recalled the considerable volume of follow-up on their part to get things done. Experience had taught them that such persistence was needed to ensure that commitments were kept, and service delays minimised,

Participant 1: We were waiting for this appointment with the child psychologist and

we were told it would be a certain amount of weeks, and it came out to three months, or two months, and that's when I rang. So if I hadn't rung....

Participant 2: waiting for people to get back to you, that never get back to you, it's so, so, so frustrating. You know, and, you know, it's like you spend all day, every day, playing tag on the phone with people, and it's just ridiculous. You know, they don't get back to you, or they make promises and they don't get back to you, yeah, it's just so frustrating.

Services delivered are not what is needed. Participants conveyed a high level of expertise regarding the services received by their families, and the services that were desired, but were undelivered. Participants often expressed frustration in the availability and frequency of informational services through seminars, and meetings, in contrast to the lack of practical help with the challenges their children faced, which was the support they most desired. One questionnaire participant expressed a great deal of frustration in being referred to lectures and seminars, when complex and highly challenging behaviours (such as running, and smearing faeces) that they were struggling with were not being addressed or helped through these informational mediums. While both of the following participants pointed out that they were knowledgeable and capable advocates, this did not negate the lack of the desired practical help,

Questionnaire Participant: Services are limited in their capacity to provide actual practically useful support to families. Many agencies give informational advice only - the number of parent education seminars I have done now is endless. I am sick to death of being referred to services for lip service parent education and information. After 2.5 years I am still wanting to know how to address my child's poo smearing and running off. My child does not talk and does not have any sense of danger. I have very good advocacy skills, know the system well and am very educated about ASD.

None of this is from the services we have been referred to - all of it is because of how useless we have found those services!

Participant 9: I feel like I don't need more knowledge about autism; I am an expert in my boy's form but I don't know about other forms of it – I am well enough informed. It was me that did the diagnosis in the first place, I must have learnt enough, more than most people, to spot it, and recognise it, and all that. Advice is missing the point, you need practical help, not advice.

Beyond informational services, other participants shared the experience of being pressured into accepting services that weren't suitable, and in some instances gave in, out of desperation, because the services were the only ones funded. Having to conform, or give in, underlined systemic issues in prioritising what caregivers believe is in the best interests of their family,

Questionnaire Participant: There is a lot of pressure to accept the supports available regardless of whether families consider those supports the 'best fit' for our child's situation. For example, I have requested to be referred to the Ministry of Education 'More than words' program to get help for my child's speech language skills. My child was diagnosed at 2 years and has had no SLT input despite not talking and now transitioning to school 2.5yrs later has not progressed with his speech skills and has had multiple referrals made for SLT input. The local Ministry of Education office referred us to an 'in house' program 'based' on the 'more than words' course for 6 group sessions with an SLT. That was not helpful- we really need actual SLT therapy and proper training - we need to do the proper course not some watered-down version of it

Questionnaire Participant: I know lots of parents who do things that they are not comfortable with because it is funded.

Gatekeeping. Gatekeeping is broadly understood to be the activity of controlling and limiting access. In the realm of service delivery, this means controlling, or limiting, access to service delivery for children on the spectrum and their families. Themes discussed earlier also serve as examples of gatekeeping; firstly, thematic analysis of ‘caregiver bullying’ also identified the additional function of gatekeeping, whereby intimidation, or silencing of parents in social exchanges, were means of maintaining the status quo and preventing access to the services needed - or preventing the desired change in method of engagement from service providers.

Secondly, gatekeeping can also be demonstrated through earlier references to preferred styles of engagement; where approval of particular styles was underlined as preferred and conducive to effective service integration and delivery; and how the inverse occurred through unfavoured styles of engagement, as caregivers who were perceived to be in the practice of “fighting the system”, were met with resistance.

Thirdly, gatekeeping can also be demonstrated through previously cited examples of not being undiagnosed, or not referred. As diagnosis and referral are both methods which trigger the entitlement to further services; denying access through either avenue denied future service delivery.

Fourthly, gatekeeping can be shown where organisations had prevented access to their services through citing unmet criteria, or encouraging caregivers to take their children elsewhere, where they were said to be better supported,

Participant 3: When we went to the first school it was like, this is never going to work, and after we had been rejected from the school before, I wanted to lay a Human Rights [Commission] complaint because there were three of us that were told basically that they didn’t want our kids there. They couldn’t support our children, and it wasn’t all ASD, one was MS (Multiple Sclerosis), and one had real behaviour issues.

Fifthly, gatekeeping was also identified where those identified as disabled were thought to detract from the academic standing and appearance of schools, as it was reportedly made plain that others wanted difference excluded from among the student body,

Participant 7: Nobody was interested in her, because it was a high decile school, with all the right people, and all the nice people, and it was made very clear, that this child was upsetting their look of a nice school. It was a very closed culture for anyone who took away from their high decile rating, and their high academic grading. They didn't have time for that, because it would stop them from being a 'nice school'.

Systemic causes of service delivery concerns

After speaking of a specific service delivery concern, many participants drew connections between an immediate concern, and systemic issues, which were thought to affect, or ultimately cause, the difficulties they were experiencing. The systemic concerns raised often fell into one of two broad categories - policy related issues, and people related issues, although frequently, a concern sometimes overlapped both.

Policy related issues. Policy oriented explanations reflected decisions made at a ministerial, or DHB, macro level which provides the social infrastructure that forms the basis of the service delivery environment, by providing guidelines, structure and funding. Aspects of policy can be affected by political priorities of a given government, the financial climate, the profile of need through lobbying and promotion, and also the visualisation of need through protest and petition.

Lack of resources. The systemic concern that was most frequently raised was the lack of resources/funding the system had in order to be effective. Ministries, service providers and DHBs were all reported to have funding issues which had a direct flow-on effect for affected service receivers. Such flow-on effects were articulated as directly affecting service availability, as well as being considered an underlying contributing factor in other aspects of

systemic shortfalls (as mentioned above e.g. through honouring commitments and the duration of initiatives),

Participant 9: I don't think it's hard, I don't think it costs much; I think that it's doable, I mean I think that it is doable. It's just the failure has been, the schools, and the education system haven't been resourced/sufficiently funded, and this is where [my older son] could have been picked up, and [my younger son] could have been picked up so much sooner, and given appropriate support, and understanding, and intervention so they weren't being bullied, and all that, you know, it's actually not that hard to do!

Questionnaire Participant: The public system for this spectrum is basically non-existent, and they never follow up when you have been to see them, the waiting lists are far too long and staff under resourced.

Lack of resources was also demonstrated through narratives which described the practice of 'topping-up'. This practice caregivers, and sometimes services providers (such as schools), were engaged in, consisted of both parties going the extra mile to personally fund services for the children in their care, when faced with the possibility that their child was not to receive the funding related support needed,

Participant 3: I had to research it, I had to fund it, I had to do everything. I had to fly people in to be trained, I've had to look for people to train up. Absolutely nothing, absolutely nothing [in the way of funding]. I'm having to do bits of it again to help my son through some stuff. You know what I'm doing? I don't even go to church, I've had to go to friends, who are church members, to ask them to donate stuff, so I can sell it down at the market to fund it.

Participant 1: Because she doesn't get ORS (Ongoing Resourcing Scheme) funding, the school went into a review for ORS funding, but she got turned down because she

is too high functioning, so again, we've been lucky in that schools have been willing to use their own resources and money out of their own RTLB (Resource Teachers: Learning and Behaviour) funding and so forth. We did have something official through the education board, where they were trying to get more funding for her, because of her dyspraxia, basically it was to do with funding, maybe her own computer, because she has trouble with handwriting, but that was turned down. So the school said, well just work that into our existing budget; its again, because the schools are willing to work around the system to help her, and help other kids like her, but it wasn't because the system was there.

Topping-up was also reported by one participant who identified that the funds available for respite care workers was beneath minimum wage. Changes in government policy wording, and low funding per hour of respite, were said to shape the conditions under which others using respite signed off on hours not used, in order to top-up respite workers to what was considered fair compensation. However, such a practice was considered immoral and not in keeping with Participant 7's, and her respite worker's, beliefs; so topping-up came at her own expense.

Participant 7: The respite care does not meet minimum hourly rate, but – that we know, and I notice the wording has been changed to say that it is a 'help', but not a 'total funding', anymore.

What's happening is people are signing off forms dishonestly; because, from a Christian point of view, I won't do it, and I am employing Christians who won't do that, I have to top that up myself to the minimum hourly rate, because the respite care rate does not cover, does not come up to the adult minimum hourly wage.

Lacking in continuity. Another common policy related systemic concern raised by participants, was that services often lacked continuity, especially amongst themselves. This frequently manifested itself through poor critical communication and information sharing,

Questionnaire Participant: The services available to families are disjointed and there is poor information sharing between providers.

Lack of systemic continuity was also expressed through unpredictability or uncertainty of service delivery for children on the spectrum, as breakdowns in service meant a stalling in a routine, and the need to rebuild rapport and communication. One participant spoke of how gaps in service delivery meant that relationship building had to start from the beginning between her son and professionals,

Questionnaire Participant: There are difficulties due to the change when getting a new professional in to help with my child (each time he gains a new educational psychologist for example). They are all great, but due to the length of time they can stay assigned to a case means that next time the school calls one in for help he has to see a new person - rapport etc. has to be started all over again which can be disruptive.

Gaps in service delivery were said to also occur because a lack of togetherness, or a willingness among service providers to work together,

Participant 2: the main problem, back then, is that nothing worked together. Like the paediatrician didn't like being told what to do by the other agency, so, he would get really huffy with them – I think they need to work together. They need to provide more for the parent, like, you know, don't just give us a diagnosis and send us away, I mean, it's really...

For parents, breaks in continuity breakdowns meant being caught in the middle and having to assume the role as a mediator between agencies, to ensure commitments were kept.

In essence, those who did not trust service providers to deliver had prompter access, and in effect, participants were conditioned to not trust. Participant 1 addressed concerns regarding the clerical / scheduling side of service continuity, as promised appointments often did not materialise without prompts from her,

Participant 1: There were times when I had to ring up, you know, we haven't been sent a card, or an appointment. So she did what she could do at her end, and then I would follow up when it seemed to have dropped through the gaps in the great New Zealand health system that we have.

Finally, Participant 7 summarises a range of breaks in continuity across services and systemically, government departments. Although many promises are made to families, few were said to eventuate,

Participant 7: it's a reflection of all the health services, and the services provided; you a promised a Rolls Royce, and a Mini Minor turns up, minus the wheels, if you're lucky! That would sum up all of my dealings, with all of the government departments – promise the earth, and it just doesn't happen.

It either doesn't exist, or, "oh, sorry, that's not available in your area"; or, "the person who does that is on leave"; or, "we had someone doing that job, but it's sort of been disbanded and someone else has taken over it"; or, "oh we would really like to do that, but our funding has been moved to a different group and they're doing it now". That's basically how it fits together.

The merits of caseworkers / kaiarahi

Most questionnaire participants were in favour of caseworkers / kaiarahi (consistent with the recommendations in the NZASG), who would act as both direct supports, and service coordinators for families. Such caseworkers were thought to be a solution to problems with systemic continuity. Although one participant noted that such a coordinator existed in

their locale, the outcomes for clients were considered very poor due to a lack of passion, skill, and knowledge. Caution was also given, that it was unwise to place all responsibility on one person,

Questionnaire Participant: We have something similar in our region an Autism Co-Ordinator. She's useless, I know more about what's available for parents than she does. Often, she's asking me for information. She's often unavailable, goes on leave without the courtesy of an email & has cc other information via email as opposed to bcc. So now every parent of a child with ASD has every other parent's name & email address. My point you really need someone who has both the passion, knowledge & skill sets for the job. Rant aside, in my experience it's not a good idea to put all your eggs in one basket.

Professionals need better preparation. Teachers were one profession that were often said to struggle, due to their lack of knowledge and training on ASD. However, Participant 1 pointed out that, unskilled teachers seemed to be a product of flawed systems which did not adequately address the balance of the training needed to be competent with children with special needs.

Participant 1: I think teachers need more support, they need more training. From what I understand, they get basic, very little training on special needs children in their actual training, when they train to be teachers. I think my sister said it was like two weeks, or something, so you've got three years of teacher training, and they get two weeks on that. You would need a whole paper on that, because you are going to get them in your class more, and more, and more.

Criteria. Criteria as a policy concern informs other systemic concerns, such as resource policy, to ensure that funds target those who stand in need of assistance. Criteria,

due to constraints in funds (resulting from resource policy), may be intended to inform the prioritisation of funds towards those who are judged as needing help the most.

Criteria set for diagnoses vary. When a child is behaving outside the usual developmental range, there is an assumption that the diagnosis process will accurately determine a child's challenges. However, several participants commented on their preference of utilising private services, over the services offered publicly. Caregivers who utilised private services tended to be those who were dissatisfied with diagnoses undertaken by the public health system, who then went through the private sector to obtain further diagnoses. 'Going private' illustrates a public / private divide in the health system as the preferred option came at significant cost to families which creates immediate exclusion for those on low incomes. Participant 5 shared her experiences of dealing with both public and private clinicians to illustrate how she had arrived at the view that private health system, although expensive, is better, while also sympathising with those who don't have the means to access a diagnostic process that was talked about as being of a high standard,

Participant 5: "He interacts nice, and he looks at you, so, no, he's not on the spectrum". Because of the behavioural things, like trying to get out of a moving car, freaking out, screaming, screaming for two hours when the car didn't start; you know, quite extreme behaviour. So we ended up going to [a local private practitioner], which you can only go to if you can afford it – but we had health insurance, and so we saw him once, and he said he wanted to do the ASD test.

I just think everyone should be entitled to see.... I mean the only person who does the diagnosis properly is going to cost hundreds and hundreds of dollars; all up it was \$6-700, and most people don't have that kind of money, so they miss out on all the help. And they are not going to get that help through the public system because of the [local] paediatrician, who is very old school.

Varying criteria has been offered as an explanation for discrepancies between public and private diagnoses. Yet the implementation of such variances are shown to be caused, at least in part, by micro level policy within the public health system; such policy becomes apparent where inadequate or dated methods are still in use in some DHB areas,

Questionnaire Participant: In our region the 'diagnosis' of ASD is antiquated and works on a three-tick system. If your child can hold fleeting eye contact they therefore can't possibly have ASD!

Criteria windows can be narrow for service receivers. The current state of services, as shared by Participants, articulated the criteria windows set by service providers, and institutions, as being difficult. However, in some circumstances participants contested the power others had in the setting, or applying, of criteria through indicating that they will hold people publicly accountable for their decisions. For Participant 2, this involved the threat of placing the criteria used to deny her son access to services into the public domain, which achieved the desired result,

Participant 2: [my son] started self-harming, and tried to cut himself with a knife, so I took him to the GP, and he said, “no, this is a whole new ballgame, he needs to be seen by the specialist”. So he referred him, and they rang me to take him in, so I took him in, and then they rang me and said they didn’t fit their.....

Researcher: criteria?

Participant 2: yeah, to fit into their service. So, I said to them, “ok, that’s fine”, I said to them, “but, can I please have that refusal in writing”? And he says, “sure”, and I said, “cool, can you please send it to me”? He said, “can I ask what you want it for”? And I said, “yeah, when he either stabs me, or the baby in the house, or himself, I’ll have this letter to go to the media with”.

Narrowness of criteria, or lack of fit, was also expressed as the opposite of service individualisation, as people had to fit within service delivery demands, or no assistance was received,

Participant 2: I think a lot of the services, it's not service individualisation, you have to fit in to the service, or you are not going to get what you need.

Participant 8: went to a thing at the Ministry of Education about this particular thing, and it was explained to us that funding is put into boxes; my daughter doesn't fit a box. Funding for these children should be on an individual basis. Does a child need help to be able to be in the school system? Yes, or no? If the answer is yes, why are they putting these kids in categories? You know, if you aren't completely disabled, you don't meet this [criteria]; or you don't have intellectual.... you don't get support; you just don't get help.

Service delivery criteria varies with location. The criteria set for intervention was said to lack uniformity between DHB areas around Aotearoa New Zealand; therefore, depending on where a family was located, they might experience very different levels of service, or no service delivery at all. Variances in criteria are arguably connected with variances in facilities, and also funding, as DHB funding, and other forms of funding, can vary between locations,

Participant 7: For arguments sake, speech therapy; speech therapy might have a two to three year waiting list at A), in a particular geographical area, and you move to another area, B), and its instant access. You find criteria meeting access to speech therapy is different in each hospital board, so while you might qualify for access to some speech therapy in [one area], when you move to [another], you don't. So that's I mean; that was specific to some speech therapy and access to those actual services for assessment.

For one family, such was the desperation to be supported, and such was the variance

between DHB zones, that they moved across the country to a DHB with a reputation of being supportive. Such a move proved fruitful, at least initially,

Participant 2: That's why we moved, that's the sole reason we moved, was to get out of that DHB to try and get help for him. When we first moved here, we got help for him, but no, just as he's gotten older, no one wants to know, they just, put him in the too hard basket.

Criteria targets are short-term in nature. A frequent theme among participants was that their autistic children were discharged after achieving a target; although they still needed help, they did not fit the criteria to remain 'active' within the system, and receive assistance. Orientation towards short term service delivery may be linked to policy relating to finances and resources, as service providers operate within constraints of how many people they can help, and how long they can help them for,

Participant 1: currently she doesn't use any services at all, she had a psychologist up until last year. The other thing is, the psychologist, the way they do it with the DHB, you can only be in the system if you have a specific problem, at this particular time, so they have to work on a goal, and it's not generalised. So, her goal was she had a phobia about dogs, so she was allowed to see the psychologist for certain period of time to try to get over the fear of dogs. But once they had gone through that 'training', now she's been 'discharged'.

Examples were salient of family members also being discharged, despite not showing much improvement. In one instance, a neurotypical sibling attending a CAFS course for a problematic relationship with food, developed during a family crisis, was discharged despite the ongoing challenges with the relationship he had with food,

Participant 4: He did a course on his feelings with CAFS, which he really enjoyed, but I can't see a massive difference in him afterwards, and basically they are discharging

him now, he still has serious food problems, I mean, he will eat food out of a bin. He steals food from the cupboards, it's a massive part of how he comforts himself.

Diagnosed very late, the son of Participant 9 has been the recipient of very little service delivery. Having a son living in a reclusive medicated state, Participant 9 expressed frustration in that the one service providing some sense of hope, a youth worker, was under the threat of cessation before a relationship between service provider and receiver could adequately develop; the situation Participant 9's son is in was thought to require that such support was ongoing,

Participant 9: He is incredibly.... fragile, I guess, to change and uhm, you know, he didn't shower between Easter and mid-May; he has got really poor, basic, self-care; and you are talking about he can have this one service, the one service that is working, for just six months? It's insane! You know, it works because he is able to come into the home, and work with him, and build rapport, so there is some tiny crumb of hope that perhaps he could, the youth worker, could maybe get him into something, but he hasn't got there yet, and it's really early days.

People related issues. People-oriented explanations reflect the systemic concerns that relate to the professionals that service receivers interact with. While acknowledging that professionals work within the constraints of a policy driven environment, macro policy dictating local service delivery was brought under scrutiny as professionals demonstrated a willingness to work around the system to aid service receivers. Participant 1 demonstrated how policy orientated systemic flaws were worked around in her situation to achieve the desired results by education professionals who recognised the need, and were skilful in working around the system, and were willing to do so.

Participant 1: We did have something official through the education board, where they were trying to get more funding for her, because of her dyspraxia, basically it was to

do with funding, maybe her own computer, because she has trouble with handwriting, but that was turned down. So the school said, well just work that into our existing budget; its again, because the schools are willing to work around the system to help her, and help other kids like her, but it wasn't because the system was there.

Willingness was elsewhere articulated as 'attitude', as evidenced by the efforts school leadership and teachers

Questionnaire Participant: Educational needs depend a lot on the attitude of the principal and the teachers at the school. We have been fortunate to have fantastic teachers, teacher aides and principals. This aspect was more helpful than the actual programs themselves, since the Ministry of Education denied us funding for the said programs often, however the school would work around this issue to help our child.

Being a professional doesn't equate to being an expert. Most qualifications are generalised with the intent that professionals will develop expertise within their given profession. However, having a generalised qualification, such as a psychologist, or occupational therapist, provides a term which is broadly trusted by service receivers, even if expertise does not necessarily reflect the amount of trust given. There is power in the trust given to professionals with a qualification. Systemically, others accept referrals and recommendations and trust they can, in turn, have good faith that the appropriate methods have been used, and the correct course is being taken. Interpersonally, service receivers typically accept the recommendations, or decisions made by professionals in similar fashion. However, the role of expert that professionals command can also work against the interests of child and family, especially when working outside their expertise.

Evidence of professionals holding the role of expert, without the expertise to validate their status, is demonstrated by Participant 5, who reflects upon seeking confirmation of ASD. Participant 5 utilised existing knowledge and expertise (gained from having a parent on

the spectrum), which enabled her to challenge the doctor's expert role, and pursue private assessment, which prevented delays in early intervention. Participant 5 confirmed that doctors are held in high esteem as experts by most people, and their expert status is not often questioned,

Participant 5: it just seems so hard to get it (diagnosis). Most people would just listen to the hospital doctor, and take his word for it, oh he's the doctor, he knows what's what. You know, not so many people would go, "oh, he obviously doesn't know what he is talking about, I'll go somewhere else". There is no access for most people, unless they make a big deal of it, and they have some money.

The reported consequence of professionals lacking individual expertise, and being found to be operating below the standards of their key competencies by service receivers, was demonstrated to contribute towards an erosion of belief in the ability of professionals to be helpful,

Participant 5: I just think that a lot of health professionals are not very clued up, are quite old school; even the CAMHS person we saw was a bit useless, and this is a health professional that I should be looking up to, and hanging on their every word, instead, I was thinking, oh my gosh, she doesn't know what she's talking about!

Furthermore, individual lack of expertise, either demonstrated through misdiagnosis, or other service failures, was shown to erode confidence in the public health system altogether.

Participant 7: So anyway, we paid a large sum of money, for a private assessment, which I feel was a fair and accurate assessment. It involved a lot of time for the assessor, and for us, and travelling. Since then I have never touched the public system, I won't go near paediatricians, I won't go near CAMHS, I won't go near any of them.

Interviewer: Just a succession of.....?

Participant 7: Failures, yeah, I won't go near them.

Not knowing limitations of own expertise. Sound training in any area of expertise arguably also includes the awareness of the limitations of the training received, which brings into question the understanding of scope of how professionals are trained regarding ASD, and how the training is received, understood and applied. Fundamental understanding, according to participants, included the variable nature of ASD, and how services can be individualised to the needs of the individual on the spectrum, and their family. Yet professionals were said to have a misplaced confidence in their own skills, after minimal training, which led to professionals acting outside their understanding, beyond their skill set, and against the interests of the families they were working with,

Participant 4: I think specifically for children with ASD, I think that there is an issue with staff in organisations being given a certain amount of training with kids with ASD. Which leads them to believe they know what they are doing, and they don't!

Overruling of recommendations. Another consideration in the public domain is that the power to make decisions regarding who gets assistance, and who doesn't, should be held by specialists, healthcare professionals, and those who have expertise directly related to the concern which service delivery seeks to address. However, feedback from participants expressed the concern that bureaucrats and administrators, with no skills relating to the needs to be addressed, had power to overrule the recommendations of the specialists who they expected to be in control of such decisions,

Questionnaire Participant: A paediatrician or psychologist may have had many, many years of specialist training and constant upskilling but a NASC (Needs Assessment and Service Coordination) service has a person who is not necessarily formally trained making decisions that affect our lives and sometimes those decisions are contrary to what a specialist recommends as best practice. When a paediatrician refers

a kid for SLT (Speech and Language Therapy) and an administrator at [the Ministry of Education] does not agree then there is no SLT given.

The assumption drawn where administrators hold sway over specialists in their fields, is that the primary concern has shifted from evaluation of suitability and need for a service, to the prioritisation and dispensing of service, in the roles that administrators fulfil; and the concern which most underlines prioritisation and service denial is the lack of resources, which relates to resource orientated policy alluded to in the previous section,

Questionnaire Participant: All the agencies we work with have a 'point of contact' person. In our experience that person is really the funding and resource gate keeper. If they have poor understanding of ASD they can actually be detrimental to the family.

Discussion

In this section, the quantitative and qualitative results are summarised, particularly in relationship to each other. Results are then linked to existing literature, through comparison and contrasting, before real life application of the results are discussed. Next, the limitations of the research are reviewed before suggestions are made towards future research in this area of investigation.

This study investigated the extent to which services are individualised for children on the spectrum, and their families, taken from the viewpoint of primary caregiver, which most often came from mothers. Overall, the results and analyses indicated that services were not individualised across all three constructs of interest: accessibility, appropriateness and adequacy; and that ASD service delivery remains a 'wicked problem'.

Diagnosis

Stress. Quantitative analyses revealed that most questionnaire participants self-reported having high levels of stress around the time of diagnosis (the average ($M = 1.56$))

response tended towards being moderately stressed, while the modal response was very stressed).

Several studies (Ludlow et al., 2012; Myers et al., 2009) have documented elevated stress levels for parents, particularly mothers, in the day to day living of families, yet little research could be found which addresses the assumed levels of elevated stress around the time of diagnosis. While Keen, Couzens, Muspratt, and Rodger (2010) investigated the value of informational interventions on stress levels within a six month period following diagnosis, no studies could be located which encapsulated stress levels during the period surrounding diagnosis, which is inclusive of the supposed stress experience before, during, and after the diagnosis.

Diagnosis period information. Information seeking about ASD was a common activity around the period of diagnosis, with questionnaire participants most frequently accessing the internet, followed by books and magazines, and then support groups – which were also sources which were considered the most useful. This differed from Magaña et al. (2013); although they did report variances between Latino and White participants, especially in the use of the internet, their combined sample indicated that healthcare professionals were most favoured, followed by the internet, and then education professionals. This contrast of preferred sources illustrates the importance individualisation plays in post diagnosis information, as different caregivers within, and between, both the current study, and Magaña et al. (2013) often preferred different avenues of support.

Despite the reported access and preferences by questionnaire participants, the possibility of information packages (similar in concept to the Autism Speaks publication as used by Banach et al. (2010), but tailored to Aotearoa New Zealand), was broadly supported. Concerns for information packs were limited to the need for such a resource to be tailored to

the specifics relevant to one's diagnosis, and especially tailored towards different audiences (service provider, caregiver, or autistic child).

Diagnosis delays. Analysis of the qualitative data broadly demonstrated ASD diagnosis to be delayed, which was consistent with the understood status of ASD diagnosis in the NZASG (Ministries of Health and Education, 2008), as diagnosis is described there as inequitable and inconsistent. One constant thread which could partially explain such inequality (and that featured throughout most aspects of service delivery) was analysis which highlighted tension between the 'haves and have-nots', as caregivers recommended 'going private' as an avenue for optimal services delivery; and nowhere was this more apparent than themes related to obtaining diagnosis.

For those navigating the public health system, analyses of the narratives mentioning diagnosis delay identified themes of concern for caregivers, as potential barriers to prompt diagnosis were theorised by participants. Similar to Gomes et al. (2014), the number of steps in the referral and eventual diagnosis sequence was one subtheme that was identified as a barrier to diagnosis. However, other barrier orientated subthemes were also identified, which were not apparent in the literature, such as the effect service provider engagement has on securing diagnosis, regional disparities for diagnosis service provision - and regional variances in diagnostic standards and methods.

Impact of diagnosis

Through the use of thematic analysis, several themes were identified which all illustrated that having a diagnosis of ASD, or having a family member diagnosed, was a significant life event for all involved.

Impact for child. The perceived impact on children with ASD receiving their diagnosis was evident in participant narratives, with the main two themes involving the

decision of caregivers to disclose diagnosis to their child, and the acceptance or rejection following the disclosure.

The narratives surrounding disclosure mentioned the tension to disclose, or not; or, if disclosing diagnosis, weighing up how much is said. Fundamentally, caregivers expressed the desire to deliver clear information to their children about their condition, that was appropriate to their understanding. The fear of information overload involved the concern it would harm their child (through affecting their sense of self and creating stigma) rather than help (through validation of and explaining differences). Additionally, the decision to disclose, or delay disclosure, was at least in part informed by level of functioning. While delaying disclosure to what was considered an appropriate time was considered successful by some participants, other research has shown that the delay may induce responses that include “feelings of shock and disappointment, and not wanting to believe or know that they had autism” (Huws and Jones (2008, p. 102).

Where disclosure occurred among the narratives gathered, analysis revealed a tension between those who accepted, or rejected their own diagnosis. Acceptance appeared to put autistics on better standing on which to live their lives and resolve frustrations as they arose. On the other hand, rejection of diagnosis was expressed as a major stumbling block to move beyond merely living, to thriving. The value of acceptance has previously been conveyed through findings which illustrate the sense of community generated, and self-worth enhanced through efforts to receive recognition of strengths, not just deficits (Carmack, 2014; Singh, 2011). However, the researcher was unable to locate literature with which to compare denial-orientated findings, and at present the current findings are consistent with the intuition that acceptance is beneficial for progressing and thriving for those on spectrum, and that denial is counterproductive.

Impact for caregiver. Although the numerical data from the questionnaire had its limitations, participants did most often self-report having high levels of stress around the time of diagnosis (including after) which is consistent with Myers et al. (2009), Ludlow et al. (2012), and Keen et al. (2010). However, thematic analysis assisted in identifying other subthemes tied to the personal impact of caregivers beyond stress.

A deeply negative, immediate, and emotional impact, as experienced by several participants, was defined by descriptions such as being in shock, being ‘in trauma’, diagnosis causing ongoing personal health concerns, being reduced to tears, being fearful of the unknown, or self-describing as going through a grieving process; all of which were not too dissimilar from themes identified by Banach et al. (2010). Similarly, other participants also reported positive themes, such as a sense of relief, reassurance, and vindication, which also draws parallels to the findings of Banach et al. (2010), and recommendations found in the NZASG (Ministries of Health and Education, 2008).

However, other talk about impact from participants illustrated the same emotional symptoms, but on a different timeline than the first kind of immediate impact, as delayed reaction occurred days, sometimes weeks, after the fact. Furthermore, perhaps the newest and most informative subtheme derived in this area, was how participants shared that the emotional impact of diagnosis was felt through what could be envisioned as an ‘alternative stages of development’ for their child, where further impacts could occur in stages when their own child failed to progress in parallel to peers their same age. Alternative development was explained Participant 1 by using the example of other girls moving through the socially expected stages and being interested in boys; whereas her own daughter was still interested in My Little Ponies. No literature could be located which reported such variances in an impact timeline postdiagnosis, as identified in this research.

Spousal impact. Consistent with Saini et al. (2015), Baker-Ericzn et al. (2005), and Freedman et al. (2012), there were only a few qualitative narratives mentioning a relationship dissolution among participants; furthermore, among those who did report a break up, the child's diagnosis was only cited as the dominating factor for one participant. However, also consistent with the findings of Freedman et al. (2012) and Saini et al. (2015), among others, were thematic subthemes to support the understanding that caregiver relationships were under significant strain.

A related thematic subtheme that evolved from addressing relationship strain, was fathers struggling with their fatherhood role with their autistic children, independent of any relationship strain. Kiwi culture, the associated cultural expectations of being a kiwi male, and personally navigating the cultural expectations of fatherhood (such as play and interaction) within the kiwi culture, were reported to be difficult for fathers. Similarities exist between the narratives highlighting masculinity and fatherhood within kiwi culture, and the literature that proposes that fathers have their own unique interaction styles with their autistic children, which remain unutilised in individualised service delivery (Elder, Valcante, Won, & Zylis, 2003; Elder et al., 2005). Future research could further deconstruct what fathers' unique interaction styles entail, and compare them against a more in-depth analysis about what is entailed in being a kiwi male. Additionally, the low response rate for men within the research (one father, and one uncle in 34 participants), even with the small sample size, suggests that barriers exist not only in the day to day interaction, but also in the participation of research.

Family impact. Other themes were constructed from narratives which accounted for how the family, as a collective entity, was impacted by diagnosis. While the first of the subthemes reaffirmed a common narrative of the uniqueness of families in the literature (Dunlap & Fox, 1999; Fox et al., 2002; Gardiner & Iarocci, 2012), the second of the

subthemes discussed was the need to re-establish a family identity, ways of functioning, and progressing towards collective goals, in response to the former identities that were not compatible with having an autistic family member.

Research is beginning to emerge which articulates both the loss of previous family identities / and the rewriting new identities (Hays & Colaner, 2016). The main themes identified as challenging for developing a family identity by Rodger and Umaibalan (2011) were that life revolved around autism, a sense of being 'robbed' among family members, the degree of engagement required to occupy or pacify a child with behavioural challenges, and the lack of opportunities to feel like a family. The main themes identified by Hays and Colaner (2016) for rewriting family identities were divided between internal and external actions and narratives. Internally, families were unified through the "usage of the name "autism," emotive and mundane daily discussions, narratives that serve functional purposes, and normal/structured rituals". Externally, efforts were made to educate and promote understanding for others, to emphasise loyalty and protection of the family, and also the normalcy of the family (Hays & Colaner, 2016).

Participating in society

Discussion here differs from the personal impact as experienced by child, and family, as it focuses on experience based themes derived from attempting to have child, and family, included into the community, and the barriers encountered in the process.

Role acquisition. Because adult involvement is pivotal in accessing the broader community, the role acquisition theme framed the narratives which showed that caregivers, most often mothers, often assumed several additional roles beyond those normally associated with motherhood.

Role acquisition has similarly been identified by Safe, Joosten, and Molineux (2012) as mothers of autistic children framed themselves as therapists, educators, defenders and

advocates due to limitations in the services provided; diminished trust in professionals as a result of prior service failure; and the expectations placed upon mothers to conduct home programs. Furthermore, Julia B. Stoner and Angell (2006) also identified the additional roles of negotiator, monitor, advocate and supporter when specifically addressing engagement with education professionals. The roles identified in both studies bear resemblance to the present research, as the roles of advocate, educator, and therapist were all indicating similar responsibilities; even the role of monitor in Julia B. Stoner and Angell (2006) is similar to the ASD services expert used in this study.

Bullying.

Children. Thematic analysis highlighted that children with autism were bullied, and for some children the frequency approached being almost constant. Bullying took the form of both physical and emotional violence, and the consequences were felt long after the fact.

Although the NZASG advises that educators should be on the lookout for bullying behaviour, no research was located within Aotearoa New Zealand which addresses this issue. In a review of ASD related victimisation, Schroeder, Cappadocia, Bebkco, Pepler, and Weiss (2014) note that despite parents and clinicians widely accepting children and young people with ASD experience more bullying behaviour than their neurotypical counterparts, research conducted in this area has been scarce. Combined, the studies reviewed by Schroeder et al. (2014) were said to confirm that children and young people with autism were perceived to be more likely to be the recipient of “physical, verbal, and relational forms of bullying relative to the general population” .

Adults. Although caregivers were not reportedly physically abused, as some of their children were, other methods of bullying were reportedly employed such as intimidation, social control, and being unheard. Bullying was said to most often occur when acquiring, and

acting within, one of the additional roles identified in the literature, particularly the role of advocate, negotiator, or monitor (Safe et al., 2012; Julia B. Stoner & Angell, 2006).

The only method of bullying which was successfully challenged by participants was being unheard; when this was successful it was achieved by reducing power distance through the application of knowledge, and the utilisation of terminology in social exchanges which signified a caregiver to be on par with a given professional. Furthermore, the changing of power distance was a challenge, as it reduced some of the privileged status of professionals; consequently, reduction in power wasn't reported to be given freely by professionals (to parents or to other professionals). No literature could be found which addresses bullying treatment received by caregivers when acting on behalf of their autistic children.

Social space configuration. Thematic analysis generated subthemes, which (when combined) convey the impression that the planning, construction and running of a society's physical environment is not conducive to the needs of autistic children and their families.

Most of the literature surrounding social space configuration is directed towards how present spaces are being run, more specifically recreational spaces. Themes similar to the current study were identified by Schleien, Miller, Walton, and Pruett (2014) who found that the battle for access for recreational facilities was fatiguing for parents, and that parents wanted to send a clear message that current inaccessibility was not acceptable. Where Schleien et al. (2014) differs from the present study, is where they were also able to identify themes relating to experiences of isolation; the tension between keeping their child safe, and their child being included; and also the unrealised dreams and desires for their children that had not yet been realised. Thompson and Emira (2011) also found themes relating to accessibility, the feeling of isolation, but also found others such which influenced if, and how, facilities were able to be utilised, such as the degree of staff training, and staff attitudes, and a lack of engagement.

Further literature surrounding the construction of social spaces, and management of it, is yet to be conducted. While provision is rightfully made in Aotearoa New Zealand for wheelchair access, and guide dogs for its citizens to overcome the barriers of immobility and blindness, other citizens on the spectrum, as featured in this study, have barriers due to crowding, loud sounds, and bright lights. Even with the lack of research in this facet of service delivery, advocacy groups and some businesses (such as Autism Spectrum Australia (Aspect) and Australian supermarket chain Coles) have worked together towards initiatives in lowering sensory stimuli; New Zealand advocacy group Autism New Zealand hopes such partnerships can build towards initiatives being undertaken in Aotearoa New Zealand (Radio New Zealand, 2017).

Meeting with the family at their level. The themes identified regarding connections between service providers and families in the qualitative narratives highlighted concerns about professionals being able to connect with families at their level, particularly in regard to the spiritual beliefs practiced by the family. The only other research to date in Aotearoa New Zealand which addresses issues of family-centeredness and ecology in service delivery was conducted by Bevan-Brown (2004) which contains themes regarding the connection between service providers and Māori families, and expectations of the provision of services for Māori that is consistent with Māoritanga (culture, practices, beliefs and way of life for Māori). As with the present study, Māori families shared concerns about how their way of life did not receive the consideration into services delivery, but were also able to offer ideas for integration of Māoritanga into existing procedures and practices (Bevan-Brown, 2004).

All of the literature located from abroad is supportive of the sort of service individualisation that also accounts for the ecology of families, with most of the literature describing how Individualised Family Service Plans (IFSP) are designed and implemented under the Individuals with Disabilities Education Act (IDEA) in the United States, as

described in Fox et al. (2002). Furthermore, while the likes of Stahmer et al. (2011) list several ways in which family characteristics need to be considered (“ethnicity, culture, marital status, parental attitudes, parental age, level of education, socioeconomic status” Stahmer et al. (2011, p. 236)), they also assert that this field of research is only just beginning to investigate how family variables interact with treatment and service effectiveness.

Locally, among all the recommendations presented in the NZASG, are calls for positivity, expertise, and a “willingness to work in a team with the family” (Ministries of Health and Education, 2008, p. 22).

Parents as the ‘problem’ Thematic analysis of the qualitative data also produced subthemes relating to interpersonal connection issues which ran deeper than a broad sense of there being a lack of fit between families and services providers, as caregivers themselves were portrayed as the sole reason for both service success and failure.

The real-life application for this finding is that where caregivers are single; don’t naturally function or interact a particular way; or can’t or won’t conform (due to workload and number of roles); then this may result in inferior service delivery, or no service delivery at all. However, having to have a particular style of interaction, or family configuration, in order to receive optimal service delivery, is arguably the opposite of service individualisation.

Service providers lack understanding and skills. Thematic analysis of participants’ narratives led to identifying themes which conveyed the sense that professionals often lacked understanding; both in terms of the nature and presentation of ASD, and also what day to day life was like with a family member with ASD. Professionals were also said to lack ASD specific skills and training, which would improve the accuracy of diagnosis (e.g. being ADOS trained), and the efficacy of treatments and interventions, and consequently, many participants went on to further state that additional training was needed. An important point

was raised by one participant in that it was her view that children on the spectrum spend most of their time with the professionals who are least skilled and educated (or paraprofessionals).

Although not yet a well-established area of investigation in the literature, support was found for notion that professionals often lacked ASD specific skills (Dymond, Gilson, & Myran, 2007), especially so in the education sector (Simpson, 2004; Starr, Foy, & Cramer, 2001). Concerns over increased use of undertrained paraprofessionals was also similarly raised by Rispoli, Neely, Lang, and Ganz (2011) who listed potential pitfalls, such as “creating prompt dependency, evoking and escalating challenging behaviours and inhibiting academic and social progress” (Rispoli et al., 2011, p. 379). However, in the same review by Rispoli et al. (2011), a summary is also offered of the existing intervention methods to upskill such paraprofessionals.

These findings suggest that both professionals and paraprofessionals need to upskill to ensure that their methods of interaction, and intervention are compatible with current understanding with ASD, taking special consideration for the fundamental of variance and lived experience between different people on the spectrum.

Not knowing where to look for help. This theme captured the narratives where participants felt that they didn’t know where to turn for help, or if the kind of help that was needed even existed. While this theme is related to service accessibility in its broadest sense, as people cannot access what they aren’t aware of, narratives from participants raised deeper questions surrounding service accessibility, such as, would a service be otherwise accessible if it had been known about? Or, is the secrecy of services just one method of deliberately preventing service uptake? Being unaware of help was also seen as having long term effects on both child and family, as it was said that provision is not made towards ‘playing catching-up’ for those who slip through service delivery cracks.

Few studies address service awareness, the most notable being Bromley et al. (2004), and Hare, Pratt, Burton, Bromley, and Emerson (2004) who investigated service delivery awareness among mothers and familial carers for children, and adults, with ASD respectively. While Bromley et al. (2004) showed that mothers were mostly aware of all services featured, a broader snapshot of possible services by Hare et al. (2004) captured wide contrasts in levels of reported awareness by familial carers ranging from most participants in their sample ($N = 26$), to almost none, being aware of particular services.

Thus, potential services that a family might apply for are not evident for some caregivers. While questions raised about how intentional such secrecy is might be hard to answer, it is apparent that caregivers wish for greater transparency about all the possibilities they might be eligible. A suggested avenue by one participant, was that service possibilities and the contact information for the applicable professionals should both be an integral part of post diagnosis information packs.

Honouring commitments. The importance of service providers making good on commitments made to service receivers was another theme that held meaning at face value i.e., that a service was delivered, but it also held other value as service receivers saw lapses as breaches of trust, which often led to the erosion of the provider-receiver relationship and affected the way caregivers chose to engage with service providers in the future. The real-life application for service receivers here is self-evident. Additionally, the consequences for future service providers is that their task towards individualising services might be made different, and more difficult, as family ecology evolves towards a defensive mode of operation against those from without, who are not trusted.

No literature could be located which bore any similarities to the themes of, the importance of honouring commitments, and the consequences of losing trust.

Services delivered are not what is needed. This area of analysis is, at face value, primarily addressing appropriateness in the realm of intervention services, and to a lesser extent, in the realm of family ecology. Many narratives were drawn upon in identifying a what appeared to be a sense of frustration with the preoccupation that many services providers had in providing a circuit of lectures, and little else. Education for caregivers was said to be useful, up to a point; but without practical help to augment the education, it was generally felt that it was hard to see their family situation improve. No literature was identified which included themes related to resistance education-only service responses.

Gatekeeping. The theme of gatekeeping, of controlling or limiting service access, was framed by drawing upon other service delivery themes such as bullying; preferred styles of engagement; the absence of diagnosis or referral which also performed the function of gatekeeping; and strict criteria, or unreasonable criteria; and also the problem of satisfying administrators when specialists had already been satisfied that assistance was justified. Gatekeeping was also demonstrated through newly introduced examples of encouraging autistic children to be placed elsewhere, and where the appearance of disability was reported to detract from the standing and appearance from schools.

Little research is salient which names and directly addresses the gatekeeping of ASD services; what literature could be sourced, including the present findings, appeared to fall into two broad categories: firstly, gatekeeping for the purposes of managing resources, and secondly, for the purposes of maintaining standing and image (which can also be connected to resources). In Aotearoa New Zealand, the gatekeeping reported by Bevan-Brown (2004) appears to be gatekeeping of the first sort, where the themes reported highlighted instances of service access being curtailed due to stringent criteria, and problems with the referral process where service was denied because of perceived overuse of services.

In contrast, the research conducted by Lilley (2013), leans towards gatekeeping of the second kind as themes here reference how autism is constructed as “individual impairment and undesirable difference” (Lilley, 2013, p. 522) within a culture of disablism. The first of two general thematic strategies employed, was the citing of own organisational inadequacy and limited resources when encouraging placement in other schools, and even suggesting children be placed out of the current region, removing the ‘problem’ completely. The second of the thematic strategies reported, was the citing the importance of the ‘common good’, where the decile rating and standing of the school was protected from students with ASD, who might lower it with poor academic performance. Both strategies were similarly employed in both private and public schooling sectors.

These findings suggest that the obstacles some families face in accessing services are multifaceted and may include professionals who potentially have agendas to follow; the most overt of reasons for denial of service is the lack of funding, or the child not reaching a criteria threshold; while the covert reasons for gatekeeping involve social standing, status, and the appearance of disability – of the two forms, it is argued that the overt is most easily addressed.

Systemic causes

Thematic analyses in this section alluded to participants narratives which raised connections between immediate concerns with specific aspects of a particular service, and broader systemic issues which were thought to be the cause of the problem. Systemic causes were divided into two general groupings, those that attributed the cause as being policy orientated, and others which were said to be people orientated. Additionally, possible interplay between systemic causes were recognised, especially in regard to policy related themes which were said to have far reaching implications. For example, resource policy had theorised links to other policy orientated issues, such as how criteria were set. Furthermore,

links were also theorised to people orientated issues, especially where administrators were seen to overrule specialists' recommendations.

Policy related systemic causes. Themes in this section were the product of analyses which framed the dialogue that was used by participants to describe how the system was a product of policy which is inherently political in nature; political institutions such as governments, both general and local, were identified as the architects of such policy.

Lack of resources. Perhaps one of the most often mentioned concerns among participants' narratives, was the perceived lack of resources from which service delivery were funded. Similar findings were also reported in Aotearoa New Zealand by Bevan-Brown (2004), who also reported concerns around the lack of transparency in the funding process; that funding systems were largely ineffective; and how disparities and funding cuts were a concern.

Of particular interest in the present study, the work of Bevan-Brown (2004), and the literature abroad, were the methods utilised by different parties to circumvent issues arising from the lack of resources, which was accepted to be the status quo in all relevant literature viewed. Combined locally the most salient strategy was the act of 'topping up' by caregivers, and schools, with Bevan-Brown (2004) particularly identifying that teacher aide hours was the target of topping up by parents. The other strategy which is most salient in the literature that outlines service provision within limited funding environments is that of diagnostic "upgrading", whereby clinicians exaggerate symptoms which are ambiguous, or uncertain, to ensure that they receive the desired service provision following diagnosis (Skellern, Schluter, & McDowell, 2005). In the first study of its kind, Skellern et al. (2005) found that 58% of the 93 practicing diagnosticians in Queensland, Australia volunteered that they personally engaged in upgrading, for the eventual provision of services for their clients. More recently, Rogers, Goddard, Hill, Henry, and Crane (2016) similarly found that most diagnosticians

surveyed (68%) in the UK would also engage in the practice of ‘upgrading’ in complex or uncertain cases; the reasoning options offered for such upgrading showed that a client’s eventual acceptance for funding or support (22%), or special education needs (10%) were motivating factors in upgrading, while many other participants reportedly felt that their justification did not fit within the specific categories offered.

The real-life application of the findings in this section mirrors the limited funding and the strategies by parents, schools and diagnosticians to attempt to prioritise those in their care. Arguably the downside for some caregivers, would be not having access or knowledge of other people, or institutions who will bend the system for the benefit of their child, through either ‘topping up’, or ‘upgrading’. For those who are neither well-resourced themselves, nor living in a well-resourced community, the likelihood of topping up is arguably reduced, which may create a further divide between the haves and the have-nots.

Services lack continuity. Thematic analysis also identified a lack of inter-service continuity among caregivers, which resulted in poor communication, succession planning, and information sharing. Inter-service continuity is here considered to be a policy orientated problem as the vast majority of services on offer, and total expenditure on services, is assumed to be found within the public sector. As such, the Aotearoa New Zealand government provides the framework for service provision, especially where they provide funding for subordinate bodies such as DHBs, and external agencies. No other studies addressing ASD service continuity were found to originate in Aotearoa New Zealand.

Some literature has been produced abroad which addressed service continuity as a barrier to ASD service delivery, many of which reference an early study by Kohler (1999) who demonstrated several strategies were used to overcome service continuity issues, some of which reportedly initiated by parents, others were demonstrative of services seizing the initiative. Since then, several studies have shown that the coordination that caregivers and

their families both need, and desire, have not been satisfactorily met (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012; Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Kogan et al., 2008; Rivard, Lépine, Mercier, & Morin, 2015).

The real-application for these findings draws upon previous discussion of role acquisition; where participants reportedly find services in disarray, the role of a coordinator is an additional role that could otherwise be filled by a professional who has the time, knowledge, expertise, and passion to coordinate different services. This further argues for the importance of such experts in the role of a caseworker, key worker, or Kaiarahi, as proposed in the NZASG (Ministries of Health and Education, 2008). However, as with the reservations raised earlier regarding coordinators, putting ‘all the eggs in one basket’, within the role of one professional, was seen as a mistake.

Professionals need better preparation. Systemic processes of educating and accrediting the professionals which work with those with ASD was framed as inadequate, with teachers, in particular, being identified as joining the workforce with minimal preparation for the challenges that students on the spectrum might present. Little literature has been conducted in this area, with Helps, Newsom-Davis, and Callias (1999) reporting that teachers and support staff in particular had quite different views on ASD, compared to mental health professionals, with the majority of them receiving little or no training on ASD; and Rodríguez, Saldana, and Moreno (2012) also observing that training has a powerful influence on perception, and the likelihood of inclusive mindsets being developed among teachers and support workers.

Instead, much of the literature focuses on upskilling of both existing teachers, as well as other existing professionals, with key competencies (Hendricks, 2007; Ling & Mak, 2012; Small, 2012); additionally, the underlying concern remains that professionals are not ready to provide the service their job might entail, and the question remains about how much damage

might occur before a given individual, organisation, or institution is motivated towards ensuring that a level of competency is achieved.

Criteria. The themes which were illustrative of the problems reported by systemically fixed criteria showed that diagnoses could vary between DHB region, as could other forms of service delivery; and that requirements to receive assistance were difficult to meet. Few instances of research could be located which specifically addressed criteria narrowness for service delivery. However, different studies in the United States have illustrated how governmental policy provided space for each state to set their own criteria across a number of service delivery domains, in effect producing inter-state variances in diagnosis, prevalence, the setting of criteria for special education assistance (MacFarlane & Kanaya, 2009; Pennington, Cullinan, & Southern, 2014; Rzhetsky et al., 2014), and the availability of health insurance options which cover ASD services (R. A. Johnson, Danis, & Hafner-Eaton, 2014). This suggests that Aotearoa New Zealand is not alone in having regionally subordinate bodies, within which different standards are in use, and consequently different service outcomes are likely.

People related systemic causes. While acknowledging that professionals operate within constraints in a policy laden service delivery environment that isn't necessarily of their making, themes here expressed challenges to systems, and systemic policy, or 'working around the system' that professionals did not think were fit for use for their clients. This also demonstrated professionals as agents of their own mind, and not merely to be acted upon. Early discussion has shown other instances of professionals, (and sometimes families) working around policy problems associated with the lack of resources, through 'upgrading' (Shattuck & Grosse, 2007; Skellern et al., 2005), or 'topping-up' as was reported in this study, and by Bevan-Brown (2004).

Being a professional does not equate to being an expert. In contrast to the highly skilled and motivated individuals who assisted families to navigate their way around systemic barriers, other professionals were perceived as an additional hindrance by caregivers and their families. The role of expert was identified as problematic where professionals were found to be operating outside of their level of expertise. Challenging the status and expert role was a challenge within itself, as it was reported that the tendency among most was to trust a professional in such a position. The additional concern arises where professionals are not aware of any deficiency in their own expertise. No other research could be located which identified this interpersonal dynamic within the context of ASD service delivery. In instances where professionals operate outside their expertise, and where caregivers are none the wiser to any deficiency, the concern is that that inferior service delivery will occur, if at all.

Research strengths

Giving voice. The research provided conversational space for caregivers to raise their views on autism service delivery for families in Aotearoa New Zealand. The act of participating in research was expressed as an important opportunity by participants, as they frequently felt unheard, and had their expertise ignored, in exchanges with service providers.

Importantly, participants were afforded the opportunity to give voice to the interplay between service failure and the acquisition of additional roles beyond those of being a caregiver. The likelihood of future service uptake was also shown to put in jeopardy by service failure, as the erosion of trust prevented caregivers from reaching out for assistance. The combined effect of additional roles, and not feeling able to trust service providers, meant that participants often felt stuck in a downward spiral of stress and emotional fatigue.

Contribution to local and individualisation literature. This research adds to the small body of literature in Aotearoa New Zealand which addresses the support needs of both autistic children and their families. Additionally, the present study also one of the first studies

to directly focus on service individualisation. While additional forms of analysis were not able to be undertaken, particularly on the quantitative data, it does provide a starting point for future research on individualisation and provokes thought on how individualisation might be operationalised and measured in the future.

Flexibility of chosen method. The mixed-methods design was suitable for both quantitative and qualitative data forms to confirm, cross-validate, corroborate or contradict one another. Despite the lower than hoped for questionnaire completions, the low response rate did not spell the end of the research. Rather, the equality of data priority was able to be shifted to prioritising the qualitative data during analysis.

Research weaknesses

Sample size. The first limitation was not achieving a large enough sample through recruitment for the online questionnaire, and incompletions of the questionnaire further reduced the data pool. As mentioned previously, having such a low rate of response meant that only the most basic of descriptive analyses were able to be conducted, and more complex analyses, such as tests of significance, were not appropriate to undertake. Furthermore, the small sample size also affected data analysis through the chosen method of concurrent triangulation. Creswell et al. (2003) advocate for equal priority, where possible, when utilising this method. However, since limited analyses were able to be conducted on the quantitative data, few instances arose where data between the two types was suitable for confirmation, cross-validation, corroboration or contradiction, as originally hoped during the research design.

Sample characteristics through recruitment methods. Recruitment through social media, advocacy organisations, and targeted public advertising, meant that the sample was descriptive in terms of those exposed through each avenue, but not descriptive of the entire

population of primary caregivers of children with autism. For example, differences in history with connecting with Autism New Zealand among caregivers differed among participants who were referred immediately after diagnosis, or found this organisation on their own accord; who maintain contact with this organisation, or those who have severed all ties. Differences among participants' initial contact differed depending on DHB location, whereas differences in maintaining contact also included interpersonal and philosophical differences.

Recent efforts abroad to move beyond recruitment biases around location and formal contact mechanisms are focused on the development of autism research registries or databases with which families can register their details for future participation, with the ASD-UK and Daslⁿe databases in the United Kingdom providing research access for over 3000 families (at the time of publication) and growing (Brett, Warnell, McConachie, & Parr, 2016; Warnell et al., 2015). In the United States, registries are also being developed within various institutions. However the most visible registry is the Interactive Autism Network, which is supported by Autism Speaks (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010). Yet biases are likely against this platform due to the position many self-advocacy organisations take against Autism Speaks given their history of having a 'cure agenda'. Such databases, or registries, for research opportunities are yet to be organised in Aotearoa New Zealand.

Sample characteristics of respondents. Although most research to date has focused on mothers of autistic children (Elder et al., 2003; Elder et al., 2005; Flippin & Crais, 2011), the present research took an inclusive approach in inviting anyone in a primary caregiving role to participate. Despite working with data from just 34 questionnaire respondents, male respondents were in the minority with just two participants numbered. Additionally, no men participated in the interview portion of the research which meant what numerical data was collected, and the stories that were told, were predominantly from the perspective of women.

Māori are also underrepresented in research, especially ASD research, and although none of the interview participants identified as being Māori or expressed a desire for a cultural or religious component to be included in the interview process, 35% of the questionnaire participants did identify as being Māori. However, even with a high representation among respondents, analyses were unable to be pursued due to sample size.

Future recommendations

Improving access for both researchers and participants. With little research available to draw upon in Aotearoa New Zealand, few examples were available to demonstrate successful pathways for recruiting participants. A master's thesis by Billie Searing (2014) at Otago University similarly used convenience sampling which included advertising promoted through ASD related organisations such as Autism New Zealand and Parent 2 Parent, and also advertisements on relevant Facebook groups. However, the current study was not able to secure a similar level of support from most ASD orientated organisations in Aotearoa New Zealand; only the IHC NZ was available to assisting in the recruitment process with a nationwide email advertisement. During the negotiation for support, it was observed by one spokesperson that ASD related organisations in Aotearoa New Zealand aren't structurally organised to deal with inquiries for research support.

The first recommendation reflects the connection between researchers and participants. As it has been illustrated above, different researchers are able to access different levels of participation, and consequently may end up with very different sample sizes. On the other hand participants are also reported to struggle as Warnell et al. (2015) broadly claim that in the UK families do want to participate in research, but lack the connections to make participation accessible. However, the desire to continue to participate in ASD research among participants has not been mapped here in Aotearoa New Zealand. Anecdotal feedback received during recruitment suggests that while most people view research involvement is

important, there are also those who have reached saturation point with their own participation, and others who seek to conserve their energy in participating in studies undertaken by well-known organisations. If the desire can be established, then the first recommendation would be to establish a research database, or registry, for autism research to increase accessibility for both researchers and participants.

Autistic participants. While the current research considers the entire family from the perspective of the caregiver who is best suited to consider the whole family, little research has been done with autistics, especially adult autistics as the primary source of data on service delivery. Future research, which has the correct ethical considerations within its scope, should seek to include those on the spectrum wherever possible.

Men. Men continue to be underrepresented in caregiver participant research, and future research should consider investigating barriers to participation in light of evidence in the present study which suggests that traditional masculinity within the Kiwi culture is problematic for service recipients.

Deconstructing individualisation. The constructs of accessibility, adequacy, and appropriateness, as used in the present study, are proposed as a starting point for further analysis of what effectively constitutes individualisation, and how to assess the extent of it within a delivered, offered, theorised, or hoped-for service. Although individualisation is seen as vital across the literature, further research is needed to develop effective models and guidelines to ensure that service providers are well equipped to deliver services in the best ways, and service receivers have a reference point with which they can evaluate their own situation.

Appendix A. Steering Group Representation

The Steering Group members include representation from:

- Adults with ASD
- Parents/families of people with ASD
- The Paediatric Society
- The Faculty of Child and Adolescent Psychiatry of the Royal Australia and New Zealand College of Psychiatrists
- Disability provider organisations
- Needs Assessment Service Coordination (NASC) services;
- Child, Youth and Family
- Pacific advisors
- School principals
- Early intervention services
- The Ministry of Education and Special Education (GSE)
- Disability Services
- Māori Health
- Clinical Services
- Mental Health directorates within the Ministry of Health

Appendix B. Legislation, Standards and Policies Impacting The NZASG

Legislation and standards

- Human Rights Act 1993
- New Zealand Bill of Rights Act 1990
- New Zealand Public Health and Disability Act 2000
- Health and Disability Services (Safety) Act 2001
- Health Practitioners Competence Assurance Act 2003
- Health Act 1956
- Public Finance Act 1989
- Public Audit Act 2001
- State Sector Act 1988
- Education Act 1989
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
- Health and Disability Commissioner Act 1994
- Code of Health and Disability Consumers' Rights 1996
- Children, Young Persons and Their Families Act 1989
- Criminal Procedure (Mentally Impaired Persons) Act 2003
- The Mental Health (Compulsory Assessment and Treatment) Act 1992
- National Mental Health standard

Policies

- Ministry of Health – Statement of Intent
- New Zealand Health Strategy
- New Zealand Disability Strategy
- He Korowai Oranga – Māori Health Strategy
- Blueprint for Mental Health Services in New Zealand

- Child Health Strategy
- Primary Care Health Strategy
- Te Tahuhu, Improving Mental Health 2005–2015

Appendix C. Service Barriers for Māori Families

- Shortage of services and qualified personnel
- Difficulty accessing services
- Funding issues
- Lack of information
- Financial strain
- Assessment hassles
- Organisational, system and procedural hassles
- A lack of knowledge amongst professionals
- Detrimental attitudes
- Parental stress
- Other barriers to social interaction and development

(Bevan-Brown, 2004)

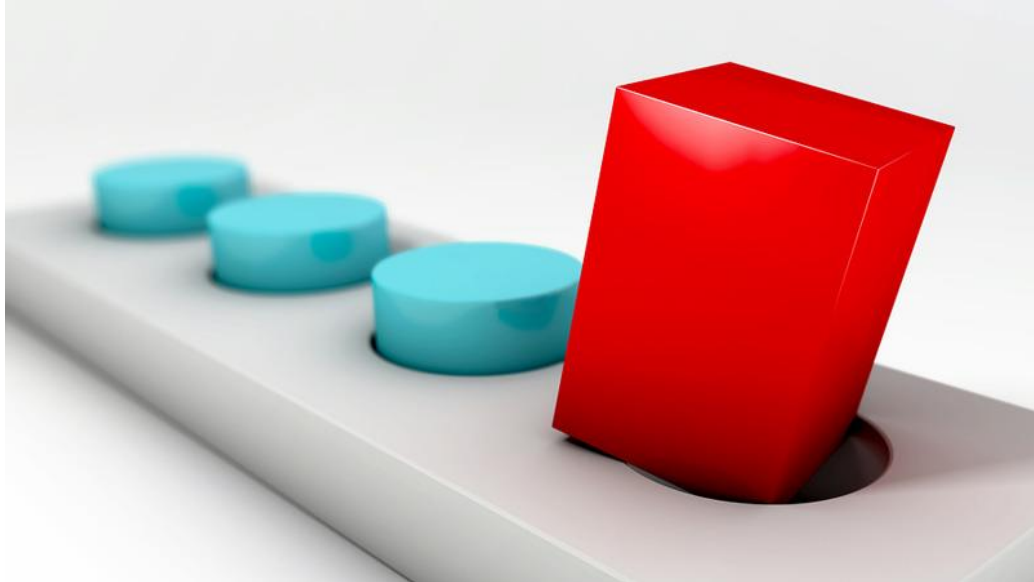
Appendix D. Barriers to Māori Service Utilization

- Differential diagnosis/misdiagnosis
- Geographic isolation (access difficulties and isolation)
- Funding and resource constraints
- Lack of culturally appropriate professionals, services and contexts
- Lack of information available for whānau
- Lack of whānau support, the resource constraints of single parenting, or the needs of other children
- Reluctance to seek treatment or a delay in treatment seeking
- Time to access respite care from initial inquiry to first response.

(Ministries of Health and Education, 2008)

Appendix E. Online Questionnaire Advertisement

ASD support services – how well do they fit?



Like other things in life, ASD support services which may suit some perfectly, may not be helpful at all for others.

If you are a caregiver of a child / young person on the spectrum, we are interested in how well different support services meet the unique needs of both your child / young person, and your family.

For the purposes of the research, we are looking for people who:

- are adult (18 years or older) primary caregivers, or co-primary caregivers, of children / young people with ASD aged between three and sixteen years.
- have resided in Aotearoa New Zealand, for a minimum of six months
- have received a clinical diagnosis of ASD for the children / young people in their care, a minimum of six months ago.
- are not employed as a professional healthcare providers for someone with ASD.

For further information on this research, and how to participate, please click the hyperlink below, email the research team, or scan the QR Code:

asdresearchmanawatuserservices@outlook.com

https://jfe.qualtrics.com/form/SV_1HXHrsMfkNrOBOB



Appendix F. Online Questionnaire Infosheet



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

School of Psychology
Massey University
Private Bag 11-222
Palmerston North 4442

Telephone : +64 6 356-9099 Extn 85071
Facsimile : +64 6 350-5673

Support needs of families with a child with ASD

ONLINE SURVEY INFORMATION SHEET

Researcher Introduction

My name is David West, and I am undertaking this research as a requirement for completing a Master's Degree in Psychology, at Massey University.

Project Description and Invitation

Although Autism Spectrum Disorder (ASD) is an increasingly common diagnosis, people on the spectrum, and their families, can experience life in very different ways. Since no particular treatment or intervention will work the same way for every person on the spectrum, or each family, there are calls to individualise services to those with ASD, and their families.

Thank you for showing interest in this research. As we invite caregivers of those with ASD to participate, we hope to be able to investigate whether or not services cater for the uniqueness of both the individual with ASD, and their families; in particular, if services are appropriate, accessible and adequate. We hope that this online survey will help us to achieve these goals.

If you choose to participate, please be assured that your insight, your experience, your views, and your feedback are valued and appreciated.

Participant Identification and Recruitment

Recruitment for the online survey is open to caregivers of those with an ASD diagnosis, across Aotearoa / New Zealand. Recruitment is being achieved through Autism New Zealand, who have notified their members regarding this research.

We ask that as a caregiver you only complete the survey once. If you care for more than one child on the spectrum, the survey allows you to comment on the services received for each of them.

For the purposes of the research, all participants must:

- be an adult (18 years or older) primary caregiver, or co-primary caregiver, of a child with ASD aged between three and sixteen years.

- have resided in New Zealand, for a minimum of six months
- have received a clinical diagnosis of ASD for the child / young person in their care, a minimum of six months ago.
- not be employed as a service care provider for those with ASD

* Please note, while we would like as many caregivers as possible to be involved, thinking about experiences with support services may be distressing for some. Please take into consideration any existing health, or mental health, conditions before deciding whether or not to participate.

Project Procedures

If you show interest by email, you will receive instructions for participating in the survey. Alternatively, you can click on the access button below.

The online survey will ask you several questions about the delivery of supports and services you have experienced as caregiver of a child / young person with ASD.

Participating in the survey is a variable time commitment. Some participants, with few experiences with support services, may complete the survey in as little as 15 minutes. For others, with more experiences to draw upon, or more children / young people with ASD, it may take much longer. However, if cookies are enabled on your web browser, your progress will be saved if you need.

Data Management Policy

The data gathered will be used strictly for the purposes of this research.

Once recorded, all data will be stored in a password protected online storage facility, which has been created for the purposes of this research only. All data will be stored for a minimum of 5 years, at which point it will be disposed.

When the research is complete, we will contact you by email to offer you a copy of the findings. Aggregated findings will also be shared with others by:

- publication in a journal article
- providing copies of the thesis to the MidCentral DHB and IHC New Zealand
- presenting at conferences, where appropriate

Summary of Participant's Rights

Please be aware, you are under no obligation to accept this invitation.

If you decide to participate in the online survey, you have the right to:

- decline to answer any particular question;
- withdraw from the study, up until the time your survey answers are submitted – the completion of the survey means that consent has been given;
- ask any questions about the study at any time during participation (your progress should be saved if your internet web browser has cookies enabled);

- provide information on the understanding that your name will not be used;
- be given access to a summary of the project findings when it is concluded.

Survey Access

Project Contacts

If you have any further questions about this research, please do not hesitate to get in contact with us

David West

(Master's candidate)

asdresearchmanawatuserVICES@outlook.com

Dr Kirsty Ross

(Research Co-Supervisor)

K.J.Ross@massey.ac.nz

Dr Don Baken

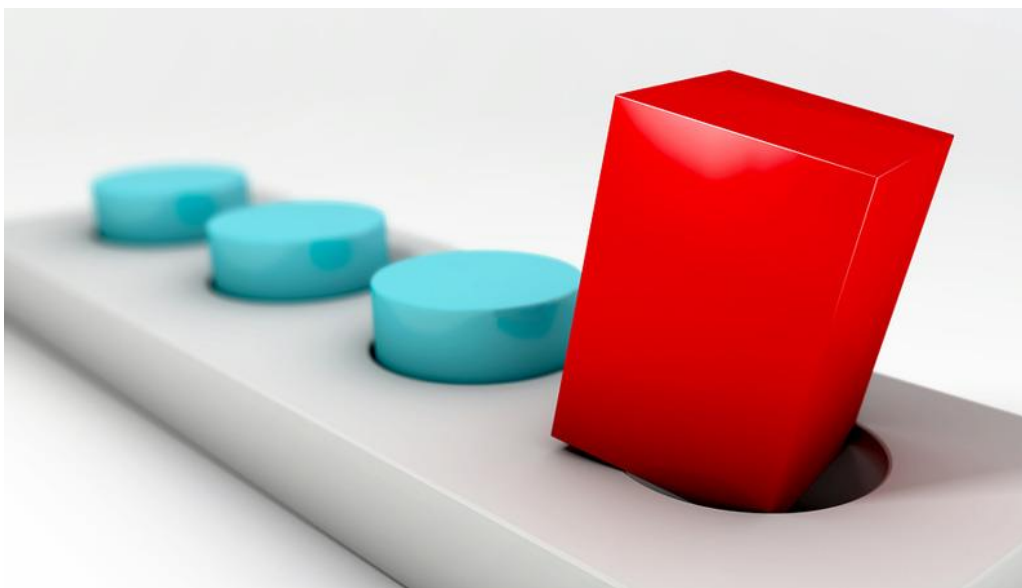
(Research Co-Supervisor)

D.M.Baken@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/43. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz.

Appendix G. Interview Advertisement

ASD support services – how well do they fit?



Like other things in life, ASD support services which may suit some perfectly, may not be helpful at all for others.

If you are a caregiver of a child / young person on the spectrum, we are interested in how well different support services meet the unique needs of both your child / young person, and your family.

For the purposes of the research, we are looking to interview people who:

- are adult (18 years or older) primary caregivers, or co-primary caregivers, of children / young people with ASD aged between three and sixteen years.
- have resided in the Mid Central, or Nelson Marlborough DHB areas, for a minimum of six months have received a clinical diagnosis of ASD for the children / young people in their care, a minimum of six months ago.
- are not employed as a professional healthcare providers for someone with ASD. For further information on this research, and how to participate, contact the research team by using the email address, or alternatively scan the QR Code:

asdresearchmanawatuservices@outlook.com



Appendix H. Interview Infosheet



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

School of Psychology
Massey University
Private Bag 11-222
Palmerston North 4442

Telephone : +64 6 356-9099 Extn 85071
Facsimile : +64 6 350-5673

Support needs of families with a child with ASD

INTERVIEW INFORMATION SHEET

Researcher Introduction

My name is David West, and I am undertaking this research as a requirement for completing a Master's Degree in Psychology, at Massey University.

Project Description and Invitation

Thank you for your continued interest in this research into how well services cater for the uniqueness of both the individual with ASD, and their families.

We invite caregivers of children / young people with ASD within the Mid Central DHB and Nelson Marlborough DHB areas to participate in interviews. It is hoped that conducting interviews will enable the research to incorporate your insight, your experience, your views, and your feedback to a greater degree, as we investigate how appropriate, accessible and adequate services are in your area.

If you choose to take part, please be assured that your participation is valued and appreciated.

Participant Identification and Recruitment

Recruitment for interviews is open to any caregiver (18 or older) living within the MidCentral DHB or the Nelson Marlborough DHB areas for a minimum of six months.

While we wish to be as inclusive as possible, time limitations mean that we have to limit the amount of interview participants, to ten.

To make participating in an interview more accessible, we have organised compensation in the form of a \$20 grocery voucher for each participant.

To meet the needs of the research, all participants must:

- be a primary caregiver, or co-primary caregiver, of a child with ASD between three and sixteen years.

- have resided in the MidCentral DHB region, or the Nelson Marlborough DHB region, for a minimum of six months
- have received a clinical diagnosis of ASD for at least one child / young person in their care, a minimum of six months ago.
- not be employed as a service care provider for those with ASD, or be employed in any capacity by the MidCentral DHB, or the Nelson Marlborough DHB.

*Please note, as with completing the online survey, participating in interviews about service delivery might be difficult for some people. If you have an existing physical, or mental, health condition which might make things particularly difficult for you, we would like you to consider this before deciding whether or not to participate.

If you do decide to participate, and you do become distressed, please be assured that appropriate procedures are in place to support you, free of charge.

Project Procedures

If you express interest in participating in an interview, you will be contacted with further information.

During an interview, you will be asked different questions about the supports and services you have experienced as a caregiver of a child with ASD. Most of the questions will be open-ended, so there are no 'right' or 'wrong' answers, and you can respond as you would like.

The interview should take about an hour, to an hour and a half to complete. If you feel as though you need to take a break, or get support, simply let the interviewer know.

Although the MidCentral DHB has endorsed this research, the research process and findings remain independent.

Data Management Policy

The data gathered will be used strictly for the purposes of this research.

As a participant, you will have the opportunity to review interview transcripts. If you wish to withdraw from the research, your last chance to do so is when you review the transcript.

Once recorded, all non-digitised data will be digitised for the purposes of storing all data on a password protected online storage facility, which has been created for the purposes of this research only. All data will be stored for 5 years, at which point it will be deleted.

When the research is complete, we will contact you by email to offer you a copy of the findings. Aggregated findings will also be shared with others by:

- publication in a journal article
- providing copies of the thesis to the MidCentral DHB and IHC New Zealand
- presenting at conferences, where appropriate

Summary of Participant's Rights

Please be aware, you are under no obligation to accept this invitation.

If you decide to participate in an interview, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any point up until you approve the transcript of your interview;

- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used;
- be given access to a summary of the project findings when it is concluded;
- ask for the audio recorder to be turned off at any time during the interview;
- ask to take a break from the interview;

Expression of Interest

In clicking the Interview Contact button below, you agree that you have read this information sheet, have understood and considered all information included within, and consent to participate

Project Contacts

If you have any further questions about this research, please do not hesitate to get in contact with us

Project Contacts

If you have any further questions about this research, please do not hesitate to get in contact with us

David West

(Master's candidate)

asdresearchmanawatuserVICES@outlook.com

Dr Kirsty Ross

(Research Co-Supervisor)

K.J.Ross@massey.ac.nz

Dr Don Baken

(Research Co-Supervisor)

D.M.Baken@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/43. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz.

Appendix I. Invitation for Cultural Component in Interviews

“One thing I should ask before the interview is regarding cultural safety. It’s important for me to be respectful of my participants and their cultural safety. So with this in mind, I need to ask if there was anything that we needed to do to help this process such as a karakia. Its voluntary, you don’t have to offer this information if you don’t want to”.

Appendix J. Online Questionnaire

If you have more than one child on the spectrum, you may have had very different experiences with different children; regarding both ASD symptoms, and the services received. To enable you to share your experiences as accurately as possible for each child, please indicate the following:

How many children in your care have been diagnosed with autism?

1) Diagnosis as a Life Event

Caregivers, and sometimes teachers, are usually the first to raise concerns over how a child is developing.

1. When you first had concerns about your child, how accessible, appropriate and adequate were services and professionals to voice your concerns?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

The best outcomes for children on the spectrum, and their families, are achieved with early identification and diagnosis, so the right kinds of help can be made available.

2. After concerns were raised, how timely, appropriate and adequate was the assessment process?

Timely

Very untimely: 1, Moderately untimely: 2, Neither timely nor untimely: 3, Moderately timely: 4, Very timely: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

A referral for an assessment can be made through different channels, by different kinds of professionals

3. Which of the following professionals was most proactive in securing an assessment?

Plunket nurse,
Well Child / Tamaki Ora professional (other than Plunket Nurse),
Preschool teacher,
School teacher,
Family doctor / GP,
Other (please specify):

Services for a child with ASD, and their family, are typically made available following a confirmed diagnosis.

4. Other than the diagnosis itself, how accessible, appropriate and adequate were support services immediately after the diagnosis?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

People look for information from different kinds of sources, depending on their worldview, their culture, their spirituality or religion, or even their personality.

5. Thinking about the time before, during, and after the diagnosis; which of the following sources of information did you utilize to find out about Autism .Which were helpful?

*Sources (Options: Utilized, (if utilized) Helpful / Unhelpful, (if unhelpful)*Why unhelpful (textbox))*

Friends
Family Members
GP
Education Professional
Other Caregivers with ASD children
Support Groups
Books and Magazines
Internet
Facebook
Religious or Spiritual Leaders
Other:

Different people have different ways of coping with uncertainties and concerns.

6. On a personal level, how stressed were you during the period around diagnosis?

Stress

Very stressed: 1, Moderately stressed: 2, Neither unstressed nor stressed: 3, Moderately unstressed: 4, Very unstressed: 5, Not applicable / don't know: -

7. Having an ASD diagnosis, as a life-event for an individual with ASD and their family, can be extremely difficult. A project in one area of the United States offers an information package to caregivers and families, to help guide them through the first 100 days following diagnosis. How beneficial do you think a similar package might be for families in Aotearoa / New Zealand?

How beneficial

Very unbeneficial, Moderately unbeneficial, Neither beneficial nor unbeneficial, Moderately beneficial, Very beneficial, Not applicable / don't know

- 7a. Are there any questions in this section would like to comment further on?

2) Education

Children on the spectrum sometimes have particular educational needs. Which of the following are services you have received, or were aware of, in your area?

Service (selection options: Awareness / Received)

Educational needs: programmes which cater to your child's specific needs.

Behavioural interventions: behavioural support which allows management of specific challenging behaviours that your child may have.

Sensory needs: supports in place to manage sensory challenges your child may have e.g. touch, taste, sound, smell, sight

Aspects of Service Delivery (selection options: Awareness / Received)

School citizenship & belonging: although not a service on its own, how your child is aided in becoming a valued member of school, and how they fit in with everyone else, is still important.

Respect for those on the spectrum: supports in place which enable both staff and students to be aware of what autism is, and how to be supportive of those with it.

Educational needs

A child diagnosed on the spectrum may struggle with some school content and programmes, which are otherwise beneficial when used with other students.

8. How accessible, appropriate, and adequate were education programmes used by education professionals to meet the particular needs of your child?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Behavioural interventions

Behavioural programmes help to uncover what challenging behaviours achieve for a child, so more appropriate alternatives can be made available.

9. How accessible, appropriate, and adequate were behavioural intervention programmes utilised by education professionals for your child?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Sensory needs

For some on the spectrum, specific sensory input (e.g. taste, touch, sounds or smells) can be difficult to manage, and can also be disruptive to learning.

10. How accessible, appropriate, and adequate were support services in meeting the sensory needs your child has?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

School citizenship & socialisation.

Learning how to fit in with others is an important, but sometimes challenging, part of school life, which can be all the more challenging for children on the Spectrum.

11. How accessible, appropriate, and adequate were the efforts of education professionals in aiding your child in becoming a valued member of the school?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Respect for those on the spectrum (staff & students)

Information, experiences, and opportunities for discussion about Autism are all important for both staff and students, to enable the best kinds of relationships at school.

12. How accessible, appropriate, and adequate were the efforts of educational professionals to maintain a school environment where those with Autism are respected?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

13. Are there any questions in this section would like to comment further on? (Yes/No)

3) Personal Fulfilment & Work-Related Services (Living in the Community)

Some on the spectrum may need assistance in finding ways of engaging as an individual, a friend, or as a member of the workforce. Which of the following services have you received, or were aware of, in your area?

Service(selection options: Awareness / Received)

Recreation and leisure: services which enable access to leisure facilities and meaningful activity.

Personal interests: services which enable the development and management of interests.

Social support: services which assist in the building and maintenance of relationships

Close relationships: services which help manage feelings and relationships that are beyond friendship

Work related interests: services which enable individuals to pursue interests that may produce meaningful employment, or a career.

Recreation and Leisure

Children on the spectrum, like anyone else, need access to leisure facilities, and programmes, which provide them opportunities to be meaningfully active.

14. How accessible, appropriate, and adequate have services been in providing access to leisure which meets the interests of your child?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Interests

People on the spectrum, like anyone else, have interests that can enhance their lives many ways.

15. How accessible, appropriate, and adequate have services been in helping your child pursue personal interests?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Social support

Many people on the spectrum have a strong network of friends and acquaintances, while others need some assistance in establishing and maintaining friendships.

16. How accessible, appropriate, and adequate have services been in supporting friendships?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Close relationship support

Managing feelings beyond friendship, or having a boyfriend, or girlfriend, can be challenging for anyone. In some circumstances, support is needed for both the child / young person on the spectrum, as well as the person of interest.

17. How accessible, appropriate, and adequate have close relationship supports been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Work related interests

Many on the spectrum have very successful and rewarding working lives.

18. How accessible, appropriate, and adequate have services been in helping your child pursue work related interests and goals?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

19. Are there any questions in this section would like to comment further on? (Yes/No)

4) Family life

While a child's family unit is likely to be the most important support he / she will ever have, the need to balance the interests of the individual, with others, and the collective, can require several additional services when a child has Autism. Which of the following services have you received, or were are aware of, in your area?

Service (selection options: Awareness / Received)

Financial assistance: support in meeting the ongoing costs for either the child with ASD, or their family, or both.

Professional advice: advice from a professional for anything related to how a diagnosis affects the child on the spectrum, or their family

Respite care: professional care for a child on the spectrum which provides caregiver with opportunity to attend to other family member's needs, or own.

Child care: professional care for a child on the spectrum, to enable caregivers to remain / re-enter the workforce

Physical therapy: services to assist those with ASD in achieving motor (movement) goals

Speech / communication therapy: services to aid children with ASD in learning and developing different communication skills

Behavioural management training: services that train caregivers to be able to manage behaviour in their own homes., ,

Sensory management at home: services that assist in managing particular sensory needs (touch, taste, sound, or sight) in the context of a family environment

Sibling relationship support: services that provide relationship support between siblings with, and without, ASD

Sibling support: support which addresses the personal needs of a sibling without ASD.

Companionship support: services that help maintain a successful caregiving companionship e.g. counselling

Family social support: services that support the social activity of a family (e.g. maintaining traditions, participating in community events)

Emergency support: services that are able to help families who have a member on the spectrum, when unexpected events occur.

Doctor visits: being able to access a doctor/ GP's clinic which caters for the needs of children on the spectrum.

Medication options: being consulted on the potential benefits, and risks, of using some medications to improve specific ASD symptoms

Financial assistance

There are often significant added costs for families with ASD members, the right financial assistance can be vital to the wellbeing of both the child on the spectrum, and every other family member.

20. How accessible, appropriate, and adequate has the funding provided for your family been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

21. How accessible, appropriate, and adequate has the funding provided for your diagnosed child been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Professional advice;

There are often instances when caregivers may feel they need advice from helping professionals (e.g. teachers, therapists, doctors, or other professionals with specific knowledge or skills for helping with ASD)

22. How accessible, appropriate, and adequate has the professional advice you have received been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Respite care

Providing care to someone on the spectrum can be intensive; time away from a child on the spectrum may be necessary to attend to the needs of other children, a partner's needs, or your own.

23. How accessible, appropriate, and adequate has professional respite care been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Child care

Like many families, those families with a member on the spectrum may need to utilise child care services, to enable caregivers to have time to concentrate on their jobs / careers.

24. How accessible, appropriate, and adequate have child care services been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Physical therapy

There is evidence of the existence of motor (movement) difficulties for many children on the spectrum, who may need physical therapy to achieve movement goals.

25. How accessible, appropriate, and adequate have physical therapies been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Speech / communication therapy

Children on the spectrum often have very different communication challenges. There are calls to encourage as many forms of communication as possible, such as speech, gestures (signing / Makaton), or through communication devices.

26. How accessible, appropriate, and adequate have speech / communication therapies been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Behaviour management training services

Behaviour management works best when there is consistency between therapy sessions, school, and home – which often means training caregivers to be additional experts in their own homes.

27. How accessible, appropriate, and adequate have behavioural intervention training services been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Sensory management at home

A child's sensory difficulties go with them, wherever they are; which means they are also present when they go places, or live, with others who do not share the same sensitivities.

28. How accessible, appropriate, and adequate have sensory needs (e.g. touch, taste, sound, sight) services been to manage your child's needs, outside of school?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Sibling relationship support

Having a sibling with ASD can sometimes be challenging, and the correct relationship support between siblings can be beneficial for the whole family

29. How accessible, appropriate, and adequate has sibling relationship support been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Sibling support

Siblings of those with ASD have their own needs, which need to be addressed when considering a complete treatment plan for the family.

30. How accessible, appropriate, and adequate has sibling support been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Relationship support

Maintaining a successful relationship between caregivers sometimes takes more than respite care, such as, counselling for couples, parental groups etc.

31. How accessible, appropriate, and adequate have services been in supporting your relationship?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Family social support

Being able to attend social gatherings, participate in group activities, and being able to visit places, can be helpful in increasing the unity, and quality of life, for the entire family. However, such social events may require extra support from a professional when a family member is on the spectrum.

32. How accessible, appropriate, and adequate have services been to support the social life of your family?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Emergency support

Unforeseen events can be challenging for any family, and may be especially challenging for families with a member on the spectrum, where specialised assistance may be required.

33. How accessible, appropriate, and adequate has emergency support been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Doctor visits

A visit to a family doctor /GP can be challenging at the best time of times with children, even more so if the child is on the Spectrum and has particular needs (e.g. sensory triggers)

34. How accessible, appropriate, and adequate have the services been during a visit to a doctor?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Medication options

Although there are no medicines that cure Autism, careful use of medication can be sometimes be helpful in improving some symptoms.

35. How accessible, appropriate and adequate have services been in consulting with you about medication options for your child on the spectrum?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

36. Are there any questions in this section would like to comment further on? (Yes/No)

5) Managing Transitions

Transition management

Life is full of changes for everyone, and such changes can be especially difficult for those on the spectrum. Consider all of the times your child has experienced a transition (e.g. from pre-school to primary school, from primary school to intermediate; from one health practitioner, to another; moving location; changes in family membership; leaving school).

37. How accessible, appropriate, and adequate have transition supports been?

Accessible

Very inaccessible: 1, Moderately inaccessible: 2, Neither accessible nor inaccessible: 3, Moderately accessible: 4, Very accessible: 5, Not applicable / don't know: -

Appropriate

Very inappropriate: 1, Moderately inappropriate: 2, Neither appropriate nor inappropriate: 3, Moderately appropriate: 4, Very appropriate: 5, Not applicable / don't know: -

Adequate

Very inadequate: 1, Moderately inadequate: 2, Neither adequate nor inadequate: 3, Moderately adequate: 4, Very adequate: 5, Not applicable / don't know: -

Point of contact

Child cancer patients have access to a single key support worker, who is able to assist them, and their families, in navigating a variety of services, and transitions; as well as providing the emotional support that is required.

38. How beneficial do you think it would be, to have a similar key support worker, or kaiarahi (guide), for those on the spectrum, and their families?

How beneficial

Very unbeneficial: 1, Moderately unbeneficial: 2, Neither beneficial nor unbeneficial: 3, Moderately beneficial: 4, Very beneficial: 5, Not applicable / don't know: -

39. Are there any questions in this section would like to comment further on? (Yes/No)

Participant information

So that we can understand a little about the people who have participated in this study, please answer the following questions:

A) Where do you live?

Aotearoa / New Zealand
Other

B) How long have you lived in your present location?

Less than 6 months
More than 6 months

C) Which of the following is your District Health Board*?

Northland
Waitemata
Auckland
Counties Manakau
Waikato
Bay of Plenty
Taranaki
Lakes
Tairāwhiti
Whanganui
MidCentral
Hawke's Bay
Capital and Coast
Hutt Valley
Wairapa
Nelson Marlborough
West Coast
Canterbury
South Canterbury
Southern

D) What is your relationship to the child?

Mother
Father
Aunt
Uncle
Grandmother
Grandfather
Foster Mother
Foster Father

Would rather not say
Other (Please specify)

E) What kind of area do you live in?

Urban
Suburban
Rural
Would rather not say

F) Which of the following ethnic groups do you identify as being a member of?

Māori
Cook Islands Māori
European New Zealander
Samoan
Tongan
Niuean
Indian
Pakistani
Asian
Would rather not say
Other (Please specify)

G) How long ago was your child diagnosed?

Years
Months

H) Who diagnosed your child?

Developmental paediatrician.
Psychiatrist.
Clinical Psychologist.
A Diagnosis Team (two to three of the following professionals who are experts regarding Autism: paediatrician, psychiatrist, psychologist, speech / language therapist, occupational therapist.
Myself / another non-professional.
Other:

I) How old is your child?

Years
Months

J) What is the gender of your child?

Male
Female
Other (please specify)

K) What is the combined income of your household, before tax?

Less than \$10,000
\$10,000 - \$20,000
\$20,000 - \$30,000
\$30,000 - \$40,000
\$50,000 - \$60,000
\$60,000 - \$70,000
More than \$70,000
Would rather not say

L) What is your highest qualification?

School certificate (NCEA 1)
Sixth form certificate
Bursary / Higher school certificate (NCEA 3)
Trade certificate
Teaching / Nursing certificate or diploma
Technician's certificate
Undergraduate certificate or diploma
Bachelor's degree
Postgraduate degree
Would rather not say
Other (Please specify):

Are there any questions in this section you would like to comment further on?

Future Contact

A) (*) We are looking for interview participants from those who have selected MidCentral as their DHB. Interviews help researchers gather different kinds of information, which cannot normally be obtained by completing a questionnaire. If you are interested in participating in an interview, please click the button below to find out more.

Interested
Not Interested

B) As mentioned in the information sheet, each participant is entitled to receive a copy of the research findings. If you would like to receive a copy of the research outcomes, please provide your contact details below.

Appendix K. Interview Schedule

Interview Schedule

A) DIAGNOSIS

1. What was the diagnostic process like for you as a caregiver, for your family, for your child?
2. Were there services you found helpful?
 - a. Why?
3. Were there services you felt that did not meet your needs or expectations?
 - a. Why?
4. Can you tell me about some positive / negative experiences that you experienced as a family around the time of diagnosis?
5. What was this time like emotionally for you?
6. How much information were you given regarding Autism?
7. How did you go about getting more information?
8. If you could change anything about how services are delivered around the time of diagnosis, what would you recommend?
9. As you have taken part in the online survey, is there anything else about diagnosis, or the events surrounding it, which is really important, but has not been mentioned?

B) EDUCATION

10. Which aspects of school services have been helpful / unhelpful for your child?
 - a. Why?
11. Which aspects of school services have been helpful /unhelpful for you as a caregiver?
 - a. Why?
12. Tell me about the process for designing a school plan for your child.
 - a. Were you able to give to provide input?
 - b. How much so?
13. Tell me how well informed you were by the school
 - a. Progress and achievements?
 - b. Upsets?

- c. Upcoming events which might be challenging?
 - d. Assessments and other things related to your child's condition?
14. What has been your experience of the attitudes of staff and students towards your child?
15. Would you say your child is mostly content with others at school?
- a. Why?
16. If you could change anything about the way services are delivered for your child's education, what would you do?
17. Is there anything that you feel is missing from the research regarding your child's education?

C) LIVING IN THE COMMUNITY

18. What are some of the kind of recreational activities, or hobbies, does your child enjoy?
- a. Has your child received any kind of support for leisure?
 - i. Which supports have worked well for your child's leisure?
 - ii. Which of the supports could use some work?
19. What are some of the interests that your child has?
- a. Has your child received any kind of support for their interests?
 - i. What has helped your child pursue their interests?
 - ii. What else could be done to help your child pursue their interests?
20. How well does your child connect with others in relationships?
- a. Has your child needed any support?
 - i. What kind of support has been helpful?
 - ii. What else could be done to help your child with relationships?
21. Has your child ever had special feelings, or attachment, or a girlfriend /boyfriend?
- a. Has your child needed any help in this area?
 - i. What kind of help has been useful?
 - ii. What kinds of support need improving?
22. Tell me about the goals for your child after they leave school?
- a. Has your child needed any help with goals to achieve this?
 - i. Has this kind of help been useful?
 - ii. Where do you think things could be improved?
23. If you could change anything about the way services are delivered for your child's personal interests, or community involvement, what would you do?

24. Is there anything that you feel is missing from the research regarding your child's personal interests or community involvement?

D) FAMILY LIFE

25. How are things financially for the child/ family?

- a. Have you received financial support?
 - i. How adequate has the support been?
 - ii. What other kinds of support could be improved?

26. Have you asked a professional for advice about how to best help your family situation?

- a. What was that like?
 - i. What was positive about this way of getting advice?
 - ii. What could be improved about getting advice?

27. Have you needed to use respite care before?

- a. What was that like?
 - i. What were some of the positives about respite care?
 - ii. What is it about respite care that could be improved upon?

28. Has your child needed physical therapy at some point?

- a. What was that like?
 - i. What are some of the positives?
 - ii. What do you think could be improved?

29. Has your child needed communication therapy at some point?

- a. What was that like?
 - i. What are some of the positive elements?
 - ii. What could be improved?

30. Have you received behavioural management training?

- a. What was it like to implement at home?
 - i. What are the positive elements of doing behavioural management?
 - ii. What could do with improving for caregivers who need to use behavioural management?

31. Does your child have sensory management issues?

- a. What kinds of supports were available?
 - i. What were the positives in the supports available?
 - ii. What were some of the things that could be improved about sensory management?

32. Does your child have a sibling?

- a. Was sibling support available?

- i. What were the positives around this sibling support?
 - ii. What were some of the things that needed improving with sibling support?
- 33. Do you have a companion?
 - a. Have you received any professional support for your companionship?
 - i. What are some of the positive / helpful supports you have received?
 - ii. What are some of the ways supports could be improved?
- 34. Do you have the opportunity to get out, and participate socially, as a family?
 - a. Did you receive any kinds of support for this?
 - i. How useful / positive were the supports you received?
 - ii. Where could these supports be improved?
- 35. What happens in emergencies?
 - a. Have you received any professional support?
 - i. How useful were the supports offered in emergencies?
 - ii. How could emergency support be improved?
- 36. What are visits like to your family doctor / GP?
 - a. Does the Doctor cater for your child's ASD during the visit?
 - i. What works really well about Doctor visits?
 - ii. What could be improved upon?
- 37. Is your child on any medication for relief of symptoms related to their ASD?
 - a. Does the management of medication between you and the prescriber work well?
 - i. What specifically is beneficial?
 - ii. What needs more attention / development?
- 38. Is there anything about family life that you feel the research doesn't address, but is important?
- 39. If you could change anything about the way supports services are delivered to improve family life, what would you do?

E) MANAGING TRANSITIONS

- 40. Transitions are really all about life changes, and how we all cope with them; for example, how people manage a change in job, school, location, or doctor. Tell me about how transitions have been for you / your child?
 - a. What kinds of support services have you received?
 - i. What are some of the positives?
 - ii. What could use some work?

41. What would it mean to have a keyworker, who specialises in Autism, to help you and your family with transitions, service navigation, and emotional support?
- a. Does someone already fill this role for you?
 - i. Who / What are they?
42. Is there anything about transitions that you feel that the research does not address?
43. If you could change anything about how transitions are managed, what would you do?
-

Is there anything about autism that you feel this research doesn't talk about, but is very important to your child / your family?

Is there anything we haven't covered that you would like to raise and talk about?

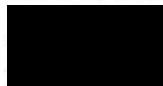
Appendix L. Ethics Committee Approval



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

17 August 2015

Mr David West



Dear David

Re: HEC: Southern A Application – 15/43
Support needs of families with a child with ASD

Thank you for your letter dated 14 August 2015.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to advise you that the ethics of your application are now 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

Mr Jeremy Hubbard, Chair
Massey University Human Ethics Committee: Southern A

cc Dr Kirsty Ross
School of Psychology
PN320

Dr Don Baken
School of Psychology
PN320

Prof James Liu, HoS
School of Psychology
PN320

Massey University Human Ethics Committee
Accredited by the Health Research Council

Research Ethics Office, Research and Enterprise

Massey University, Private Bag 11222, Palmerston North 4442, New Zealand T 06 3505573; 06 3505575 F 06 350 5622
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz www.massey.ac.nz

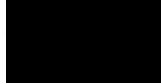
Appendix M. Ethics Amendment Approval



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

23 September 2015

Mr David West



Dear David

Re: HEC: Southern A Application – 15/43
Support needs of families with a child with ASD

Thank you for your letter dated 16 September 2015 outlining the changes you wish to make to the above application.

The changes, recruit through IHC NZ and Facebook groups have been approved and noted.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee. If over time, more than one request to change the application is received, the Chair may request a new application.

Yours sincerely

Mr Jeremy Hubbard, Chair
Massey University Human Ethics Committee: Southern A

cc Dr Kirsty Ross
School of Psychology
PN320

Dr Don Baken
School of Psychology
PN320

Prof James Liu, HoS
School of Psychology
PN320

Massey University Human Ethics Committee
Accredited by the Health Research Council

Research Ethics, Research and Enterprise

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E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz www.massey.ac.nz

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Aston, M. (2012). Asperger syndrome in the bedroom. *Sexual and Relationship Therapy*, 27(1), 73-79.
- Autism New Zealand. (2013). Autism New Zealand Strategy 2013-2017. Retrieved 22/07/2016 2016 from http://www.autismnz.org.nz/__data/assets/pdf_file/0016/43441/Autism_NZ_Strategy.pdf
- Autistic Advocacy Network. (2014). Joint letter to the sponsors of Autism Speaks. Retrieved from <http://autisticadvocacy.org/2014/01/2013-joint-letter-to-the-sponsors-of-autism-speaks/>
- Baeza-Velasco, C., Michelon, C., Rattaz, C., Pernon, E., & Baghdadli, A. (2013). Separation of parents raising children with autism spectrum disorders. *Journal of Developmental and Physical Disabilities*, 25(6), 613-624. doi:10.1007/s10882-013-9338-0
- Bainbridge, J. (2014). 'It is a Pokémon world': The Pokémon franchise and the environment. *International Journal of Cultural Studies*, 17(4), 399-414. doi:10.1177/1367877913501240
- Baio, J. (2014). Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *MMWR Surveillance Summaries*, 63(1).
- Baker-Ericzn, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, 30(4), 194-204.
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups*, 33(1), 69-83.
- Baranek, G. T. (2002). Efficacy of sensory and motor interventions for children with autism. *Journal of Autism and Developmental Disorders*, 32(5), 397-422. doi:10.1023/A:1020541906063
- Bayer, K. (2015). Tributes flow for autistic boy who died after suffering serious head injuries. *The New Zealand Herald*. Retrieved from http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11456670
- Bayer, K. (2017). Tragedy of mum driven to kill daughter. *NZ Herald*. Retrieved from http://m.nzherald.co.nz/health/news/article.cfm?c_id=204&objectid=11793296
- Benson, P. R., & Kersh, J. (2011). Marital quality and psychological adjustment among mothers of children with ASD: Cross-sectional and longitudinal relationships. *Journal of Autism and Developmental Disorders*, 41(12), 1675-1685. doi:10.1007/s10803-011-1198-9
- Bevan-Brown, J. (2004). *Māori perspectives of autistic spectrum disorder*. Wellington, New Zealand: Ministry of Education.

- Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism, 15*(1), 7-20. doi:10.1177/1362361309346066
- Bishop, D. V. M., Whitehouse, A. J. O., Watt, H. J., & Line, E. A. (2008). Autism and diagnostic substitution: Evidence from a study of adults with a history of developmental language disorder. *Developmental Medicine and Child Neurology, 50*(5), 341-345. doi:10.1111/j.1469-8749.2008.02057.x
- Blaska, J. (1993). The power of language: Speak and write using "person first." *Perspectives on Disability, 25*-32.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Brett, D., Warnell, F., McConachie, H., & Parr, J. R. (2016). Factors affecting age at asd diagnosis in UK: No evidence that diagnosis age has decreased between 2004 and 2014. *Journal of Autism and Developmental Disorders, 46*(6), 1974-1984. doi:10.1007/s10803-016-2716-6
- Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*(1), 38-49.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*(4), 409-423.
- Brown, H. K., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet needs of families of school-aged children with an autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 25*(6), 497-508.
- Calder, L., Hill, V., & Pellicano, E. (2013). 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism, 17*(3), 296-316. doi:10.1177/1362361312467866
- Carmack, H. J. (2014). Social and tertiary health identities as argument in the DSM-V Asperger's/Autism debate. *Western Journal of Communication, 78*(4), 462-479. doi:10.1080/10570314.2013.845792
- Cassidy, A., McConkey, R., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum disorders: The impact on families and the supports available to them. *Early Child Development and Care, 178*(2), 115-128.
- Cheak-Zamora, N. C., Farmer, J. E., Mayfield, W. A., Clark, M. J., Marvin, A. R., Law, J. K., & Law, P. A. (2014). Health care transition services for youth with autism spectrum disorders. *Rehabilitation Psychology, 59*(3), 340-348. doi:10.1037/a0036725
- Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics, 131*(3), 447-454.

- Clarkson, A. (2016). Emma Le Fleming Roberts discharged on medical treatment charge. *The New Zealand Herald*. Retrieved from <http://www.stuff.co.nz/national/crime/79448746/Emma-Le-Fleming-Roberts-discharged-on-medical-treatment-charge>
- Clarkson, D. (2016). Murder case over Leon Jayet-Cole's death ends. *The Press*. Retrieved from <http://www.stuff.co.nz/the-press/news/83096795/Murder-case-over-Leon-Jayet-Coles-death-ends>
- Collier, R. (2012). Person-first language: Noble intent but to what effect? *Canadian Medical Association Journal*, 184(18), 1977-1978. doi:10.1503/cmaj.109-4319
- Constantino, J. N., Zhang, Y., Frazier, T., Abbacchi, A. M., & Law, P. (2010). Sibling recurrence and the genetic epidemiology of autism. *American Journal of Psychiatry*, 167(11), 1349-1356.
- Coo, H., Ouellette-Kuntz, H., Lloyd, J. E. V., Kasmara, L., Holden, J. J. A., & Lewis, M. E. S. (2008). Trends in autism prevalence: Diagnostic substitution revisited. *Journal of Autism and Developmental Disorders*, 38(6), 1036-1046. doi:10.1007/s10803-007-0478-x
- Courtney, D. (1998). Health worker speaks out on Helm deaths. *The Nelson Evening Mail*.
- Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). An expanded typology for classifying mixed methods research into designs. In *Handbook of Mixed Methods in Social and Behavioral Research*. (pp. 209-240). California: Sage.
- Denkyirah, A. M., & Agbeke, W. K. (2010). Strategies for transitioning preschoolers with autism spectrum disorders to kindergarten. *Early Childhood Education Journal*, 38(4), 265-270. doi:10.1007/s10643-010-0407-z
- Dunlap, G., & Fox, L. (1999). Supporting families of young children with autism. *Infants & Young Children*, 12(2), 48-54.
- Durie, M. (1998). *Whaiora: Māori health development*. Auckland: Oxford University Press.
- Durie, M. (2001). *Mauri ora: The dynamics of Māori health*. Auckland: Oxford University Press.
- Durie, M. (2007). *Whaiora: Māori health development* (2nd ed.). Auckland: Oxford University Press.
- Dymond, S. K., Gilson, C. L., & Myran, S. P. (2007). Services for children with autism spectrum disorders. *Journal of Disability Policy Studies*, 18(3), 133-147.
- Elder, J. H., Valcante, G., Won, D., & Zylis, R. (2003). Effects of in-home training for culturally diverse fathers of children with autism. *Issues in Mental Health Nursing*, 24(3), 273-295.
- Elder, J. H., Valcante, G., Yarandi, H., White, D., & Elder, T. H. (2005). Evaluating in-home training for fathers of children with autism using single-subject experimentation and group analysis methods. *Nursing Research*, 54(1), 22-32.
- English, B. (1998). Review of autism services [Press release]. Retrieved from <https://www.beehive.govt.nz/release/review-autism-services>
- Falkmer, M., Anderson, K., Joosten, A., & Falkmer, T. (2015). Parents' perspectives on inclusive schools for children with autism spectrum conditions. *International Journal of Disability, Development and Education*, 62(1), 1-23. doi:10.1080/1034912X.2014.984589

- Fava, L., & Strauss, K. (2014). Response to Early intensive behavioral intervention for autism—An umbrella approach to issues critical to treatment individualization. *International Journal of Developmental Neuroscience*, 39, 49-58.
- Fava, L., Strauss, K., Valeri, G., D'Elia, L., Arima, S., & Vicari, S. (2011). The effectiveness of a cross-setting complementary staff-and parent-mediated early intensive behavioral intervention for young children with ASD. *Research in Autism Spectrum Disorders*, 5(4), 1479-1492.
- Fava, L., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Strauss, K. (2012). Intensive behavioral intervention for school-aged children with autism: Una Breccia nel Muro (UBM)—A comprehensive behavioral model. *Research in Autism Spectrum Disorders*, 6(4), 1273-1288.
- Flippin, M., & Crais, E. R. (2011). The need for more effective father involvement in early autism intervention: A systematic review and recommendations. *Journal of Early Intervention*, 33(1), 24-50.
- Fombonne, E. (2003). The prevalence of autism. *Journal of the American Medical Association*, 289(1), 87-89. doi:10.1001/jama.289.1.87
- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, 65(6), 591-598. doi:10.1203/PDR.0b013e31819e7203
- Fox, L., Dunlap, G., & Cushing, L. (2002). Early intervention, positive behavior support, and transition to school. *Journal of Emotional and Behavioral Disorders*, 10(3), 149-157.
- Fox, L., Dunlap, G., & Philbrick, L. A. (1997). Providing individual supports to young children with autism and their families. *Journal of Early Intervention*, 21(1), 1-14.
- Freedman, B. H., Kalb, L. G., Zablotzky, B., & Stuart, E. A. (2012). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders*, 42(4), 539-548. doi:10.1007/s10803-011-1269-y
- Friedman, N. D., Warfield, M. E., & Parish, S. L. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry*, 3(2), 181-192.
- García-Villamizar, D. A., & Dattilo, J. (2010). Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research*, 54(7), 611-619. doi:10.1111/j.1365-2788.2010.01289.x
- Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, 33(6), 2177-2192.
- Gau, S. S. F., Chou, M. C., Chiang, H. L., Lee, J. C., Wong, C. C., Chou, W. J., & Wu, Y. Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 263-270.

- Gernsbacher, M. A., Dawson, M., & Goldsmith, H. H. (2005). Three reasons not to believe in an autism epidemic. *Current Directions in Psychological Science*, 14(2), 55-58.
doi:10.1111/j.0963-7214.2005.00334.x
- Ghaziuddin, M. (2010). Should the DSM-V drop Asperger's syndrome? *Journal of Autism and Developmental Disorders*, 40(9), 1146-1148. doi:10.1007/s10803-010-0969-z
- Giles, D. C. (2014). 'DSM-V is taking away our identity': The reaction of the online community to the proposed changes in the diagnosis of Asperger's disorder. *Health (United Kingdom)*, 18(2), 179-195. doi:10.1177/1363459313488006
- Gladding, S. T. (2010). *Family therapy: History, theory, and practice* (5th ed.): Merrill.
- Gomes, P. T., Lima, L. H., Bueno, M. K., Araújo, L. A., & Souza, N. M. (2014). Autism in Brazil: A systematic review of family challenges and coping strategies. *Jornal de Pediatria*, 91(2), 111-121. doi:10.1016/j.jped.2014.08.009
- Goode, E. (2001). Cases: A disorder far beyond eccentricity. *The New York Times*. Retrieved from <http://www.nytimes.com/2001/10/09/health/cases-a-disorder-far-beyond-eccentricity.html>
- Greenspan, S. I., & Wieder, S. (1999). A functional developmental approach to autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, 24(3), 147-161.
- Haney, M. R. (2012). After school care for children on the autism spectrum. *Journal of Child and Family Studies*, 21(3), 466-473.
- Hare, D. J., Pratt, C., Burton, M., Bromley, J., & Emerson, E. (2004). The health and social care needs of family carers supporting adults with autistic spectrum disorders. *Autism*, 8(4), 425-444.
- Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(11), 2604-2616. doi:10.1007/s10803-013-1812-0
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457. doi:10.1037/a0019847
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629-642.
doi:10.1007/s10803-012-1604-y
- Hays, A., & Colaner, C. (2016). Discursively constructing a family identity after an autism diagnosis: Trials, tribulations, and triumphs. *Journal of Family Communication*, 16(2), 143-159.
- Helps, S., Newsom-Davis, I., & Callias, M. (1999). Autism: The teacher's view. *Autism*, 3(3), 287-298.
- Hendricks, D. R. (2007). *A descriptive study of special education teachers serving students with autism: Knowledge, practices employed, and training needs*. (Doctoral dissertation, Virginia

- Commonwealth University). Retrieved from
<https://scholarscompass.vcu.edu/cgi/viewcontent.cgi?article=2312&context=etd>
- Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 22(4).
- Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), 125-137. doi:10.1177/1362361305051403
- Horlin, C., Falkmer, M., Parsons, R., Albrecht, M. A., & Falkmer, T. (2014). The cost of autism spectrum disorders. *PLoS One*, 9(9), 106552. doi:10.1371/journal.pone.0106552
- Houser, L., McCarthy, M., Lawer, L., & Mandell, D. (2014). A challenging fit: Employment, childcare, and therapeutic support in families of children with autism spectrum disorders. *Journal of Social Service Research*, 40(5), 681-698. doi:10.1080/01488376.2014.930944
- Huws, J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability*, 33(2), 99-107.
- IHC NZ. (2015). Community specialist services. Retrieved 17/08/2015 2015 from
<http://www.ihc.org.nz/services/autism>
- Johnson, R. A., Danis, M., & Hafner-Eaton, C. (2014). US state variation in autism insurance mandates: Balancing access and fairness. *Autism*, 18(7), 803-814.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14-26.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133.
- Jolliffe, T., Lakesdown, R., & Robinson, C. (1992). Autism: A personal account. *Communication*, 26(3).
- Jones, L., Totsika, V., Hastings, R. P., & Petalas, M. A. (2013). Gender differences when parenting children with autism spectrum disorders: A multilevel modeling approach. *Journal of Autism and Developmental Disorders*, 43(9), 2090-2098.
- Kaland, N. (2011). Brief report: Should Asperger syndrome be excluded from the forthcoming DSM-V? *Research in Autism Spectrum Disorders*, 5(3), 984-989. doi:10.1016/j.rasd.2011.01.011
- Kassiane, S. (2012). Acceptance vs. awareness. Retrieved from
<http://autisticadvocacy.org/2012/04/acceptance-vs-awareness/>
- Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, 4(2), 229-241.

- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
- Khare, R., & Mullick, A. (2014) Research tools to study vulnerable populations: A case of designing inclusive spaces for autism. In: *Vol. 35. Assistive Technology Research Series* (pp. 269-278).
- King, M., & Bearman, P. (2009). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology*, 38(5), 1224-1234. doi:10.1093/ije/dyp261
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, 122(6), 1149-1158.
- Kohler, F. W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities*, 14(3), 150-158.
- Lake, J. K., Milovanov, A., Sawyer, A., & Lunskey, Y. (2015). Parent perspectives on psychotropic medication use and interactions with prescribing health care providers among adolescents and adults with an autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, 30(3), 165-173. doi:10.1177/1088357614559215
- Lee, G. K., & Carter, E. W. (2012). Preparing transition-age students with high-functioning autism spectrum disorders for meaningful work. *Psychology in the Schools*, 49(10), 988-1000.
- Lilley, R. (2013). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia. *Disability & Society*, 28(4), 514-526.
- Ling, C., & Mak, W. (2012). Coping with challenging behaviours of children with autism: Effectiveness of brief training workshop for frontline staff in special education settings. *Journal of Intellectual Disability Research*, 56(3), 258-269.
- Loyd, D. (2013). Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities*, 41(2), 133-140. doi:10.1111/j.1468-3156.2012.00734.x
- Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, 17(5), 702-711. doi:10.1177/1359105311422955
- MacFarlane, J. R., & Kanaya, T. (2009). What does it mean to be autistic? Inter-state variation in special education criteria for autism services. *Journal of Child and Family Studies*, 18(6), 662.
- Macintosh, K. E., & Dissanayake, C. (2004). The similarities and differences between autistic disorder and Asperger's disorder: A review of the empirical evidence. *Journal of Child Psychology and Psychiatry*, 45(3), 421-434.

- Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities, 51*(3), 141-153.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S., . . . Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*(3), 493-498. doi:10.2105/AJPH.2007.131243
- Matson, J. L., & Konst, M. J. (2014). Early intervention for autism: Who provides treatment and in what settings. *Research in Autism Spectrum Disorders, 8*(11), 1585-1590.
- Matson, J. L., Tureck, K., Turygin, N., Beighley, J., & Rieske, R. (2012). Trends and topics in Early Intensive Behavioral Interventions for toddlers with autism. *Research in Autism Spectrum Disorders, 6*(4), 1412-1417.
- McGoldrick, M., Carter, E. A., & Garcia-Preto, N. (1999). *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed.): Allyn and Bacon.
- McGonigle, J. J., Migyanka, J. M., Glor-Scheib, S. J., Cramer, R., Fratangeli, J. J., Hegde, G. G., . . . Venkat, A. (2014). Development and evaluation of educational materials for pre-hospital and emergency department personnel on the care of patients with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(5), 1252-1259. doi:10.1007/s10803-013-1962-0
- Mieres, A. C., Kirby, R. S., Armstrong, K. H., Murphy, T. K., & Grossman, L. (2012). Autism spectrum disorder: An emerging opportunity for physical therapy. *Pediatric Physical Therapy, 24*(1), 31-37.
- Ministries of Health and Education. (2008). *New Zealand autism spectrum disorder guideline*. Wellington: Ministry of Health.
- Ministries of Health and Education. (2016). *New Zealand autism spectrum disorder guideline*. Wellington: Ministry of Health.
- Ministry of Health. (2015). Implementing the guideline. Retrieved from <http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/autism-spectrum-disorder-guideline/implementing-guideline>
- Moes, D. R., & Frea, W. D. (2002). Contextualized behavioral support in early intervention for children with autism and their families. *Journal of Autism and Developmental Disorders, 32*(6), 519-533.
- Moodie-Dyer, A., Joyce, H. D., Anderson-Butcher, D., & Hoffman, J. (2014). Parent-caregiver experiences with the autism spectrum disorder service delivery system. *Journal of Family Social Work, 17*(4), 344-362. doi:10.1080/10522158.2014.903581
- Mortensen, L. (2009). *Satoshi Tajiri: Pokémon creator* London, UK: Cengage Gale.

- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670-684.
- Nairn, R., Pega, F., McCreanor, T., Rankine, J., & Barnes, A. (2006). Media, racism and public health psychology. *Journal of Health Psychology*, 11(2), 183-196.
- Nikora, L. W., Karapu, R., Hickey, H., & Te Awekotuku, N. (2004). *Disabled Māori and disability support options*. Retrieved from <https://waikato.researchgateway.ac.nz/bitstream/handle/10289/460/content.pdf?sequence=1&isAllowed=y>
- Nur, Y. (2012). It helps that Susan Boyle has made her Asperger's public. *The Guardian*. Retrieved from <http://www.theguardian.com/commentisfree/2013/dec/10/susan-boyle-singer-aspergers-syndrome-late-diagnosis>
- O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: A literature review. *British Journal of Nursing*, 18(22), 1358-1365.
- Odom, S., Hume, K., Boyd, B., & Stabel, A. (2012). Moving beyond the intensive behavior treatment versus eclectic dichotomy evidence-based and individualized programs for learners with ASD. *Behavior Modification*, 36(3), 270-297.
- Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Evidence-Based Child Health: A Cochrane Review Journal*, 8(6), 2380-2479.
- Owen-DeSchryver, J. S., Carr, E. G., Cale, S. I., & Blakeley-Smith, A. (2008). Promoting social interactions between students with autism spectrum disorders and their peers in inclusive school settings. *Focus on Autism and Other Developmental Disabilities*, 23(1), 15-28.
- Papageorgiou, V., & Kalyva, E. (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders*, 4(4), 653-660.
- Pennington, M. L., Cullinan, D., & Southern, L. B. (2014). Defining autism: Variability in state education agency definitions of and evaluations for autism spectrum disorders. *Autism Research and Treatment*, 2014.
- Perry, R. (2014). Asperger's disorder on life support. *Journal of Autism and Developmental Disorders*, 44(8), 2072-2073. doi:10.1007/s10803-014-2067-0
- Peters-Scheffer, N., Didden, R., Korzilius, H., & Matson, J. (2012). Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in the Netherlands. *Research in Developmental Disabilities*, 33(6), 1763-1772.
- Petrina, N., Carter, M., & Stephenson, J. (2014). The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 8(2), 111-126. doi:10.1016/j.rasd.2013.10.016

- Planche, P., & Lemonnier, E. (2012). Children with high-functioning autism and Asperger's syndrome: Can we differentiate their cognitive profiles? *Research in Autism Spectrum Disorders*, 6(2), 939-948. doi:10.1016/j.rasd.2011.12.009
- Quintero, N., & McIntyre, L. L. (2011). Kindergarten transition preparation: A comparison of teacher and parent practices for children with autism and other developmental disabilities. *Early Childhood Education Journal*, 38(6), 411-420. doi:10.1007/s10643-010-0427-8
- Radio New Zealand. (2017). Oz supermarket 'quiet hour' for autism spectrum. *Radio New Zealand*. Retrieved from <https://www.radionz.co.nz/news/world/344458/oz-supermarket-quiet-hour-for-autism-spectrum>
- Rispoli, M., Neely, L., Lang, R., & Ganz, J. (2011). Training paraprofessionals to implement interventions for people autism spectrum disorders: A systematic review. *Developmental Neuropsychology*, 14(6), 378-388.
- Rivard, M., Lépine, A., Mercier, C., & Morin, M. (2015). Quality determinants of services for parents of young children with autism spectrum disorders. *Journal of Child and Family Studies*, 24(8), 2388-2397.
- Roberts, J., Williams, K., Carter, M., Evans, D., Parmenter, T., Silove, N., . . . Warren, A. (2011). A randomised controlled trial of two early intervention programs for young children with autism: Centre-based with parent program and home-based. *Research in Autism Spectrum Disorders*, 5(4), 1553-1566.
- Rochford, T. (2004). Whare Tapa Whā: A Māori model of a unified theory of health. *Journal of Primary Prevention*, 25(1), 41-57.
- Rodger, S., & Umaibalan, V. (2011). The routines and rituals of families of typically developing children compared with families of children with autism spectrum disorder: An exploratory study. *British Journal of Occupational Therapy*, 74(1), 20-26.
- Rodríguez, I. R., Saldana, D., & Moreno, F. J. (2012). Support, inclusion, and special education teachers' attitudes toward the education of students with autism spectrum disorders. *Autism Research and Treatment*, 2012.
- Rogers, C. L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2016). Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism*, 20(7), 820-831.
- Rutter, M. (2005). Incidence of autism spectrum disorders: Changes over time and their meaning. *Acta Paediatrica, International Journal of Paediatrics*, 94(1), 2-15. doi:10.1080/08035250410023124
- Rzhetsky, A., Bagley, S. C., Wang, K., Lyttle, C. S., Cook Jr, E. H., Altman, R. B., & Gibbons, R. D. (2014). Environmental and state-level regulatory factors affect the incidence of autism and intellectual disability. *PLoS Computational Biology*, 10(3).

- Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual and Developmental Disability*, 37(4), 294-302.
- Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., . . . Zwaigenbaum, L. (2015). Couple relationships among parents of children and adolescents with autism spectrum disorder: Findings from a scoping review of the literature. *Research in Autism Spectrum Disorders*, 17, 142-157. doi:10.1016/j.rasd.2015.06.014
- Schleien, S. J., Miller, K. D., Walton, G., & Pruett, S. (2014). Parent perspectives of barriers to child participation in recreational activities. *Therapeutic Recreation Journal*, 48(1), 61.
- Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1520-1534.
- Searing, B. M. J. (2014). *Support needs of families living with children with autism spectrum disorder*. (Master's thesis, University of Otago, Dunedin, New Zealand). Retrieved from <http://hdl.handle.net/10523/4946>
- Shattuck, P. T., & Grosse, S. D. (2007). Issues related to the diagnosis and treatment of autism spectrum disorders. *Developmental Disabilities Research Reviews*, 13(2), 129-135.
- Shtayermman, O. (2013). Stress and marital satisfaction of parents to children diagnosed with autism. *Journal of Family Social Work*, 16(3), 243-259. doi:10.1080/10522158.2013.786777
- Simpson, R. L. (2004). Finding effective intervention and personnel preparation practices for students with autism spectrum disorders. *Exceptional Children*, 70(2), 135-144.
- Sinclair, J. (2013). Why I dislike “person first” language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2).
- Singh, J. S. (2011) The vanishing diagnosis of Asperger's disorder. In: *Vol. 12. Advances in Medical Sociology* (pp. 235-257).
- Skellern, C., Schluter, P., & McDowell, M. (2005). From complexity to category: Responding to diagnostic uncertainties of autistic spectrum disorders. *Journal of Paediatrics and Child Health*, 41(8), 407-412.
- Small, S. (2012). *Autism spectrum disorders (ASD): Knowledge, training, roles and responsibilities of school psychologists*. (Doctoral dissertation, University of South Florida). Retrieved from <http://scholarcommons.usf.edu/etd/4225/>
- Smith, M. J. (2008). Vaccination and autism 10 years on: Why are parents still worried? *Pediatric Health*, 2(6), 667-669.
- Smith, M. J., Ellenberg, S. S., Bell, L. M., & Rubin, D. M. (2008). Media coverage of the measles-mumps-rubella vaccine and autism controversy and its relationship to MMR immunization rates in the United States. *Pediatrics*, 121(4), 836-843.

- Song, Z., Giannotti, T., & Reichow, B. (2013). Resources and services for children with autism spectrum disorders and their families in China. *Infants & Young Children*, 26(3), 204-212.
- Spillers, J. L. H., Sensui, L. M., & Linton, K. F. (2014). Concerns about identity and services among people with autism and Asperger's regarding DSM-5 changes. *Journal of Social Work in Disability and Rehabilitation*, 13(3), 247-260. doi:10.1080/1536710X.2014.912186
- Stace, H. (2011). *Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy*. (Doctoral thesis, Victoria University, Wellington, New Zealand). Retrieved from <http://hdl.handle.net/10063/1920>
- Stahmer, A. C., Schreibman, L., & Cunningham, A. B. (2011). Toward a technology of treatment individualization for young children with autism spectrum disorders. *Brain Research*, 1380, 229-239. doi:10.1016/j.brainres.2010.09.043
- Starr, E. M., Foy, J. B., & Cramer, K. M. (2001). Parental perceptions of the education of children with pervasive developmental disorders. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(1), 55-68.
- Stoner, J. B., & Angell, M. E. (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities*, 21(3), 177-189.
- Stoner, J. B., Angell, M. E., House, J. J., & Bock, S. J. (2007). Transitions: Perspectives from parents of young children with autism spectrum disorder (ASD). *Journal of Developmental and Physical Disabilities*, 19(1), 23-39. doi:10.1007/s10882-007-9034-z
- Strauss, K., Mancini, F., Fava, L., & The SPC Group. (2013). Parent inclusion in early intensive behavior interventions for young children with ASD: A synthesis of meta-analyses from 2009 to 2011. *Research in Developmental Disabilities*, 34(9), 2967-2985.
- Thompson, D., & Emira, M. (2011). 'They say every child matters, but they don't': An investigation into parental and carer perceptions of access to leisure facilities and respite care for children and young people with Autistic Spectrum Disorder (ASD) or Attention Deficit, Hyperactivity Disorder (ADHD). *Disability & Society*, 26(1), 65-78. doi:10.1080/09687599.2011.529667
- Tsai, L. Y. (2013). Asperger's disorder will be back. *Journal of Autism and Developmental Disorders*, 43(12), 2914-2942. doi:10.1007/s10803-013-1839-2
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners*, 19(5), 251-260.
- Vismara, L. A., Colombi, C., & Rogers, S. J. (2009). Can one hour per week of therapy lead to lasting changes in young children with autism? *Autism*, 13(1), 93-115.
- Warnell, F., George, B., McConachie, H., Johnson, M., Hardy, R., & Parr, J. (2015). Designing and recruiting to UK autism spectrum disorder research databases: do they include representative children with valid ASD diagnoses? *BMJ Open*, 5(9).

- Watson, R., Parr, J., Joyce, C., May, C., & Le Couteur, A. (2011). Models of transitional care for young people with complex health needs: A scoping review. *Child: Care, Health and Development*, 37(6), 780-791.
- Wilczynski, S. M., Menousek, K., Hunter, M., & Mudgal, D. (2007). Individualized education programs for youth with autism spectrum disorders. *Psychology in the Schools*, 44(7), 653-666.
- Willingham, E. (2013). 'Wall Street' actress Daryl Hannah is an autistic woman. *Forbes Magazine*. Retrieved from <http://www.forbes.com/sites/emilywillingham/2013/09/29/wall-street-actress-daryl-hannah-also-autistic-woman/>
- Woods, J. J., & Wetherby, A. M. (2003). Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language, Speech, and Hearing Services in Schools*, 34(3), 180-193.